Implementing a First Nations cancer coordinator role

A toolkit for healthcare providers

Acknowledgment of Country

The research team respectfully acknowledges the Traditional Owners of the land on which this project was conducted, the Wurundjeri People of the Kulin Nation. We extend this respect to all Aboriginal and Torres Strait Islander peoples across Victoria, upon whose lands this implementation toolkit may be used. We pay our respects to Elders past, present and emerging.

We also wish to acknowledge the Aboriginal and Torres Strait Islander patients, families, health workers, researchers and community members who generously shared their insights and time to contribute to the outcomes of this work. We thank them for their profound contributions to the community and to the health and wellbeing of all peoples in Victoria.

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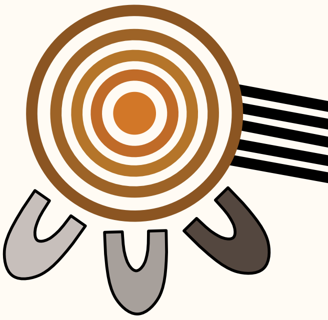

Contributors

About the Artwork

All artwork is by Marissa Mulcahy, a proud Gomeroi and Kamilaroi woman and First Nations cancer coordinator.

The front cover artwork, represents the journey of a soul and the different support systems encountered throughout their journey.

The sun rising over the mountains symbolises the beginning of a new day and what that brings.

This artwork was created to honour the diverse experiences of individuals and the role of community, culture, and care throughout their journey.

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Abbreviations

ACCHO	Aboriginal Community Controlled Health Organisation
AHLO	Aboriginal Hospital Liaison Officer
CFIR	*Consolidated framework for implementation research*
FNCC	First Nations cancer coordinator
FNHU	First Nations health unit
MDM	Multidisciplinary meeting
OCP	Optimal care pathway

Summary

Aboriginal and Torres Strait Islander people (hereafter respectfully referred to as First Nations people) experience significantly poorer outcomes in cancer compared with non-Indigenous Australians including higher cancer mortality rates. This widening gap is exacerbated by limited access and engagement with quality cancer care services.

The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* and the Victorian Aboriginal Community Controlled Health Organisation’s *Cancer journey strategy* have identified the need for a cultural support and coordination model, that supports First Nations people with cancer to navigate the healthcare system and provide continuity of care between services and community. A First Nations cancer coordinator (FNCC) role can improve access to quality cancer care services through:

- proactive and early engagement with patients (before their hospital admission)
- cultural advocacy within the hospital setting
- coordination support throughout the cancer illness course.

A best practice model of an FNCC role was designed and endorsed by a First Nations community advisory group and implemented at a large metropolitan hospital in 2023. The core components of this role are:

- strong connections with First Nations health units in hospitals and community health settings and multidisciplinary cancer teams
- continuous, between-service coordination
- knowledge about cancer-specific needs
- advocacy and education about cultural safety in cancer care.

This implementation toolkit has been assembled to guide other health services who are developing and implementing an FNCC role. The toolkit includes a collection of background material, implementation steps, strategies/activities, recommended outcome measures and resources to support services in their implementation goals.

The toolkit is presented according to the three phases of the project: planning and engagement, implementation, and maintenance. Each of these phases is accompanied by suggested activities and strategies. Materials developed within this project are available to support these activities.

While this toolkit provides a framework for implementation, it is designed to be adapted to local site resources and needs.

Scan the QR code to access a digital version of the toolkit’

1. Introduction

1.1 Purpose of the toolkit

This toolkit guides health service providers in implementing a First Nations cancer coordinator (FNCC) role. The FNCC role aims to improve cancer care for First Nations people. This toolkit was developed as part of a project where an FNCC role was designed, implemented and evaluated at The Royal Melbourne Hospital from 2022 to 2024. Western & Central Melbourne Integrated Cancer Service funded the project.

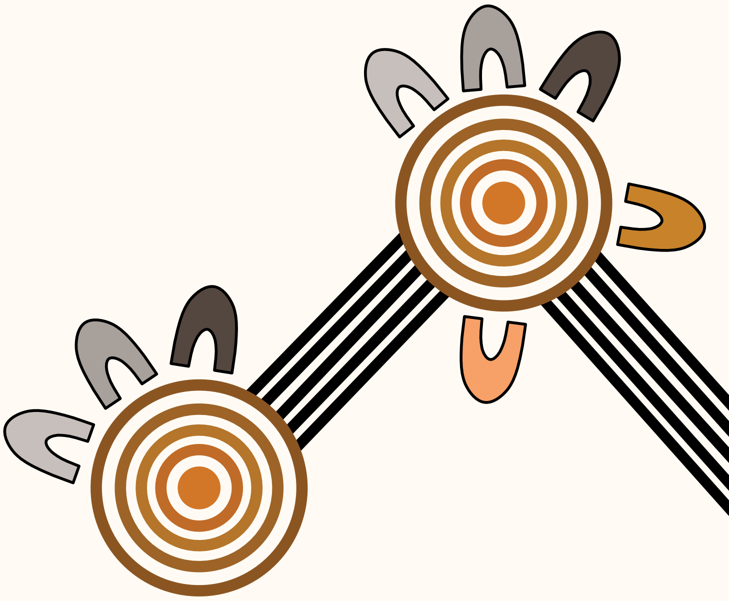
First Nations governance was integral to this project, through the leadership of senior First Nations researcher Professor Gail Garvey and ongoing partnership with a community advisory group. The advisory group included First Nations health professionals, community members and First Nations people with lived experience of cancer. The group governed all aspects of the project, ensuring the research and resulting outcomes were informed by First Nations priorities, values, perspectives and voices.[1] It is essential that future implementation projects connect with key community members including local Aboriginal Community Controlled Health Organisations (ACCHOs) to ensure relevance for local communities.

This implementation toolkit is a collection of background materials, implementation strategies/activities, recommended outcome measures and resources. The contents of this toolkit can be adapted to local organisational contexts and needs.

1.2 Target audience

This implementation toolkit has been developed for health service planners, clinical researchers, executive teams and multidisciplinary cancer service team members including those working in:

- screening and diagnostics
- surgery
- medical oncology
- clinical haematology
- psychosocial cancer care
- palliative care
- inpatient acute care
- chemotherapy day unit
- specialist clinics
- First Nations health units (FNHUs)
- other health care.



2. Background

First Nations people conceive health as holistic, involving social, emotional, physical, cultural and spiritual wellbeing.[2] This goes beyond the mere absence of disease, encompassing broader topics including connection to Country, self-determination, traditional knowledge and healing, equity and social justice. Health involves the whole community throughout an entire life course.

2.1 Current state of cancer care for First Nations people in Australia

Cancer is the leading cause of death for First Nations people in Australia, accounting for 23% of all deaths in 2024.[3] The gap in cancer outcomes between non-Indigenous and First Nations Australians is widening. While cancer mortality rates for non-Indigenous people have declined by 10% in the last decade, the mortality rate for First Nations people has increased by 12%.[4] First Nations people have a higher incidence of fatal, screen-detectable and preventable cancers. They are more likely than non-Indigenous Australians to be diagnosed at a later stage and with a higher likelihood of complex comorbidities.[5]

There are several complex causes for the disparate cancer outcomes that First Nations people experience. These include historical and current policy decisions that have been imposed on First Nations people without their consent or consultation.[6] These disparities are exacerbated by ongoing barriers to access and engagement with quality cancer care services.[7] Research exploring First Nations people's experiences of cancer care cite multiple reasons why people may experience challenges in accessing cancer services, including:

- fear or mistrust of mainstream healthcare facilities[8]
- experiences of racism
- healthcare staff with unconscious biases and/or limited cultural understanding[9]
- being away from Country[10]
- out-of-pocket costs[11]
- cultural beliefs or stigma around cancer that elicit feelings of shame and avoidance.[12,13]

Miscommunication and a lack of care coordination within and between services exacerbate issues with engagement.[10,14]

It is vital that future research, policymaking and services are culturally informed and tailored to the needs of First Nations people affected by cancer. Thankfully, there is a growing international body of First Nations-led cancer and health research that uses Indigenist research approaches. This research prioritises the needs, perspectives and cultures of First Nations people and communities.[15–18] In Australia, national and state ACCHOs have released cancer plans that are strengths-based, culturally centred and community-engaged.[19,20] The shift towards First Nations-led health initiatives has the potential to have a positive impact on policymaking and improve cultural safety in mainstream healthcare services.

2.2 The need for care coordination

Evidence suggests that tumour stream cancer coordinators can play a positive role in improving cancer care for all patients, including facilitating timely access to care, coordinating complex treatment plans and improving adherence to cancer care.[21,22] To better support the access and engagement needs of First Nations people affected by cancer, there is a vital need for a navigator role to provide culturally safe and responsive care coordination, as outlined in:

- the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*[23]
- the Victorian Aboriginal Community Controlled Health Organisation's (VACCHO) *Cancer journey strategy*[19]
- the National Aboriginal Community Controlled Health Organisation's *Cancer plan*.[20]

Evidence supports the positive impact of Aboriginal hospital liaison officers (AHLOs) and First Nations health workers in providing cultural expertise and safety in hospitals and in improving communication between patients and healthcare teams.[10,24] First Nations people report feeling less guarded and more comfortable asking questions when a First Nations staff member is present.[10] Extending this concept of cultural support and reflecting on existing cancer coordination models, there is potential to create a complementary First Nations patient navigator or FNCC role. First Nations people affected by cancer have expressed their support for a First Nations patient navigator or FNCC role, particularly in terms of patient advocacy, cultural knowledge and potential links between community, family and hospital.[25] An FNCC role would complement the existing cultural support of the AHLO team by assisting patients and families with service navigation and coordinating care between teams.

A cultural support and coordination model such as the FNCC could increase access and engagement, reduce anxiety and improve cancer outcomes for First Nations people affected by cancer and their families. For example, an FNCC could attend regular tumour-stream clinics and multidisciplinary team meetings (MDMs) to identify First Nations patients. Through early contact work, they could ensure First Nations patients visiting a hospital are culturally safe. The FNCC could contact the patient before their hospital admission or diagnosis, encouraging earlier interaction with health services. Throughout the cancer illness course, the FNCC would work closely and collaboratively with multidisciplinary cancer teams to ensure care is timely and aligns with the wishes of the patient and their family.

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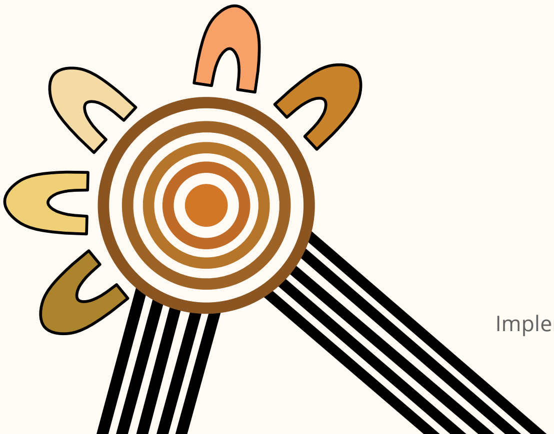


3. First Nations cancer coordinator role

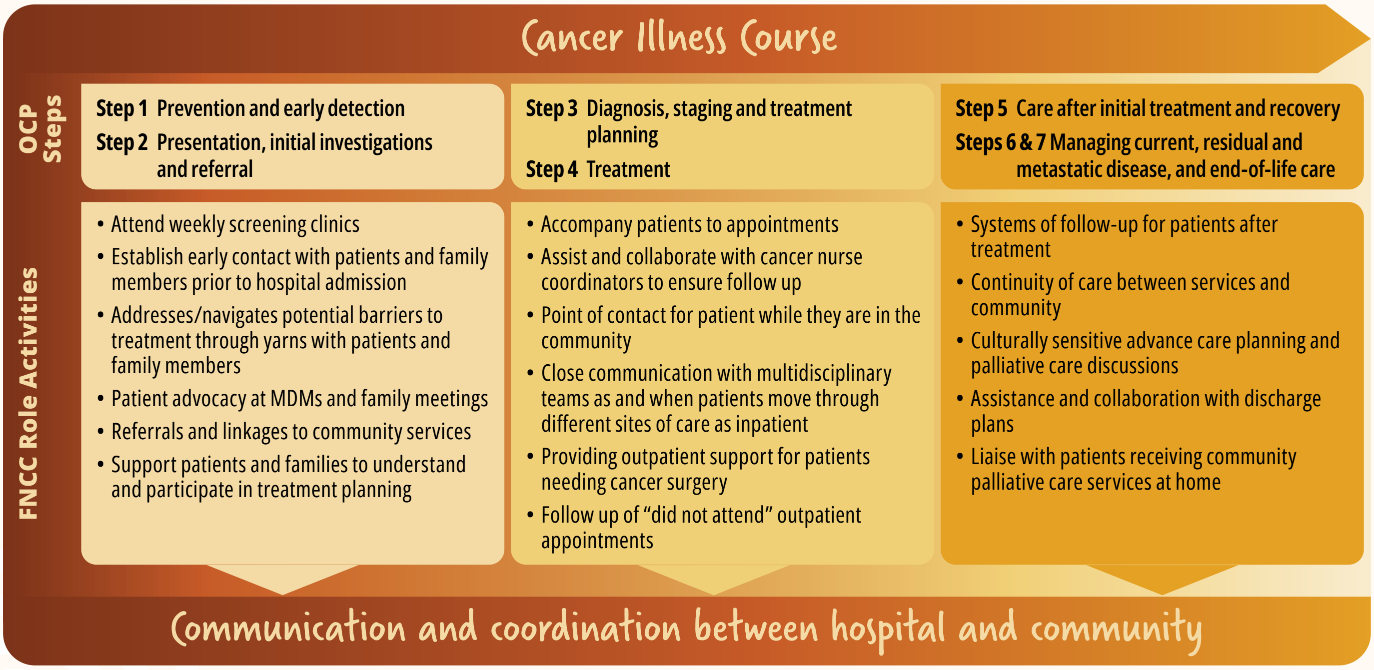
The community advisory group developed a best practice FNCC model that was implemented at The Royal Melbourne Hospital in 2023. This role was based on existing research, resources and pathways including the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*[23] and VACCHO's *Cancer journey strategy.*[19] The community advisory group endorsed the FNCC title for its emphasis on the cancer-specific care coordination that the role could provide.

Future adaptions of this role may wish to consider a cultural name for the role, with permission and guidance from local First Nations communities.

The FNCC:

- proactively engages with patients, often before the first hospital visit
- supports patients at all stages of their cancer illness course, including navigation across the healthcare system during screening, diagnosis and treatment, and supporting their return to community in survivorship and/or palliative care (Figure 1)
- is physically located in the hospital and can access patient medical records
- can see patients in the community and support patients to attend telehealth appointments from the patient's preferred location
- is responsible for effective liaison and links with First Nations health services, ensuring a continuity of care between community-based and acute healthcare services
- provides a point of contact for cancer clinicians as an integral, trusted member of the cancer care team.

Figure 1: First Nations cancer coordinator — patient-facing responsibilities



Cancer Illness Course

OCP Steps	**Step 1** Prevention and early detection **Step 2** Presentation, initial investigations and referral	**Step 3** Diagnosis, staging and treatment planning **Step 4** Treatment	**Step 5** Care after initial treatment and recovery **Steps 6 & 7** Managing current, residual and metastatic disease, and end-of-life care
FNCC Role Activities	• Attend weekly screening clinics • Establish early contact with patients and family members prior to hospital admission • Addresses/navigates potential barriers to treatment through yarns with patients and family members • Patient advocacy at MDMs and family meetings • Referrals and linkages to community services • Support patients and families to understand and participate in treatment planning	• Accompany patients to appointments • Assist and collaborate with cancer nurse coordinators to ensure follow up • Point of contact for patient while they are in the community • Close communication with multidisciplinary teams as and when patients move through different sites of care as inpatient • Providing outpatient support for patients needing cancer surgery • Follow up of "did not attend" outpatient appointments	• Systems of follow-up for patients after treatment • Continuity of care between services and community • Culturally sensitive advance care planning and palliative care discussions • Assistance and collaboration with discharge plans • Liaise with patients receiving community palliative care services at home

Communication and coordination between hospital and community

3.1 Core components of the First Nations cancer coordinator role

The core components of the FNCC role are:

- strong connections with FNHUs and multidisciplinary cancer teams
- advocacy and education
- continuous, between-service coordination
- cancer-specific and cultural expertise.

The FNCC works closely with AHLOs *and* multidisciplinary cancer teams to coordinate care. Ideally, the FNCC is located in the hospital's existing FNHU. If the role is not in the FNHU, it is vital that the FNCC develops strong relationships and standardised handover systems with this team. While there is a need to delineate between the FNCC and AHLO roles, the FNCC role is designed to work alongside AHLO teams to ensure continuity of culturally safe care for First Nations patients. AHLO teams have deep, lasting relationships with the First Nations community and individual patients. Their support encompasses broader advocacy and access to culturally safe spaces, resources and support services. In addition but separate to this, the FNCC brings detailed knowledge of cancer care and provides specialised support for cancer care that complements the cultural support that AHLO teams provide.

Strong and collaborative relationships with multidisciplinary comprehensive cancer care teams offer opportunities for the FNCC to advocate for the cultural needs of First Nations people affected by cancer. A core component of managing cancer patients is in the MDMs where the multidisciplinary teams discuss investigation and treatment pathways.

Through attending these MDMs, the FNCC ensures cultural supports are embedded in care plans at the outset. This also provides an opportunity for 2-way learning, whereby the FNCC can receive up-to-date information about patients' illness stage, treatment plan and coordination needs. Non-Indigenous healthcare workers can improve their understanding of their patients' cultural needs and preferences. The FNCC attending MDMs is vital to building relationships with the cancer workforce.

Continuous, between-service coordination — support across the cancer journey

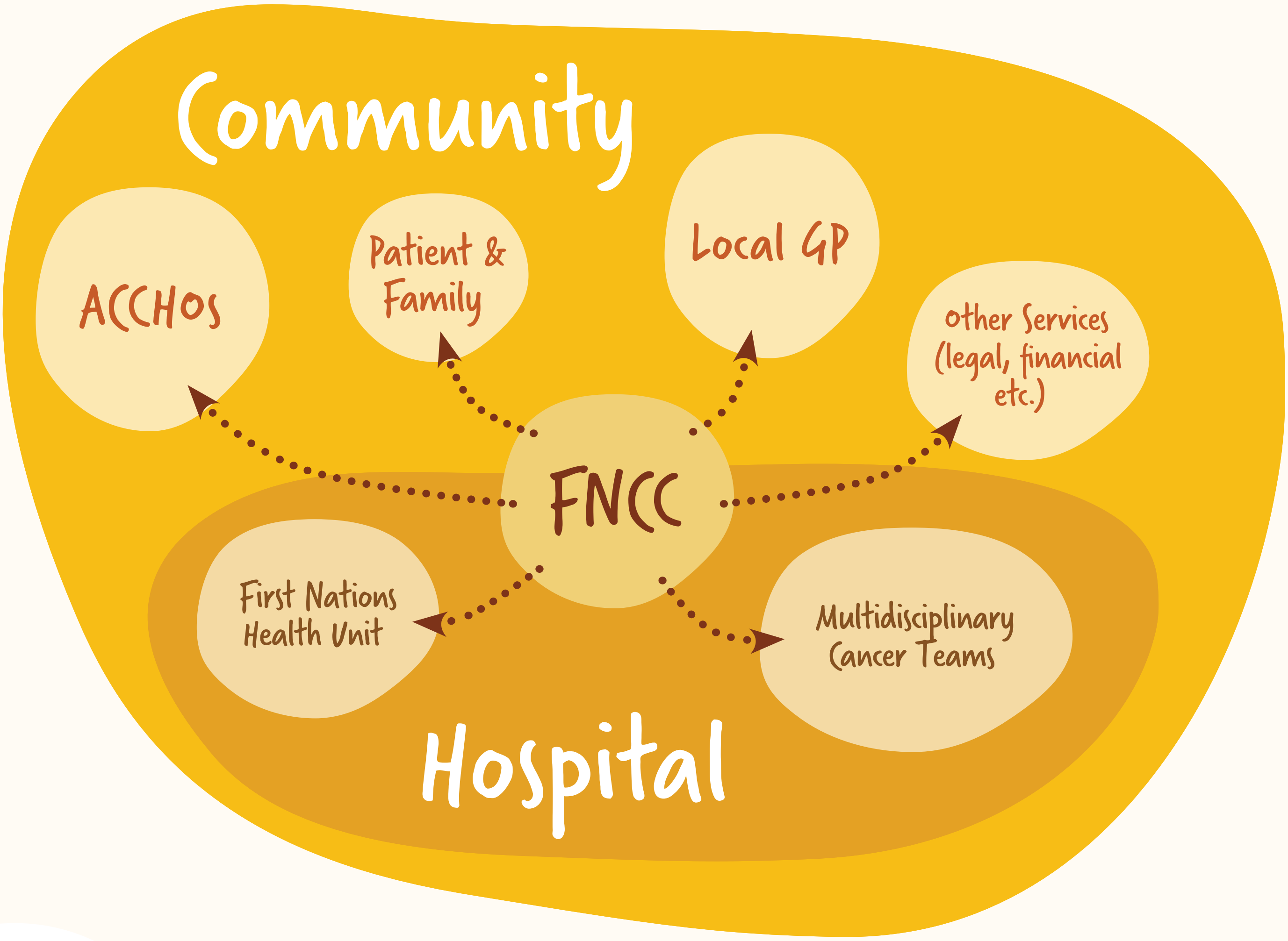
Within and outside of the hospital setting, the FNCC supports patients to navigate systems at all stages of their illness course, depending on the individual needs of the patient and their families. Regular attendance at outpatient clinics and MDMs enables the FNCC to identify patients early and offer coordination support before their hospital admission or diagnosis. FNCCs are closely linked with local ACCHOs and other First Nations health services and may receive referrals to see patients in the community, before they enter the hospital system. This can lessen hesitancy about hospital attendance and reduce the numbers of missed outpatient appointments. FNCCs can also support patients to attend telehealth appointments from a culturally safe location of their choice, such as a local ACCHO. This proactive cultural engagement encourages timely access to healthcare services.

As a consistent point of contact throughout the cancer journey, the FNCC can stay up to date with treatment progress and assist with appointment coordination and follow-up. FNCCs provide emotional, cultural and coordination support to patients and their families, whether they are inpatients, outpatients or receiving care in community. They ensure patients have access to culturally appropriate services and support at every stage of their cancer journey.

The FNCC is closely linked with local ACCHOs and will often receive referrals before a patient has entered the hospital system. Where possible, the FNCC will proactively contact patients before their hospital admission to tell them that the FNCC support is available if and when they require it. This can improve engagement, particularly for rural patients, who may need coordination support for transport and accommodation before they enter the hospital system.

Alternatively, the FNCC may support patients to attend their appointments from a culturally safe location of their choice (including local ACCHOs).

Figure 2: Conceptual representation of the FNCC-facilitated connections between patients and family, community and the hospital



Cancer-specific and cultural expertise

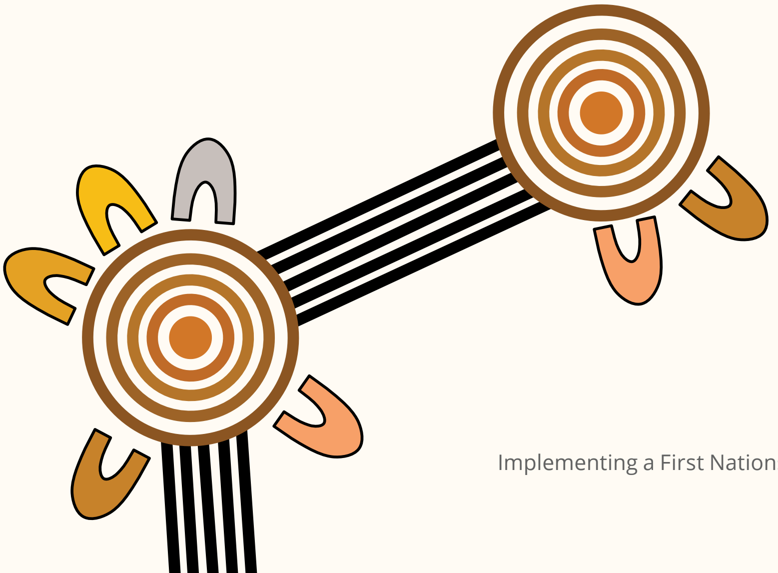
The FNCC position is trained to understand the unique cultural, spiritual and practical needs of First Nations people affected by cancer and their families. As well as cultural expertise, the FNCC has cancer-specific knowledge and brings these combined sets of understanding — of cultural needs and of cancer care — to enhance care. As the FNCC provides continuous, between-service support, they have a unique insight into their patient's needs, values and preferences.

As multidisciplinary team members, FNCCs may attend appointments and family meetings and be involved with supporting both patients and their clinicians in treatment and discharge planning. The FNCC should have knowledge of referral, diagnostic and treatment pathways to help First Nations patients to navigate the cancer care system. FNCCs may support the wider First Nations workforce by developing culturally appropriate education about cancer and providing culturally appropriate cancer resources.

Simply put, the FNCC can enhance the cancer workforce's understanding and capability in delivering culturally safe care. They can enhance a First Nations health worker's knowledge and skills with cancer care.

Patients and families often report feeling more comfortable and less guarded when they can speak to a First Nations healthcare worker about their questions and concerns. As embedded members of the multidisciplinary team, the FNCC can support patients to voice their concerns or highlight these concerns at the MDM on the patient's behalf. This ensures patients have genuine self-determination and that their cultural needs are prioritised in care plan discussions.

> "The [FNCC role] having that specific cancer skill set helps the patient know that they're more supported and that you have a better understanding of the decisions they're making. And not helping them make the decision but making sure they've made the right decision for themselves."
>
> Cancer nurse consultant



Advocacy and education about cultural safety in cancer care

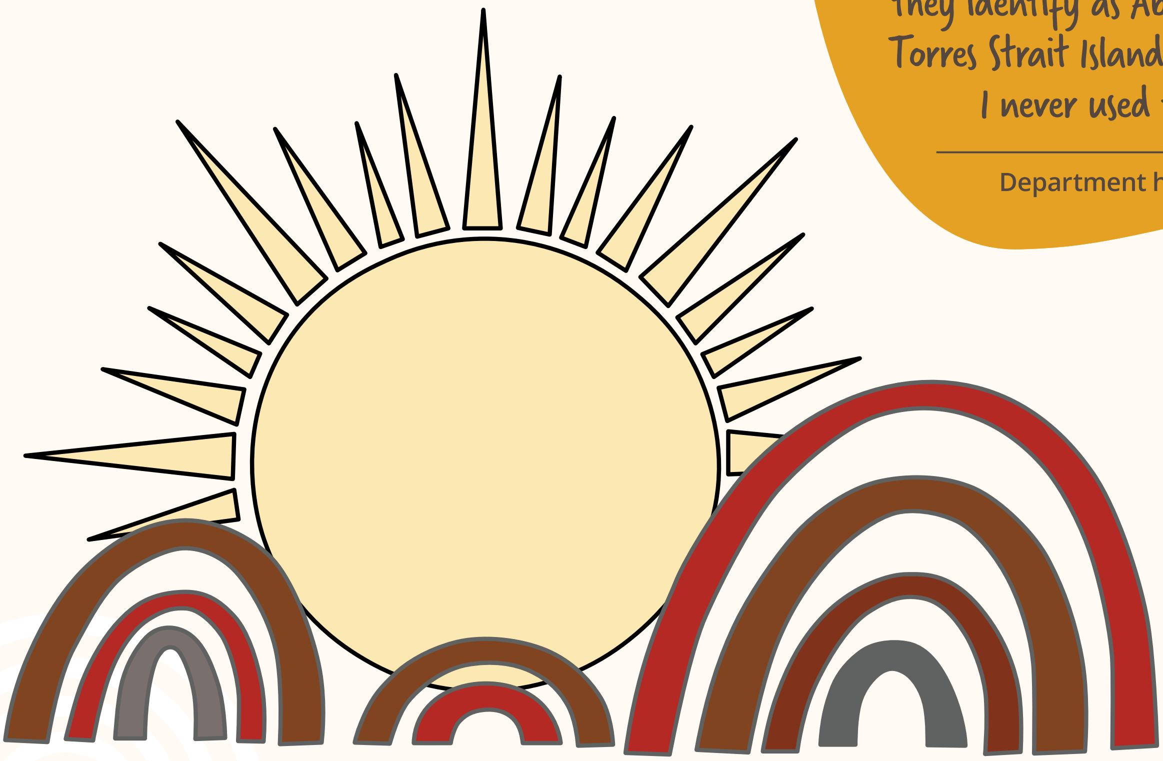
The delivery of culturally safe care is not the sole responsibility of First Nations health workers — it is the responsibility of the entire organisation. Nonetheless, the FNCC's unique expertise equips them to inform non-Indigenous healthcare workers about cultural needs in cancer care.

There are also particular sets of needs and cultural supports required in cancer care. As active members of the multidisciplinary cancer teams, with established relationships with fellow health professionals, the FNCC enhances the cultural capability of non-Indigenous healthcare workers. This helps create an environment where they feel more confident to ask questions and seek guidance on culturally appropriate practices.

For example, many non-Indigenous healthcare workers reported feeling more comfortable to ask about a patient's First Nations status when they knew they could refer the patients to a cultural support service.

> "It's about educating us and informing us on what's going to be appropriate for the patient and making sure that we are offering or delivering things in a culturally appropriate and safe way. So, it's about us drawing on their expertise to ensure that, you know, we're managing this group of patients appropriately. Because if we're not, we're not going to be able to deliver good care."
>
> Consultant

> "I find that roles like [the FNCC], they're so valuable in raising awareness for us of how we might do it differently...I now feel really comfortable asking patients whether they identify as Aboriginal or Torres Strait Islander, whereas I never used to..."
>
> Department head



4. Implementation strategies, tools and resources

Implementing the FNCC role is a continual process, acknowledging the diverse practical and cultural needs of local communities and individual healthcare settings. In alignment with the *Consolidated framework for implementation research* (CFIR),[26] this section outlines the key phases that organisations can navigate to seamlessly integrate the FNCC role into their existing systems. Emphasising flexibility and adaptability, the framework aims to respect the nuances of individual health services while ensuring a culturally sensitive and effective implementation.

It is important to note that the CFIR is a generic implementation framework that is not informed by First Nations ways of knowing and being. In a critical review of implementation frameworks conducted by First Nations and non-Indigenous researchers, the CFIR was found to be lacking:

- a focus on community-driven health care
- two-way learning between communities and healthcare systems
- the relationship-building aspects of workforce.[27]

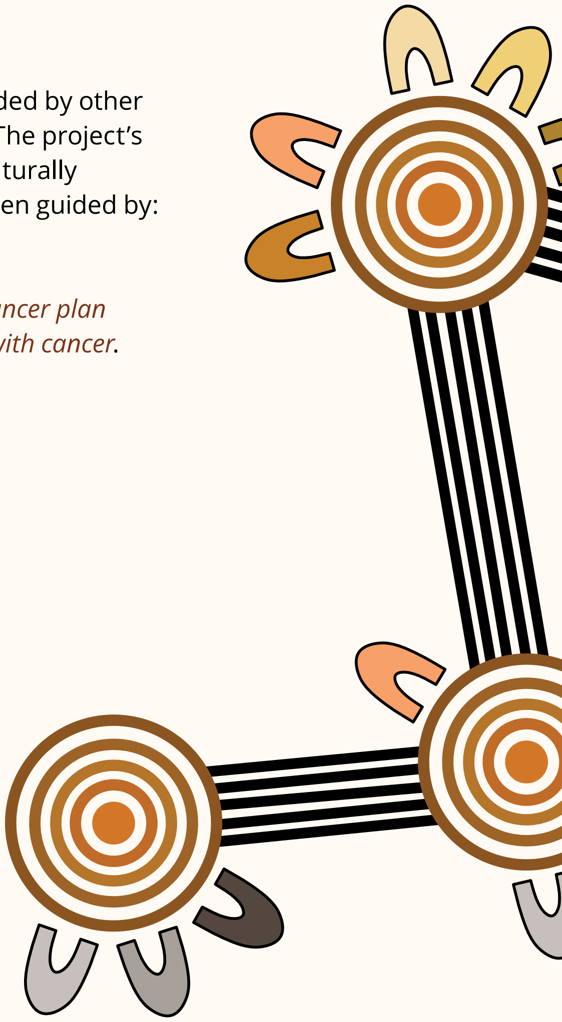
While this toolkit employs the CFIR, it has been contextually informed and guided by other principles of community governance, empowerment and self-determination. The project's community advisory group has ensured the implementation strategies are culturally appropriate and useful for the First Nations community. This work has also been guided by:

- VACCHO's *Cancer journey strategy*
- the National Aboriginal Community Controlled Health Organisation's *Cancer plan*
- the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*.

The following section details three phases of FNCC implementation:

- planning and engagement
- implementation
- maintenance.

At every phase, it is vital to ensure a two-way relationship exists between the health service and the First Nations community, respecting self-determination and ensuring implementation is embedded in culture and community partnership.[28]

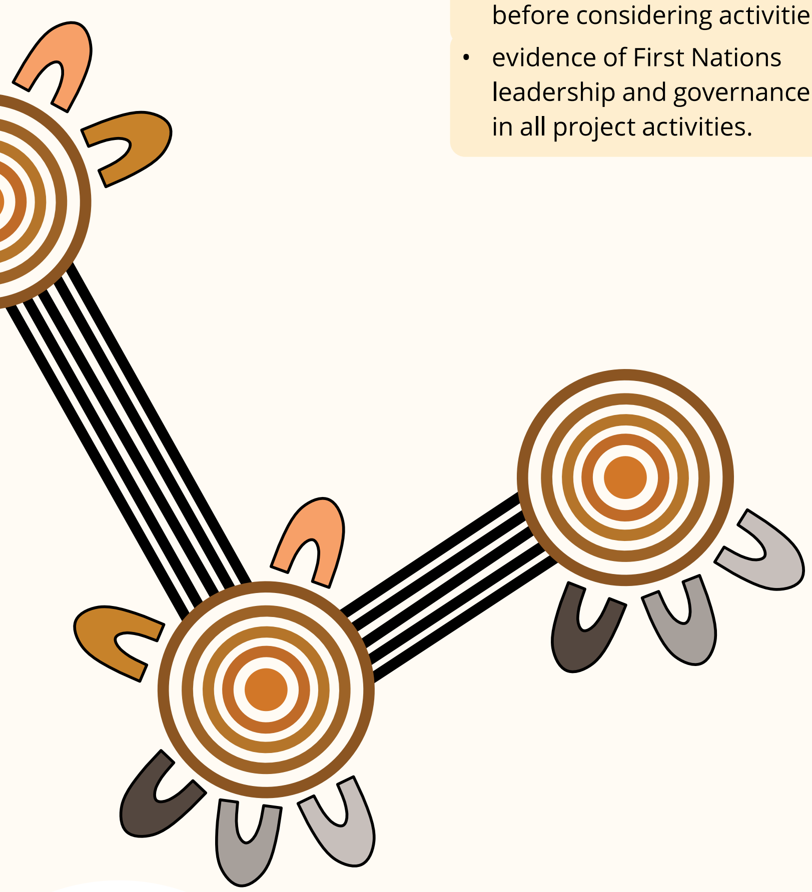


4.1 Planning and engagement phase

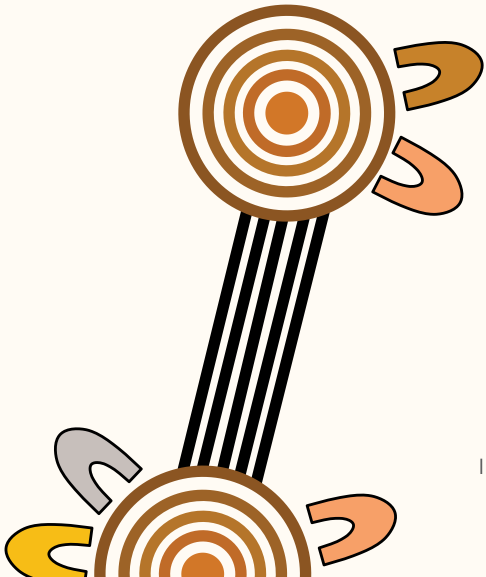
Table 1 outlines implementation strategies, tools and activities for the planning and engagement phase.

Table 1: Implementation strategies, tools and activities — planning and engagement phase

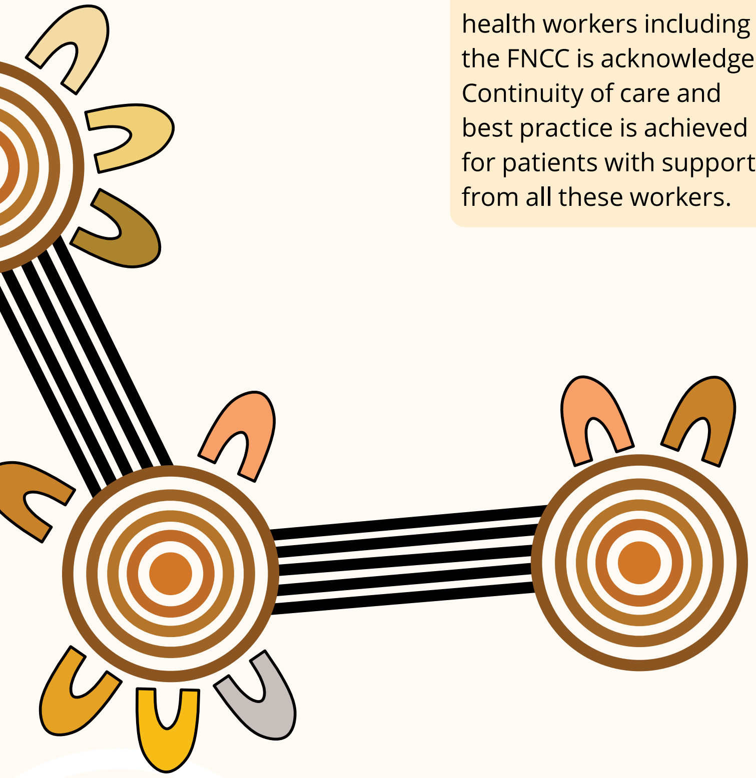
Aim	Implementation strategies	Potential activities
1. Engage and partner with community stakeholders	Identify key opinion leaders and local advocates including Elders, First Nations health workers and representatives from ACCHOs.	Informal yarning circles to identify local attitudes and needs in your community.
	All activities and planning are informed by self-determination:	Developing a First Nations-led community advisory group to oversee all project activities.
	• focus on community and cultural strengths in planning and implementation	Getting involved in community health promotion days.
	• create space and time for partnerships to be developed before considering activities	Connect early with First Nations health workers and health units at the sites to be targeted for implementation. Regularly re-engage because personnel may change.
	• evidence of First Nations leadership and governance in all project activities.	Education and training in cancer with concurrent building of networks with key providers and organisations (for example, Cancer Council Victoria).
		Progress markers:
		• Establishing a community advisory group
		• Local community endorsement



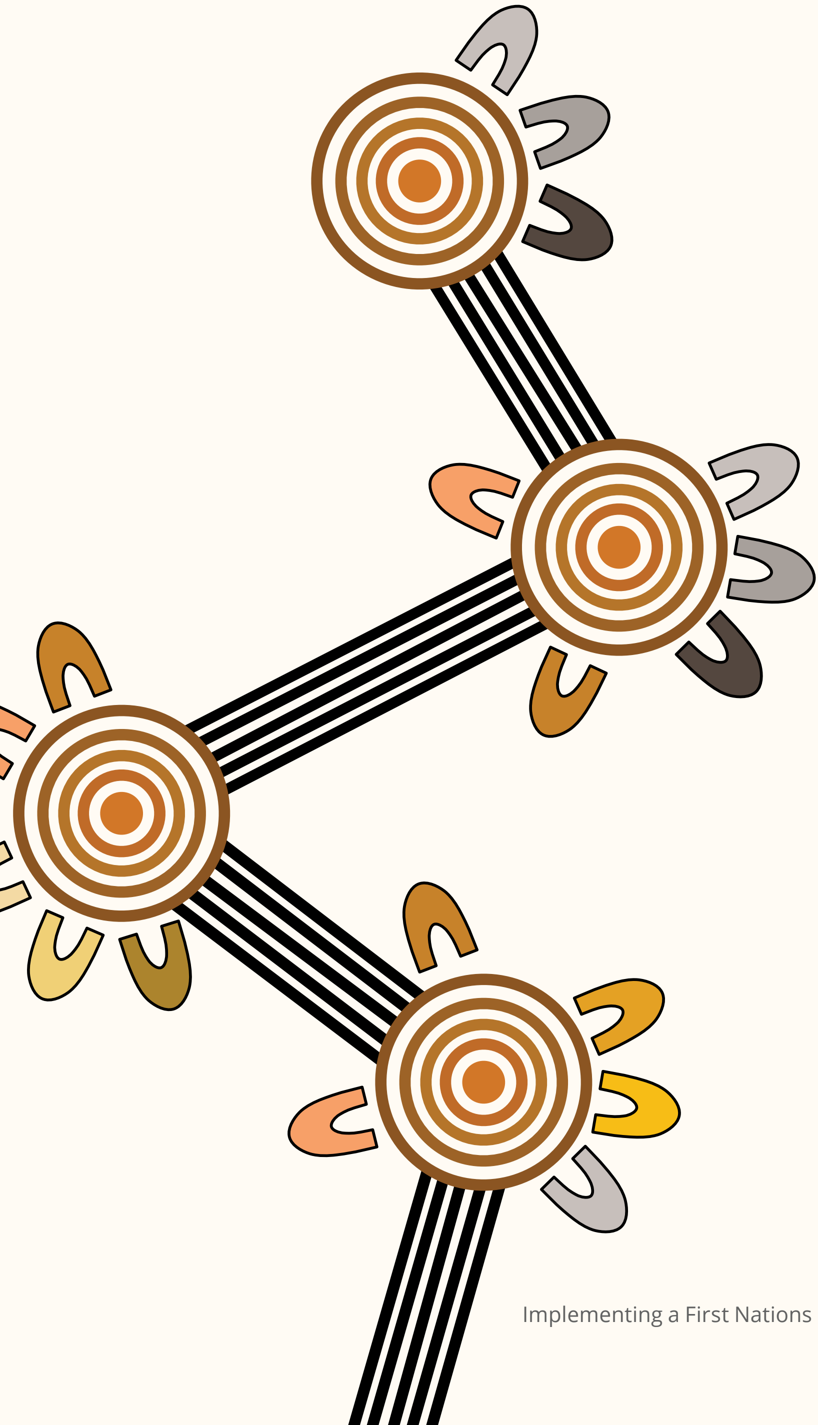
Aim	Implementation strategies	Potential activities
2. Establish implementation funding	Identify funding for the position. (Is it project funding from an external entity or is there internal funding to establish a new position?)	Ensure enough funding for the scope of the position, recognising the enhanced position responsibilities.
		Meet with relevant stakeholders: external funders and leaders within the organisation including the FNHU and cancer teams.
		Consider funding from multiple sources; for example, community organisations partnering with one or more hospitals.
		Consider non-traditional sources of funding such as contributions from cancer screening programs, cultural organisations and non-governmental organisations.
		Progress markers:
		• Funding acquired • A plan for sustainability in place
3. Gain executive sponsorship/support for establishing an FNCC role	Identify high-level leaders in your healthcare setting. Get endorsement from key hospital and policy leaders.	Meet with relevant stakeholders including tumour stream department heads, FNHU managers and hospital executive teams.
	Make visible the hierarchical/departmental support required to implement the FNCC role. Set out lines of responsibility and accountability.	Offer evidence to show the gaps in current cancer care for First Nations patients. The following resources may be useful evidence: • *Aboriginal and Torres Strait Islander optimal care pathway* • VACCHO's *Cancer journey strategy*. There is a growing evidence base for the effectiveness of First Nations patient navigator roles. Refer to: • *Perspectives of Aboriginal People Affected by Cancer on the Need for an Aboriginal Navigator in Cancer Treatment and Support: A Qualitative Study* • *The Role of the Indigenous Patient Navigator: A Scoping Review.*
	Lines of supervision and support should encompass both lines for clinical support and lines for cultural support.	
	Continue the ongoing process for engaging executive, departmental and consumer support throughout this phase.	Check site-specific processes for establishing new roles.
		Progress markers:
		• Endorsement of the FNCC role by the cancer service, First Nations health workers and target tumour stream cancer teams • Lines of clinical and cultural supervision established



Aim	Implementation strategies	Potential activities
4. Determine where the FNCC will be physically located	The FNCC role should ideally be embedded within an existing FNHU. Determine resources and desk space in the FNHU. Identify the culturally appropriate cancer resources currently used at the site.	Meet with key stakeholders from the FNHU. Get endorsement for the FNCC to be physically located in the FNHU. Prepare business cards and posters to promote the FNCC role. Give the FNCC a computer and mobile phone for patient contact. Utilise the *Patient yarning guide* (in Section 5) which includes culturally appropriate cancer resources.
5. Establish delegation and supervision arrangements	Develop a scope of practice for the FNCC role. This includes how the FNCC works with and is distinct from AHLOs. Ensure the FNCC has a cultural mentor to help support their cultural load. Establish systems of clear communication and handover between teams. Ensure the skill sets and contributions of all First Nations health workers including the FNCC is acknowledged. Continuity of care and best practice is achieved for patients with support from all these workers.	In collaboration with key stakeholders (FNHU manager, executive, cancer services), develop a role description outlining the position details, key functions and responsibilities of the role, the education and training requirements and the pay category. Define roles and responsibilities including the timeframe of support — for example, the length of time a patient receives FNCC support after curative resection for cancer. Refer to Appendix B for a sample template. • Speak with the FNHU to define a structure for decision-making, patient handovers and cultural support. • Determine the delegation process for when the FNCC is absent. • Link the FNCC with the First Nations staff network. Refer also to: • 'Strategic Direction 2: A strong and supported Aboriginal workforce' in VACCHO's *Cancer journey strategy* • *Aboriginal workforce strategy 2021–2026* • *Barring Djinang: First Peoples Workforce Development Framework*
		Progress markers: • The FNCC has a cultural support network and cultural supervision by a senior staff member of Aboriginal and/or Torres Strait Islander descent • Patient handover system developed in collaboration with the FNHU



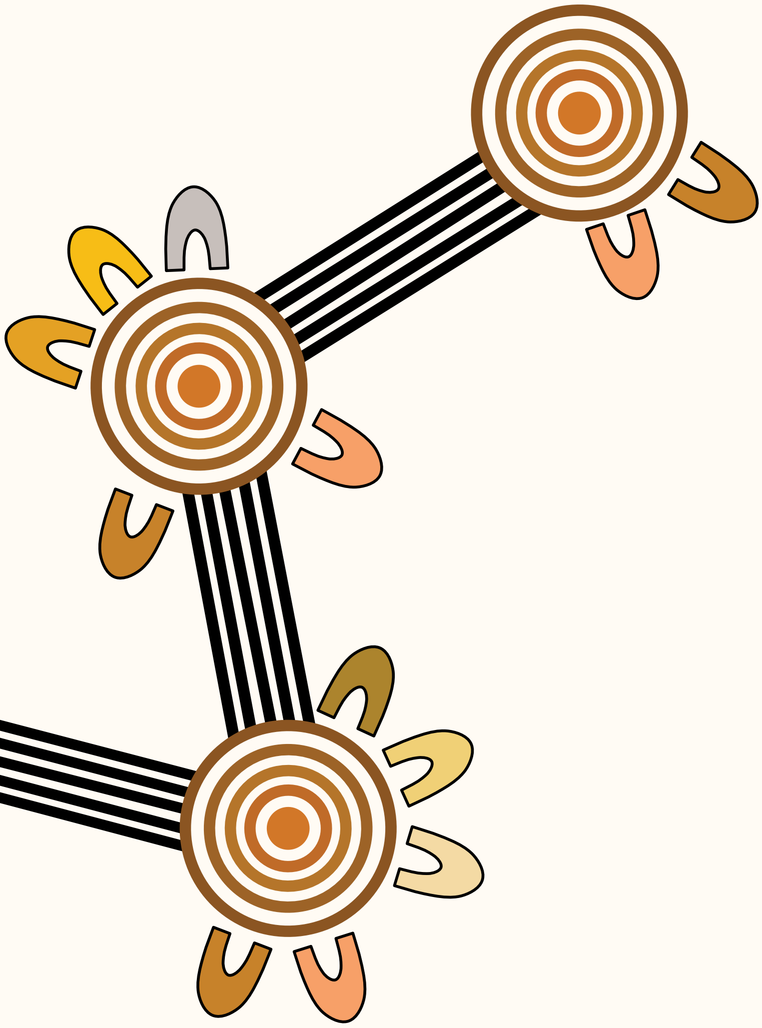
Aim	Implementation strategies	Potential activities
6. Organise recruitment	Recruit an appropriately qualified and skilled person to the position. Develop a culturally safe and appropriate orientation program for the new employee.	Advertise the FNCC role via appropriate hospital and community networks. Also consider: • First Nations recruitment organisations such as *Shine People Solutions* • Referring to 'Domain 2: Culturally responsive recruitment and selection' in the *Aboriginal workforce strategy 2021–2026* • Including First Nations staff in the recruitment process and interviews • Emphasising that the position includes connection with the First Nations workforce. Essential requirements: • The role must be filled by a person of Aboriginal and/or Torres Strait Islander descent. Desirable requirements: • Qualifications in a relevant healthcare discipline such as nursing, medicine, allied health, and/or public health. • Demonstrated knowledge of First Nations culture, values, wellbeing and social health issues. Consider including: 'Even if you do not meet all of the desirable criteria for the role, we would still love to hear from you'. Onboarding: • Provide induction and orientation training for the FNCC. • Identify any additional training needs (cancer-specific knowledge to be acquired pre or post appointment). • Ensure the FNCC has a cultural mentor and a senior medical mentor with experience in cancer care. **Progress markers:** • Appropriate person recruited • Cultural support network available • Culturally appropriate orientation • Senior mentor allocated



Aim	Implementation strategies	Potential activities
7. Facilitate the planning and implementation of an FNCC with relevant clinics or tumour streams	Identify all staff members who will be involved in the referral processes and cancer care for mutual patients.	Identify the staff members who the FNCC will need to work with. Have the FNCC's manager introduce them to relevant members of multidisciplinary cancer teams including screening and diagnostics, surgery, medical oncology and clinical haematology.
	Provide training and education to staff about the new role and its significance. Address staff concerns and provide support for the role transition.	Meet with administrative staff to understand the booking processes. Advertise the FNCC role in the hospital. Start by approaching the appropriate staff and seeking permission to put up posters in the ward and in clinic rooms (for patients and clinicians). This provides a friendly reminder for patients to request FNCC support and for clinicians to remember to refer patients to the FNCC. Check if the organisation has generic posters available. Refer to Appendix C for an example FNCC poster. The FNCC should contribute to MDMs and in-service meetings (refer to Appendix D for an example introductory presentation). Relationship building through regular meeting attendance heightens the FNCC's visibility and awareness about cultural aspects of care. MDM attendance prompts discussions about particular patients and the cultural aspects of their care, increasing confidence of cancer teams to refer patients to the FNCC. Provides an opportunity for informal upskilling and cultural training for cancer teams and the FNCC.

Progress markers:

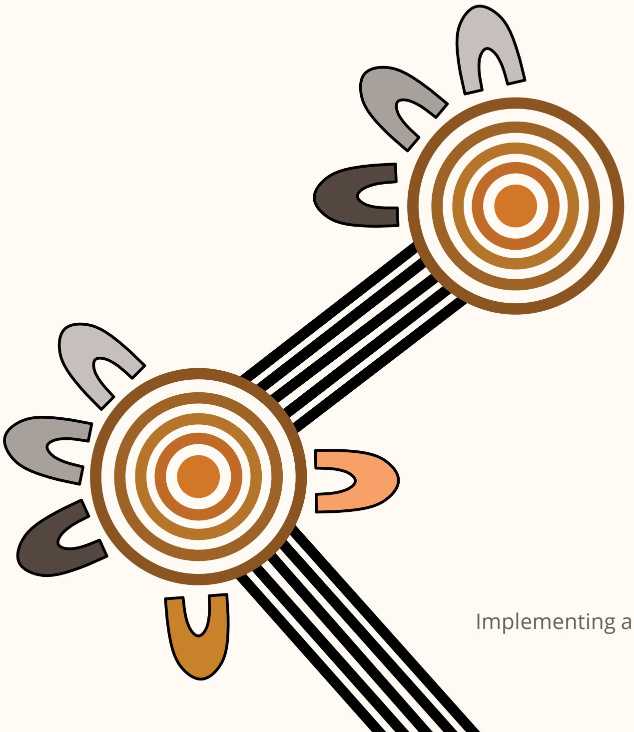
- Discussion of cultural needs and preferences at the MDM
- Increased cultural awareness among cancer staff
- Regular referrals and communication from cancer teams to the FNCC
- Inclusion of the FNCC in family meetings and treatment planning



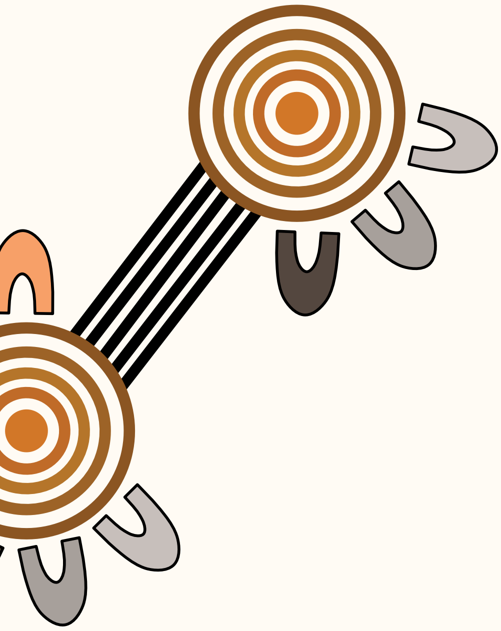
Aim	Implementation strategies	Potential activities
8. Determine the system for FNCC documentation and referral pathways	Follow organisational documentation standards so staff can easily find FNCC documentation in the patient medical record and ensure differentiation from AHLO documentation. Develop FNCC documentation template. Develop a standardised referral point and process for participating tumour streams. Referral pathways before diagnosis (screening and outpatient clinics). Referral pathways and standardised handover systems within the FNHU. Establish systems of regular communication with relevant cancer teams. Map patient entry into system and determine processes for the identification of First Nations patients.	Contact medical record support/site-specific IT and develop a customised list of all First Nations patients diagnosed with cancer or screening for cancer. If this is not possible, set aside time to manually read through patient notes to check for cancer diagnoses. A medical record report that lists all First Nations patients with cancer who have an upcoming appointment may use the following filters: 1. An appointment within the date range specified, AND 2. Indigenous status of: Aboriginal OR Aboriginal and Torres Strait Islander OR Torres Strait Islander, AND 3. Has a cancer diagnosis on their active problem list, OR 4. A 'tumour' or 'mass' diagnosis on their active problem list. Determine the identification process for inpatients, outpatients and patients at MDMs. When/where is the question asked? How/where is First Nations status recorded in patient medical records? • *'Asking the Question' Training and Resources* • Check if your service has 'Asking the question' training with local protocols. Determine the appropriate time for patient referral. Patients should be made aware of available FNCC support from the outset. Uphold patient self-determination by exchanging contact details and explaining the support available, letting patients choose if they would like FNCC support.

Progress markers:

- Early identification of patients
- FNCC introducing themselves to patients before hospital admission or at the first appointment



Aim	Implementation strategies	Potential activities
9. Understand the site context, environment, resources and organisational factors	Service mapping and patient journey mapping. Understanding how First Nations people affected by cancer access the cancer care health system (screening to survivorship and palliative care).	Patient journey mapping of a sample of patients to understand how they access the system. Refer to the: • *Optimal care pathway checklist* • Appendix E: Optimal care pathway outcome measures for medical record audit. Discussions with department heads, clinicians and consumers. Relationship building with FNHUs and local ACCHOs. Decide the process for identifying inpatients, outpatients and patients at MDMs. How/where is First Nations status recorded in patient medical records?
		Progress markers: • Standardised and timely identification processes for First Nations people affected by cancer • All patients identified and notified of FNCC support before their first admission • Gaps in care identified and addressed via FNCC support • Treatment timeframes align with optimal care pathway guidelines
10. Determine the system of communication and handover with local ACCHOs	Build relationships with doctors and relevant staff from local ACCHOs and other First Nations medical services. Develop processes and handover systems for shared patients moving between health services.	Attend AHLO forums and introduce the FNCC role to other health services and local ACCHOs. Advertise the FNCC role at local ACCHOs. Start by approaching the appropriate staff and seeking permission to put up posters. Conduct regular visits to local ACCHOs to build relationships and establish trust.
		Progress markers: • Increased referrals from local ACCHOs • Culturally safe coordination of patients between services



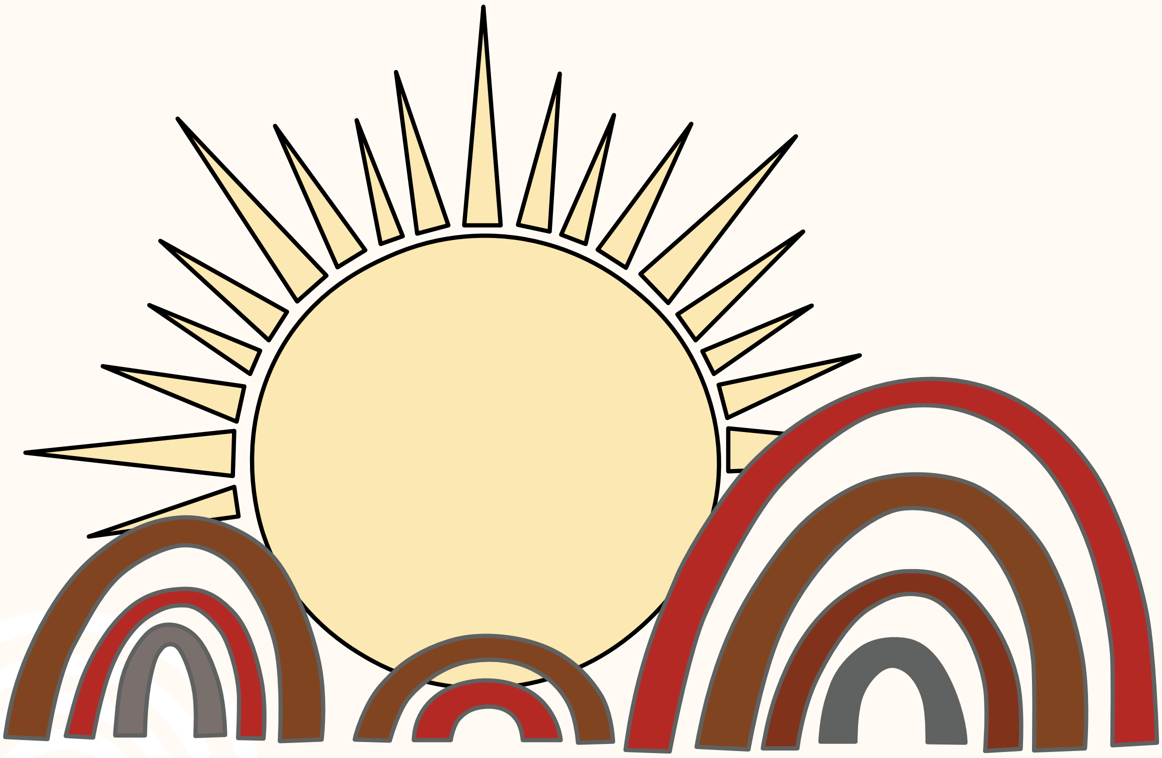
4.2 Implementation phase

Table 2: Implementation strategies, tools and activities — implementation phase

Purpose/aim	Implementation strategies	Potential activities
1. Ongoing communication and partnership with community stakeholders	Regular updates to key opinion leaders and local advocates including Elders, First Nations health workers and ACCHO representatives.	Involvement in community health promotion days. Ongoing sharing with key stakeholders in community and representatives from local ACCHOs. Participation in focus groups, research projects, advisory groups and conference presentations related to improving cultural care for First Nations people affected by cancer. **Progress markers:** • The FNCC role meets the needs of the local community • Ongoing community outreach and advocacy
2. Continue to foster ongoing executive, departmental and patient sponsorship/support for the FNCC role	Implement a communication strategy to raise awareness about the FNCC role with hospital and community stakeholders.	Ongoing consultations with cancer staff. In collaboration with the FNHU, attend educational events and share learnings with other health teams. Promote the FNHU, teaching staff members about cultural care and the support that the FNHU and FNCC provide. **Progress markers:** • Ongoing, executive support beyond the implementation project • Growing recognition about the FNCC role and the importance of culturally safe cancer care

Purpose/aim	Implementation strategies	Potential activities
3. Understand the site context, environment, resources and organisational factors	Ongoing and flexible development of the FNCC role and responsibilities, depending on site-specific needs.	Ongoing and flexible development of the FNCC role and responsibilities, depending on site-specific needs. Regularly check MDM agendas so the FNCC attends all meetings where a First Nations patient is being discussed. Regular presentations and updates to clinical teams including: • description of FNCC referral pathway • education modules such as 'Asking the question', barriers to access and engagement, and cultural safety in cancer care. Develop a system to monitor outpatient clinics and First Nations people entering the system. Weekly checking of patient lists and confirming diagnoses in patient medical records and/or communication with cancer teams. Liaise with the medical record team to improve lists where necessary.
		Progress marker: • The FNCC role meets the needs of First Nations patients and their families, cancer teams and First Nations health workers

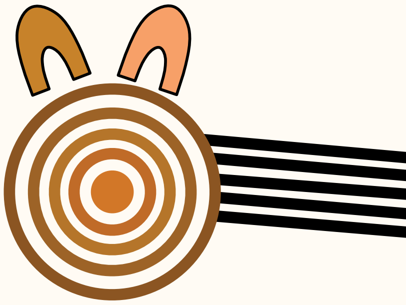
Ongoing and flexible development of the FNCC role and responsibilities, depending on site-specific needs.



4.3 Maintenance phase

Table 3: Implementation strategies, tools and activities — maintenance phase

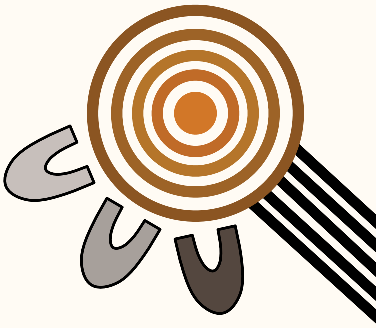
Purpose/aim	Implementation strategies	Potential activities
1. Ongoing communication and partnership with community stakeholders	Regular updates to key opinion leaders and local advocates including Elders, First Nations health workers and ACCHO representatives.	Relationship building is a continuous and intentional process. Ensure ongoing communication with key stakeholders from the planning and implementation phases. Reach out to new employees and extend relationship networks in the community. Get involved in community health promotion days.
2. Foster ongoing executive, departmental and patient sponsorship/ support for the FNCC role	To consider composite funding from a number of sources such as community organisations partnering with hospitals. Consider non-traditional sources of funding such as contributions from cancer screening programs, cultural organisations and non-government organisations.	Share evaluation findings (quantitative and qualitative data) with relevant stakeholders.
3. Monitor and support ongoing implementation, commitment and feasibility of the FNCC role	Data collection from key stakeholders (community members, patients and family members, First Nations and non- Aboriginal healthcare staff, FNCC): • What is required for the FNCC role to continue? • Can the FNCC role be maintained with existing resources?	Yarning groups, focus groups and interviews with key stakeholders (department heads, First Nations health workers, community members, First Nations patients, families) for feedback on the FNCC role. Refer to: • Appendix F for an example medical record audit (based on the optimal care pathway) • Appendix G for example interview guides. Assess the FNCC's job satisfaction and any changes required following this review.



5. First Nations cancer coordinator — patient resource and yarning guide

This section assists the FNCC to provide culturally responsive support at every stage of a patient's cancer journey. It includes yarning guides, links to culturally appropriate resources and considerations at each stage. This section has been designed in line with the second edition of the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer.*

Note that step 1 of the optimal care pathways is prevention and early detection.



Step 2. Presentation, initial investigations and referral

The FNCC's introduction to patients is very important. Being honest with a patient about your role title is necessary, but for patients who are still in the screening phase, this can be confronting. It is essential that you emphasise the role scope from the outset, which is to support patients from the screening phase, regardless of their diagnosis. It may also be helpful to explain how your role differs from an AHLO or liaison nurse.

Check your patient's medical record before introducing yourself. Find out what type of cancer they have, their planned appointments and/or treatments, their support systems, and whether they live locally. It is important to note if your patient has failed to attend any appointments. This is something you might want to enquire about: Is there anything that you could do to help your patient attend future appointments?

Example introductory script (before patient has been diagnosed)

> *Hello, my name is [your name] and I'm the First Nations Cancer Coordinator at [health service]. I support First Nations people during the screening process up to their diagnosis if this happens, and on throughout their journey. I'm calling to introduce myself and to introduce this service to you. The support I provide is generally of a cultural nature and to help you navigate the hospital system.*
>
> *Unlike other hospital staff, I can support patients throughout their journey, whether they're an inpatient or outpatient in the hospital or out in the community. If I can't answer a question or query, I'll do my best to find someone who can. Please feel free to save my number and don't hesitate to contact me. I do have set work hours, but if you have a question and text me outside of these hours, I'll get back to you when I'm back at work. Do you have any questions for me?*

If the introduction is over the phone, it is important to mention that you can meet your patient at their next outpatient appointment or, if nothing is booked, that you will keep an eye out for their next appointment and try to meet them when they attend. It might be helpful for you to mention some culturally appropriate services they can use for extra support (for example, local yarning circles for survivors and Cancer Council helplines).

Assessing patient needs

Once you have introduced yourself to your patient and they have expressed interest in FNCC support, it is important to have a yarn about:

- how your patient is feeling about their cancer or potential cancer
- any potential barriers to their treatment
- the support that is available to them.

Although these conversations are better unscripted as a casual yarn, you should have an idea of the things you want to talk about. These conversations might include the following:

- **Person-centred care:** Everybody's cancer is different and so everybody's journey is different. It's important to think about what's important to you. The care that I provide will be based on your individual needs. I will help you ensure your needs are heard and respected by your healthcare team.

Make sure to document what is important to your patients and encourage your patient to speak up about their values and needs throughout their healthcare journey. Where appropriate, you may communicate these needs to the multidisciplinary team on your patient's behalf.

- **Involving family members:** Feeling supported during this journey is just as important as getting treatment. You don't have to go through this alone, and you can choose the best people to support you on this journey. Whoever you choose, being able to yarn with people will help you make the best decisions. Are there any family members or friends who you would like to be involved in your decision-making process?

Make sure you clearly document all the key people and their contact details. Let the multidisciplinary cancer team know that these people should be present for important conversations and decision-making.

Other questions to ask:

- Are you feeling crook at times? If so, how often? Are you feeling anxious or sad?
- Do you have any responsibilities at home that you're worried about? Do you have any questions about your cancer diagnosis?
- Do you live rurally or locally?
- Do you have any money worries? (for example, cost of accommodation and travel)

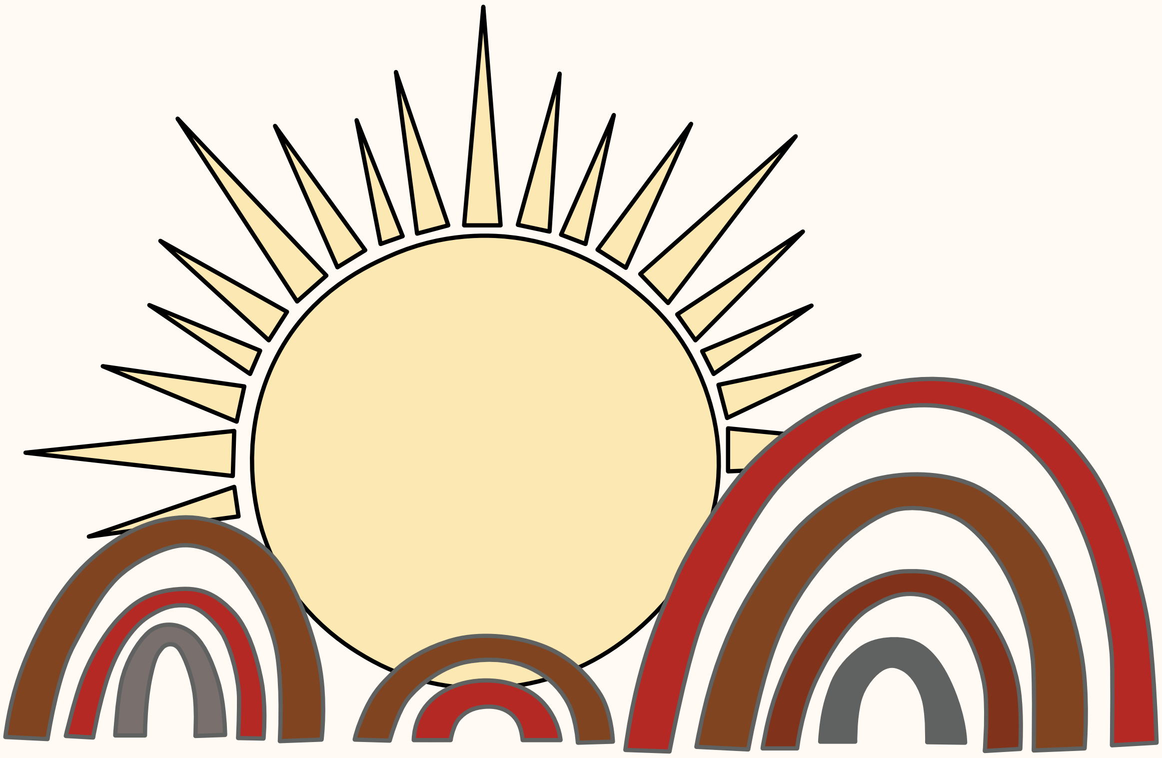
For a more comprehensive checklist for initial consultations, refer to the *Supportive care needs assessment tool for Indigenous people*. If you would also like to use a social and emotional wellbeing checklist, refer to the Menzies School of Health Research *Strong souls assessment tool*.

Helpful resources and services

Finding out or worrying that you might have cancer can be a confusing and emotional time. Many patients want to learn as much as they can about their diagnosis and potential treatment, while others may find too much information overwhelming. It is important that patients can access culturally appropriate resources that are tailored to their own needs.

After you have assessed your patient's needs and preferences, you will have an idea of the kind of resources they will find helpful. Some culturally safe resources that may be useful at this stage include:

- *Checking for cancer — what to expect*
- *Our mob and cancer* — short, video-based information from screening and testing through to sorry business. This website has information about specific tumour-streams. Created by mob for mob.
- *Cancer Council resources on cancer diagnosis, treatment and support* — support service links and helpful information for mob with a recent diagnosis.
- *Cancer Council Victoria support services* — list of support services (including Cancer Council support line, videos of mob yarning about cancer, financial counselling program, legal support program, managing cancer workshops).
- *Cancer Council Victoria Havin' a yarn: cancer journeys* — local community members yarn about their cancer journeys. They talk about their own cancer experiences, or caring for someone with cancer, and share messages of strength and wisdom.
- *VAHS Yarning SafeNStrong* (1800 959 563) — 24/7 phone support that can provide support with social and emotional wellbeing, financial wellbeing, medical support and drug and alcohol counselling.
- *Local Cancer Yarning Circle* — led by the AHLOs at Peter MacCallum Cancer Centre, this is a monthly platform for First Nations people with lived experiences of cancer to yarn and share stories and information.



Step 3. Diagnosis, staging and treatment planning

Multidisciplinary meetings

All newly diagnosed patients should be discussed by multidisciplinary teams. It is important to check if there are any First Nations patients being discussed at each week's MDMs. If you do have a patient being discussed, you should attend the MDMs to advocate for the patient's cultural needs and provide guidance around culturally safe care.

Even if you don't have any patients attending, it can still be helpful to attend the MDM meetings. It is good to stay visible and develop strong relationships with the multidisciplinary cancer team so they can contact you easily and quickly when new patients are referred.

Given the combination of ongoing cultural and coordination support that the FNCC provides, you may have a unique insight into the needs and values of your patient. It is important that you speak up in MDMs and ensure the cancer care team is considering these needs carefully.

Here are some examples of topics you might want to raise at an MDM:

- Supporting the multidisciplinary team to balance the cultural and medical needs of your patient. Highlighting the things that are important to your patient such as including family members in decision-making, using traditional bush medicine alongside pharmaceutical interventions.
- Highlighting the importance of women's business and men's business.
- Communicating potential barriers to engagement and treatment such as transport and accommodation for rural patients. Is it possible to arrange a telehealth appointment?
- Some patients are not outspoken or comfortable asking questions. Remind the multidisciplinary team to check in with patients to ensure they are comfortable with the amount of information that they are receiving.
- Helping the multidisciplinary team understand why some mob feel culturally unsafe in the healthcare system. Supporting the multidisciplinary team to provide culturally safe cancer care.

Even when you don't have patients being discussed at an MDM, there are opportunities for learning:

- Broader education about First Nations culture and events such as encouraging MDMs to open their meetings with an Acknowledgment of Country and taking part in NAIDOC Week events.
- Highlighting patients whose First Nations status has not been established ('unable to be asked') and encouraging clinicians to incorporate 'Asking the question' into their practice so they can refer to cultural supports in a timely manner.

Coordination between services

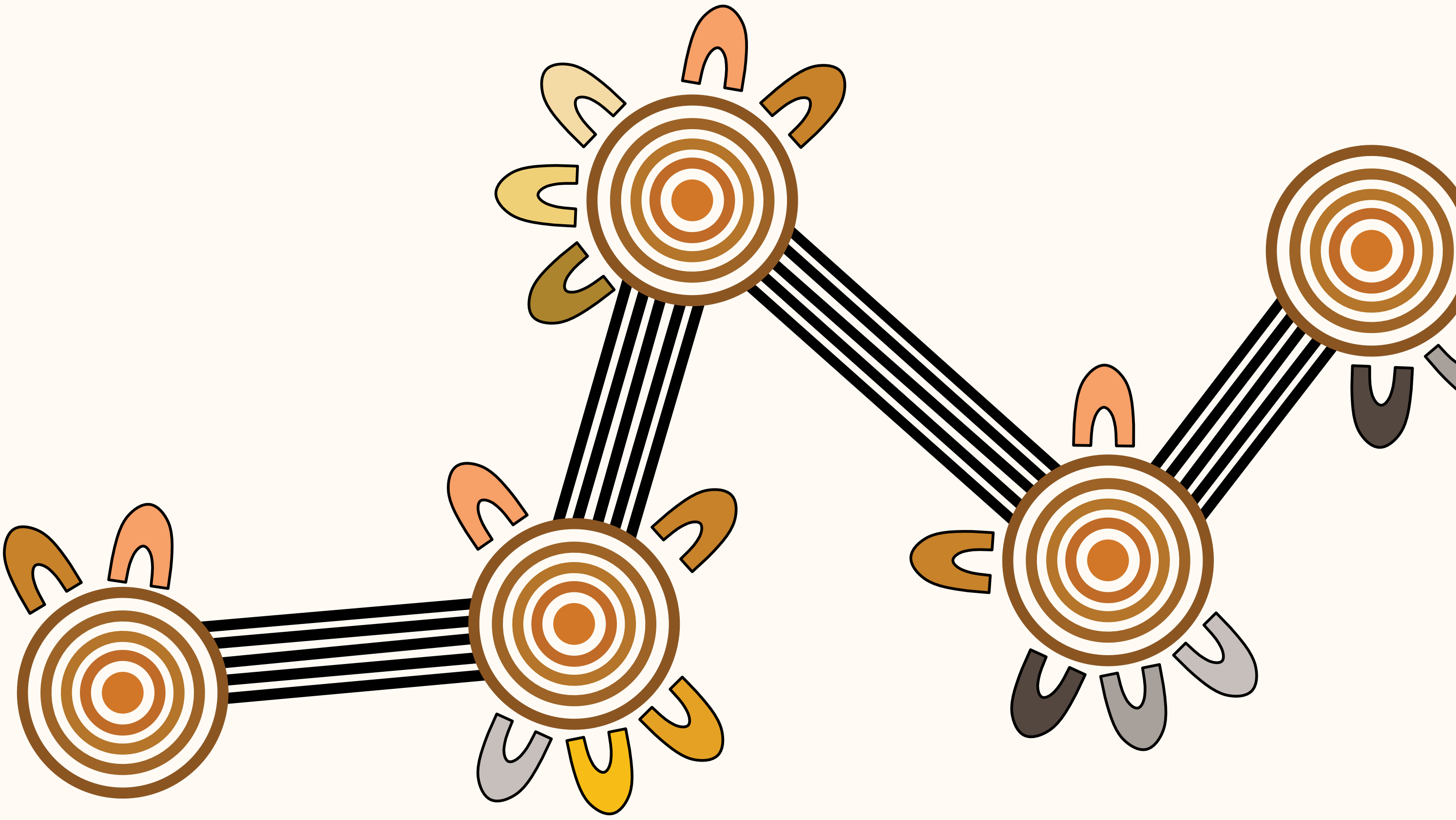
During treatment planning, it is vital that the many services providing patient care are on the same page. Because the FNCC has ongoing relationships with patients throughout their cancer journey, you are often the point of contact for patients, health professionals and other services such as:

- ACCHOs
- transport and accommodation services
- allied health professionals
- legal services
- financial services.

A scenario

> *The FNCC reaches out to Uncle before he comes into hospital to see if he needs any support. Uncle says he lives a few hours out of the city and he is a bit worried because he doesn't have a car — he doesn't know how he will get in for his appointments or where he will stay while he is getting treatment. Uncle has made several calls, including some over the weekend. He knows he can call and leave a message on the FNCC's work phone and his messages will be answered when the FNCC is back at work. On Uncle's behalf, the FNCC contacts the local ACCHO, which provides a free transport service to city hospitals. The FNCC organises accommodation near the hospital and ensures Uncle has taxi vouchers to get around the city.*

During treatment planning, it is vital that the many services providing patient care are on the same page.



Patient yarning guide

Lots of mob can feel scared, angry, lonely or sad. These feelings are normal, and it is important to remind mob that they are not alone, and it is okay to yarn about it.

Questions to ask:

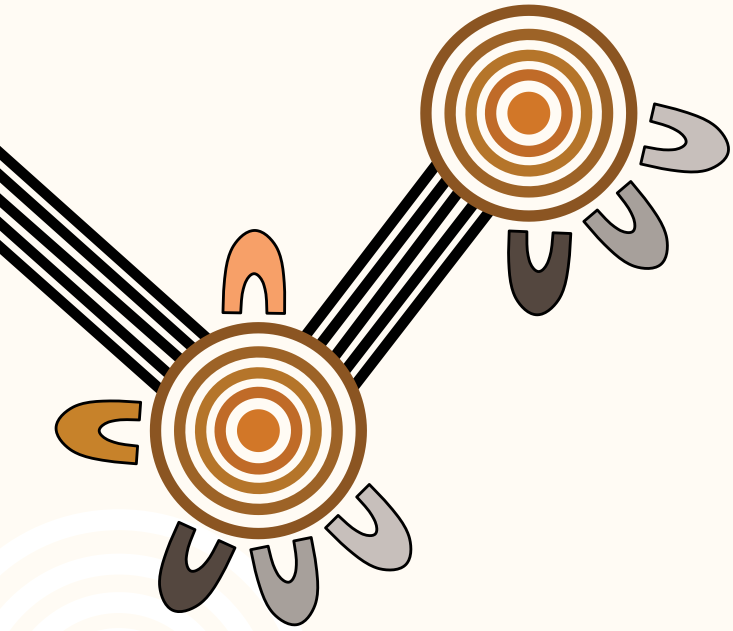
- What are your biggest concerns about your cancer? (for example, worrying about your illness getting worse, worrying about treatment results, concerns about the worries of your loved ones)
- Do you have a clear understanding of the good and bad effects of treatment?
- Would you like anything explained to you?
- Are you happy with your treatment plan?
- Is there anything you would like me to ask or request from your healthcare team on your behalf?
- Do you need any assistance or directions to get around the hospital?
- Are there any cultural needs you would like your healthcare team to be aware of (for example, seeing a health professional of the same gender, using bush medicine)

For a more comprehensive checklist for treatment consultations, refer to the *Supportive care needs assessment tool for Indigenous people*.

Helpful resources and services

Here is a list of resources that may be helpful and relevant to your patient during diagnostic staging and treatment planning:

- *Our mob and cancer* — where can I get help and support?
- *Cancer Council 'Transport' factsheet*
- *Cancer Council 'Help with money' factsheet*
- *Cancer Council — Cancer Information*.



Lots of mob can feel scared, angry, lonely or sad. These feelings are normal, and it is important to remind mob that they are not alone, and it is okay to yarn about it.

Step 4. Treatment

Treatment intent

Cancer teams will establish and document if treatment is either:

- curative
- involves anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- involves symptom palliation.

It is important that you are familiar with the optimal care pathways for each tumour stream. Keep an eye on the treatment timelines and ensure the care plan is on track. It can be helpful to send patients a text, email or phone call reminder about any upcoming appointments.

Patient yarns

The yarns that you will have will depend on the intent of treatment. It will also depend on your patient and their family, and what is important to them.

Some patients want to know everything so they can plan accordingly. Encourage the healthcare team to respect your patient's wishes and provide them with all the information. Other patients don't want to know anything, and they don't want to talk about death or dying. It is equally important that you respect these wishes and communicate them with the healthcare team.

Some questions to ask (keep it open-ended):

- What type of treatment are you happy to go forward with? What are your concerns?
- Who would you like to talk to?
- Do you have any pain? Are you feeling crook? If so, how often? (Encourage patients to communicate any pain to their cancer team, and communicate on their behalf, where appropriate.)
- What are some of the things you value most in life?

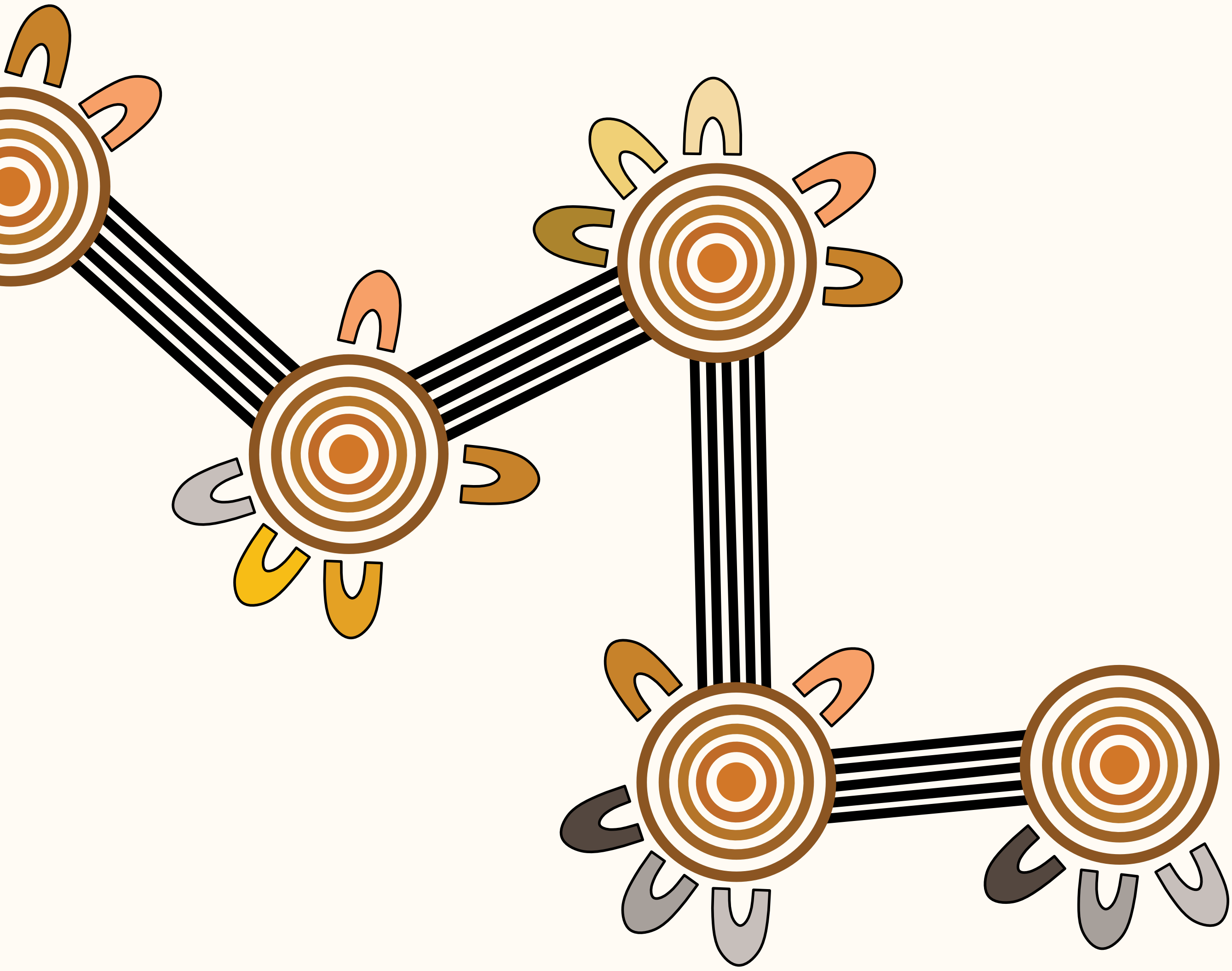
It is important to know about cancer treatment side effects so you can yarn with patients about how to recognise and manage these. It is recommended that you read *Cancer treatment side effects: a guide for Aboriginal health workers* by Cancer Institute NSW.

If the intent is best supportive care only, you may want to discuss advance care planning or palliative care, where appropriate. The *Dying to Talk* discussion starters are a great way to start this conversation. It is also recommended that you familiarise yourself with the process of setting up an advance care plan. Does your service have any local advance care planning resources for mob? Who needs to be involved in the process of setting up an advance care plan?

Helpful resources and services

Here is a list of resources that may be helpful and relevant to your patient during their treatment stage:

- *Cancer Australia 'Cancer — what to expect'* — information about what to expect before, during and after your cancer treatment
- *Dying to Talk discussion starters* (for conversations about advance care planning)
- *Advance care planning: taking control of your health journey* — a helpful guide to the advance care planning process. It is recommended that you use the Dying to Talk discussion starter first.



Step 5. Care after initial treatment and recovery

Patient yarns

- It is important to discuss your patient's beliefs and definition of living well to ensure health services are working towards your patient's ideal outcome.
- Follow-up care planning: discuss any potential barriers to the follow-up care plan (travel or cost) and strategies or referrals to support services to address these barriers.
- Make sure to send your patient reminders about any follow-up appointments.
- Even though your patient has finished with treatment, make sure they know that the FNCC support is still available to them, and they are not alone.

Helpful resources and services

- *WellMob* — Social, emotional and cultural wellbeing online resources for First Nations people
- *13Yarn* — (13 92 76) 24/7 confidential crisis support service
- *MindSpot Indigenous Wellbeing Course* - Five lessons, designed to provide information and skills equivalent to those received from a mental health professional
- Cancer Council NSW has a collection of short videos of First Nations cancer survivor stories: *Mick Pittman* (prostate cancer survivor), *Darren Barton* (bowel cancer survivor), *Rube Nixon* (breast cancer survivor) and *Sandra Markwell* (cervical and breast cancer survivor)
- *Breast Cancer Network Australia: Aboriginal and Torres Strait Islander women share their breast cancer journey*

> Even though your patient has finished with treatment, make sure they know that the FNCC support is still available to them, and they are not alone.

Step 6. Managing recurrent, residual and metastatic disease

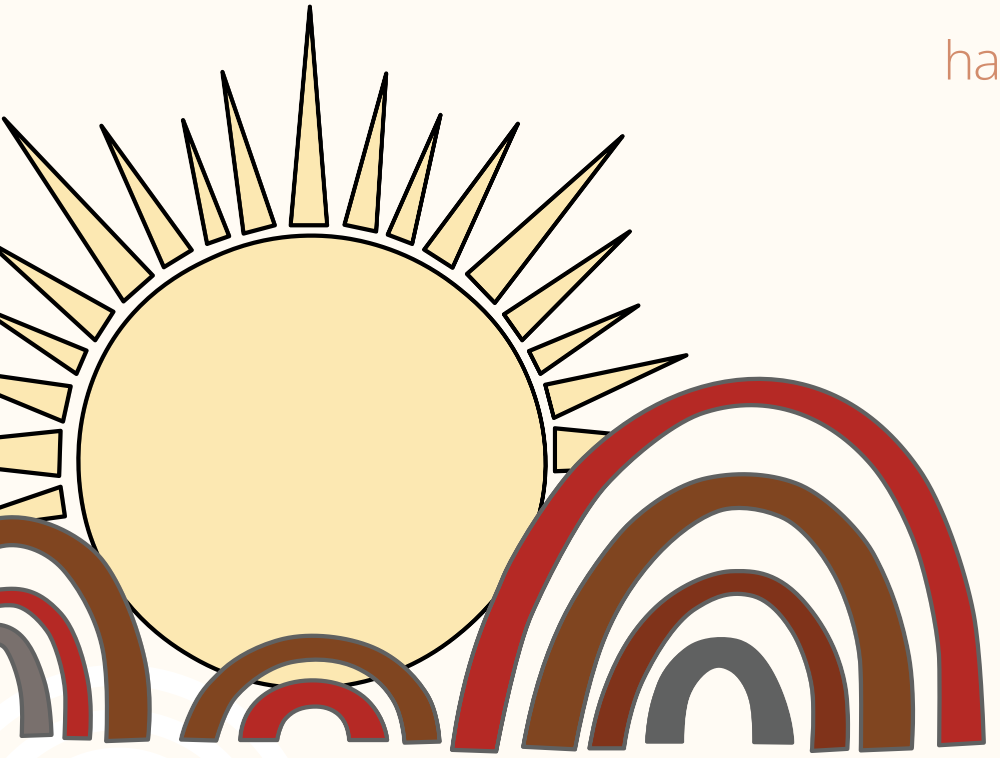
Patient yarns

For some people, finishing up with treatment can be a confusing and emotional time. It might feel like their healthcare team has forgotten about them, or it might be hard to talk about their experience when they are in the community. It is important that your patient knows they have support networks after treatment. Remind them that they can call you for a yarn at any time, even if they are not coming in for a follow-up appointment.

Helpful resources and services

- *Dying to Talk discussion starters* — starting conversations about advance care planning and end-of-life wishes
- *Our mob and cancer* — life with and after cancer
- Peter MacCallum Cancer Centre *Cancer survivorship for Aboriginal and Torres Strait Islander People and their carers* — information about cancer survivorship and a comprehensive list of support services

It is important that your patient knows they have support networks after treatment.



Step 7. End-of-life care

Patient yarns

At this stage, it is important to read the room. It can be helpful to yarn with your patient and their loved ones, read the doctors' and social workers' notes and make sure everyone is on the same page. It is important to plan ahead, talk through all options and yarn about your patient's wishes. The *Dying to Talk discussion starters* are a great way to start this conversation.

It is important to remind your patients that palliative care can help them to live the best life they can.

Some questions to ask:

- What is important to you?
- Where would you like to be for your journey to Dreaming? How do you want to be cared for?
- Who do you want to be around you?

Supporting patients in hospital

If your patient will be staying in hospital, there are lots of things you can do to make them feel more comfortable on their journey to Dreaming. Some things that might be helpful:

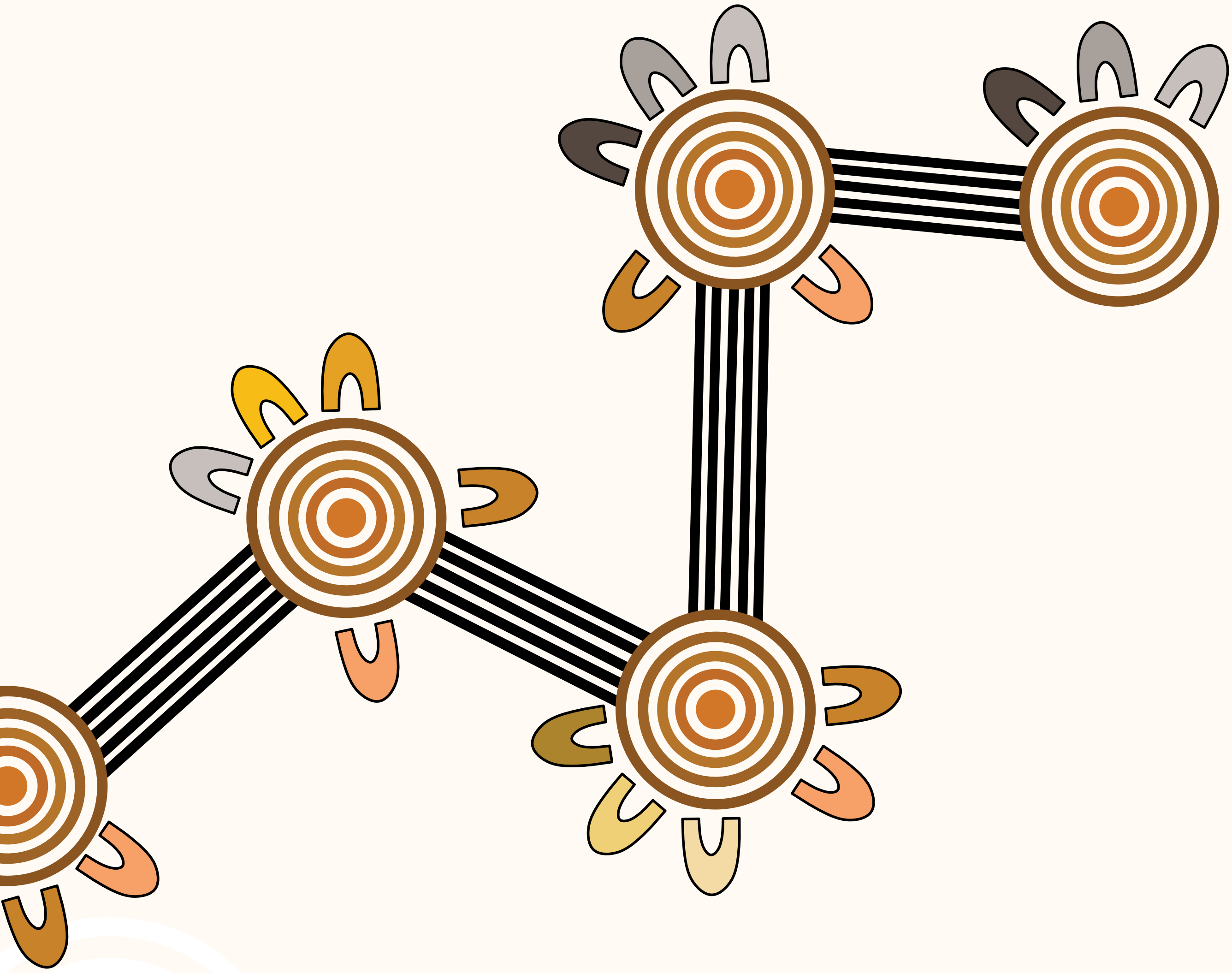
- Advocate for your patient to have space for family members to be present.
- Familiarise yourself with your service's policies around smoking ceremonies and other cultural ceremonies that may be important to your patient at the end of life. Is there a space to conduct these ceremonies?
- Ensure your patient has a trusted family or community spokesperson.

A scenario

> *Aunty was discussed at the MDM and the team has concluded that there is no further curative treatment they can offer her. A meeting was organised to relay this information to Aunty and her family. Due to Aunty's vulnerabilities and the distance and obligations of her family, Aunty requested that the FNCC be present to support her for the meeting. Aunty is told her cancer is aggressive, not getting better, and a referral has been made to palliative care. Aunty is quite distressed because she doesn't want to be in hospital, but the palliative care team don't think there will be enough time to get Aunty back home to Country. The FNCC speaks to Aunty and her family about what is important to them. They want a space for everyone to be together and they would like to organise a smoking ceremony for Aunty. The FNCC advocates for Aunty to be moved to a bigger room with less restrictions on visitors. The FNCC and the AHLO team come and see Aunty every day. They give her a possum skin pelt and a quilt with First Nations art to wrap herself in. They organise to host the smoking ceremony in an outdoor courtyard near her room.*

Helpful resources and services

- *IPEPA animated video series* — a series of animated videos, narrated by Sean Choolburra, including: What is palliative care?, Understanding trajectories of serious illness, Loss, grief and healing, Feelings, and Pain management
- *Palliative Care Australia's Aboriginal and Torres Strait Islander pack* - VACCHO's Welcome to our journey and VACCHO's Understanding the palliative care journey — a guide for individuals, carer communities and family
- *Gwandalan Palliative Care* — online resources and e-learning modules about palliative care
- *Our mob and cancer — If the cancer comes back or won't go away* — information about sorry business, palliative care and making wills for free or at a low cost



6. Evaluation

Evaluation is crucial for understanding the true impact of a new healthcare role, as well as identifying the key factors contributing to the success or failure of its implementation. This project used the RE-AIM framework[29,30] to assess the implementation strategies undertaken. The impact of the FNCC role was assessed according to measures related to the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer.*

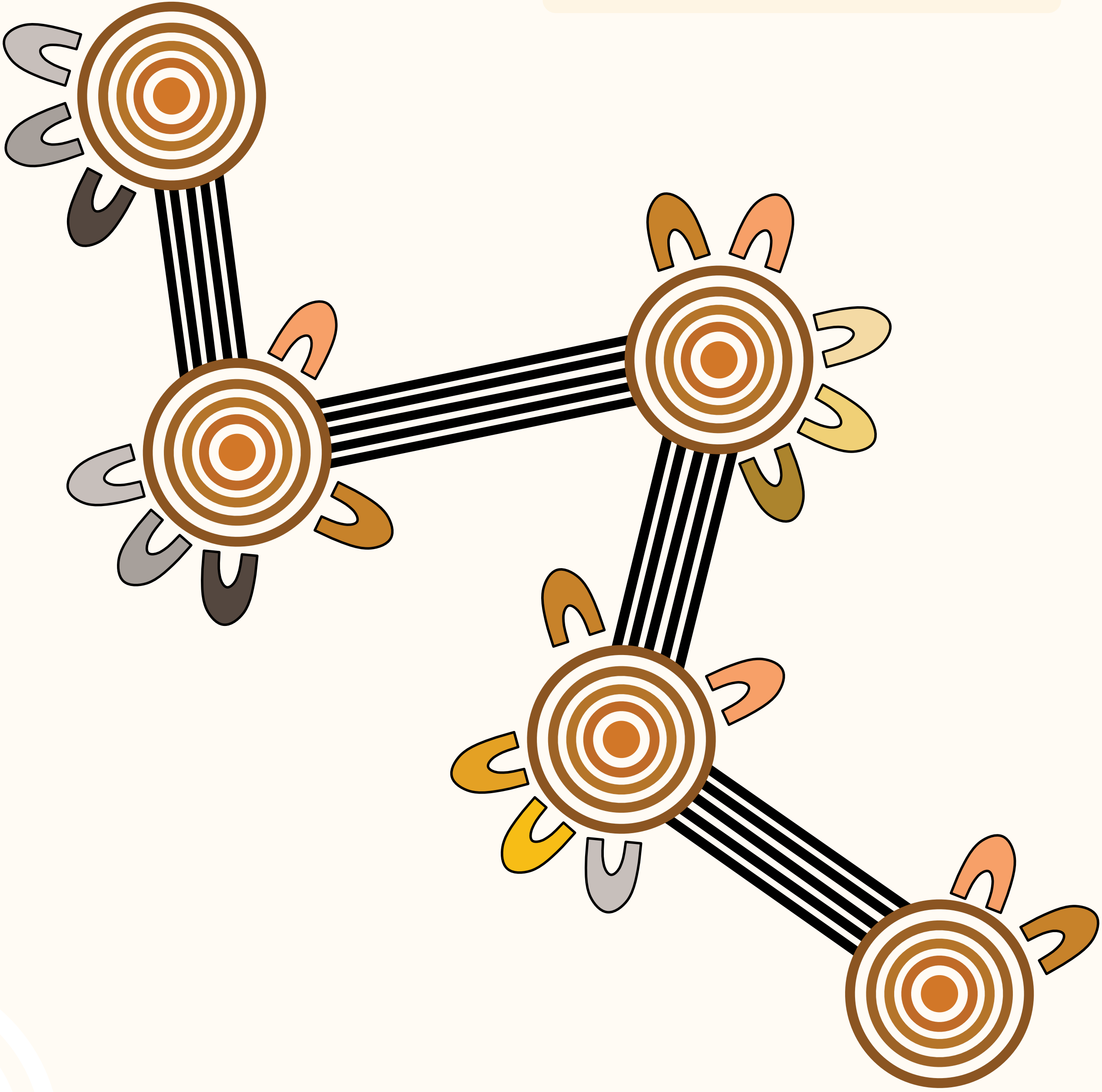
Table 4 summarises the RE-AIM domains and presents examples of the methods that might be used to evaluate each domain. Appendix E has audit tools for evaluating the FNCC impact according to the optimal care pathway, and Appendix F includes sample interview guides.

The quotes throughout this toolkit are taken from our qualitative evaluation.

Table 4: Evaluation measures for RE-AIM domains

RE-AIM domain	Questions to ask	Potential measures
Reach (individual level)	What percentage of the target population came in contact with the program?	Target population: First Nations people affected by cancer (target tumour streams) receiving treatment at healthcare service(s).
Effectiveness (individual level)	Does the intervention affect key targeted outcomes? Any unintended adverse consequences? Difference between intervention effectiveness and implementation effectiveness?	Target outcomes: Adherence with optimal care pathway targets (refer to Appendix E for quantitative outcome measures and Appendix F for an example interview guide): • medical record audit • questionnaires • in-depth interviews with multidisciplinary team members who interacted with the FNCC.
Adoption (setting or organisational level)	What percentage of the target settings and organisations will use the program, and under what circumstances?	Determine the number of settings approached and the number of settings that agreed to implement the FNCC role. Settings might include cancer care services, community-based healthcare services, MDMs and clinics, FNHUs. Measures include: • in-depth interviews with multidisciplinary team members exploring reasons for adopting or not adopting the FNCC role • number of clinicians introduced/ involved compared with the number of clinicians referrals to the FNCC role • referral rates from ACCHOs, GPs, multidisciplinary cancer teams, FNHUs • field notes and observation.

RE-AIM domain	Questions to ask	Potential measures
Implementation (setting or organisational level)	Did multidisciplinary team members follow protocols for implementation? Were various components delivered as intended?	• Referral rates from ACCHOs, GPs, multidisciplinary cancer teams, FNHUs • In-depth interviews with multidisciplinary team members • Field notes and observation
Maintenance	What is the intended use of the program after its evaluation at the clinician level? Recommendations for use in other settings?	• Cultural awareness questionnaire delivered to multidisciplinary cancer teams • In-depth interviews with multidisciplinary team members exploring cultural awareness in cancer care • Patient outcome data • Barriers to sustainability explored via interviews with key stakeholders



7. Conclusion and future directions

This implementation toolkit provides a guide for healthcare and research teams to establish and implement an FNCC role. The implementation strategies outlined in this toolkit emphasise the importance of community governance, partnership and First Nations self-determination throughout the planning, implementation and maintenance phases. Engaging with local community from the outset is crucial to ensuring the role responds to community needs.

Successful implementation of the FNCC role requires commitment from executive leadership, multidisciplinary collaboration and ongoing support from clinicians and First Nations staff in the healthcare service and community. Establishing clear referral pathways, a documented process and communication channels between the FNCC, FNHUs, multidisciplinary cancer teams and community-based health services is essential for coordinated, culturally safe care. Through these connections, the FNCC can serve as a conduit for two-way learning, enhancing cultural competency among non-Indigenous cancer teams while also increasing cancer-specific knowledge within the First Nations health workforce.

While this implementation toolkit has presented an FNCC model that operates primarily within one acute-based service, the project has identified alternative models and areas for future research:

- Consider co-locating the FNCC role across multiple healthcare services if the patient load at a single site is small. This could involve the FNCC being based at one hospital but supporting patients across the region. It would be key that the role had formal appointments and linkages with cancer teams at all healthcare services.
- Establish dedicated cultural education roles to build on the significant education and training component that emerged as part of the FNCC role.
- Explore similar cultural navigation models for other health areas and departments such as palliative care, emergency departments, maternity services, renal care, cardiac services and respiratory care.

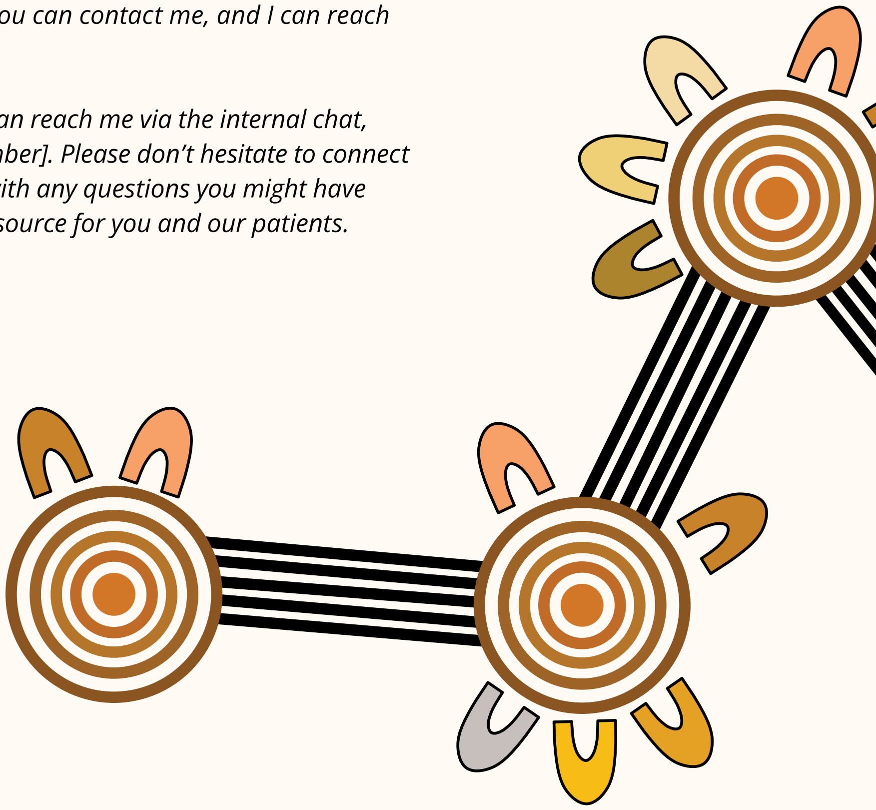
As healthcare services implement and refine the FNCC role, ongoing evaluation and community engagement will be crucial to ensure the role continues to meet the evolving needs of First Nations communities.

> Through these connections, the FNCC can serve as a conduit for two-way learning, enhancing cultural competency among non-Indigenous cancer teams while also increasing cancer-specific knowledge within the First Nations health workforce.

Appendix A

First Nations cancer coordinator 'elevator pitch' (1-minute summary) for multidisciplinary cancer staff

> *Hello, my name is [your name] and I'm the First Nations cancer coordinator. My role focuses on improving cancer care for our First Nations community. My role aims to make cancer care more accessible to our First Nations patients by providing continuous and culturally safe care coordination throughout their cancer journeys. This role complements the cultural support already provided by the First Nations health unit, but it's a bit different because it's an integrated part of the cancer care team. While you focus on providing clinical care, I can help patients communicate their cultural needs and make sure they are supported in their journey. I attend multidisciplinary meetings, clinics and appointments, but I'm also available to speak with my patients when they are back in the community.*
>
> *I understand that remembering to ask about First Nations status and making referrals can be challenging with all the other demands on your time. While I try very hard to identify patients through clinic and admissions lists, I also rely on your referrals. The earlier that cultural supports are offered, the better. As soon as you've identified a patient as First Nations, please ask them if they would like to see the First Nations cancer coordinator and provide my details. Alternatively, you can contact me, and I can reach out to the patient directly.*
>
> *I'm based in the First Nations health unit, and you can reach me via the internal chat, email [provide email], or phone [provide phone number]. Please don't hesitate to connect me with any First Nations patients you identify, or with any questions you might have about your patients' cultural needs. I'm here as a resource for you and our patients.*



Appendix B

First Nations cancer coordinator position description template

The core responsibilities/duties/activities associated with this position are to:

- contribute to the mapping and understanding of points of access to cancer services
- provide input and advice on collating resources for First Nations people affected by cancer and their families
- establish systems of support of tumour-specific cancer care coordinators to facilitate optimal culturally appropriate and safe care of First Nations people affected by cancer
- work alongside tumour-specific cancer care coordinators to support First Nations people affected by cancer and their families
- establish systems of support and collegiate sharing with AHLOs or First Nations health workers to facilitate best cancer care of First Nations people affected by cancer
- work alongside First Nations health workers to support First Nations people affected by cancer and their families
- establish systems of support and collegiate sharing with healthcare teams at local ACCHOs and First Nations health services
- work alongside the research team to assist with data that will contribute to evaluating the First Nations cancer coordinator model of care.

Duties relevant to patient care

- Ensure cultural supports and planning are embedded in the multidisciplinary cancer treatment planning for all First Nations people affected by cancer.
- All First Nations patient care is provided along the agreed cancer care treatment plan.
- First Nations people affected by cancer receive optimal treatment without unnecessary delays or gaps in service provision.
- Perform a liaison role to ensure an effective referral process that enhances communication between the patient, the health service and the general practitioner or ACCHO.
- Actively manage cancer patients' progression through the system to ensure equitable access to care within desired timeframes.
- Be a cultural liaison between tumour stream cancer coordinators and the patient.

Duties relevant to coordination, mentorship, support, education, connection

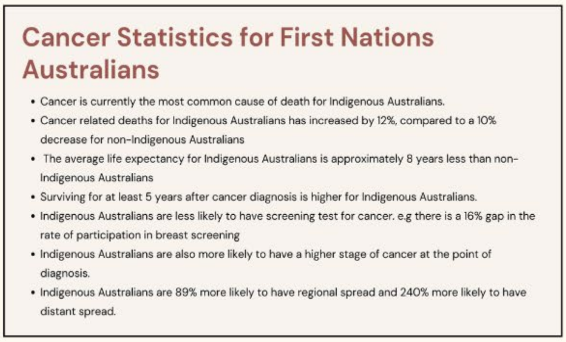
- Orientate and educate other health professionals regarding Cancer Australia's *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* and their families.
- Provide secondary consultation for the cancer workforce working with First Nations patients and their families.
- Facilitate and embed routine use of existing First Nations co-designed resources to support patients with cancer and their families, and the cancer care workforce.

Appendix C

Powerpoint presentations for FNCC introductions to multidiciplinary teams

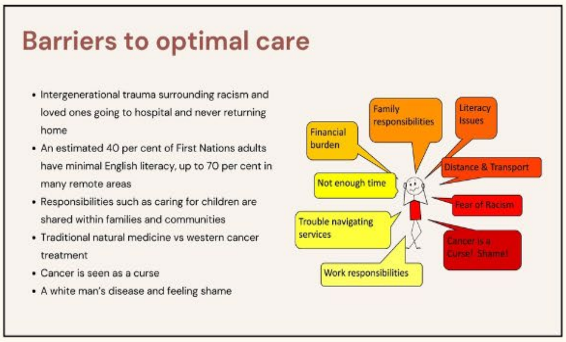
Introducing: First Nations Cancer Coordinator

Improving cancer outcomes and enhancing cultural safety for the Aboriginal and Torres Strait Islander Community in Victoria



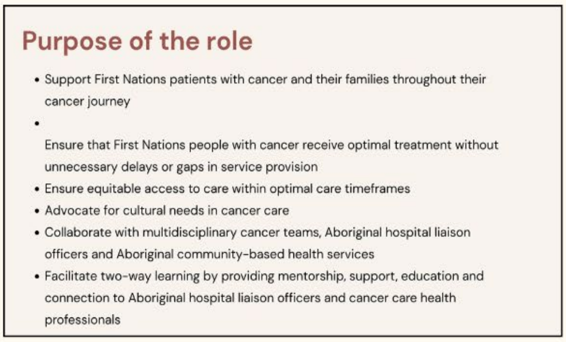
Cancer Statistics for First Nations Australians

- Cancer is currently the most common cause of death for Indigenous Australians.
- Cancer related deaths for Indigenous Australians has increased by 12%, compared to a 10% decrease for non-Indigenous Australians
- The average life expectancy for Indigenous Australians is approximately 8 years less than non-Indigenous Australians
- Surviving for at least 5 years after cancer diagnosis is higher for Indigenous Australians.
- Indigenous Australians are less likely to have screening test for cancer. e.g there is a 16% gap in the rate of participation in breast screening
- Indigenous Australians are also more likely to have a higher stage of cancer at the point of diagnosis.
- Indigenous Australians are 89% more likely to have regional spread and 240% more likely to have distant spread.



Barriers to optimal care

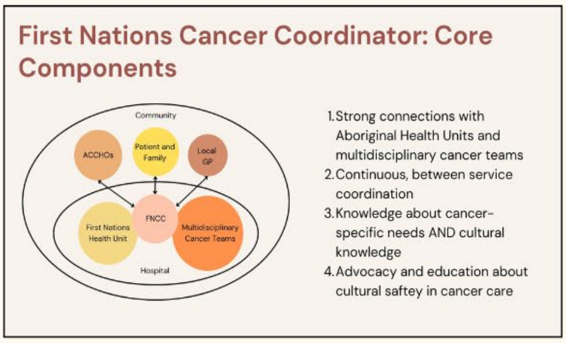
- Intergenerational trauma surrounding racism and loved ones going to hospital and never returning home
- An estimated 40 per cent of First Nations adults have minimal English literacy, up to 70 per cent in many remote areas
- Responsibilities such as caring for children are shared within families and communities
- Traditional natural medicine vs western cancer treatment
- Cancer is seen as a curse
- A white man's disease and feeling shame



Purpose of the role

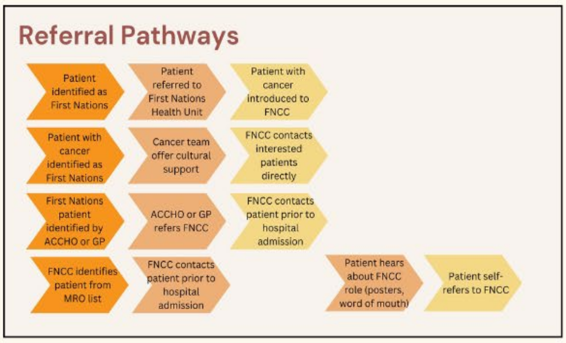
- Support First Nations patients with cancer and their families throughout their cancer journey
-

  Ensure that First Nations people with cancer receive optimal treatment without unnecessary delays or gaps in service provision
- Ensure equitable access to care within optimal care timeframes
- Advocate for cultural needs in cancer care
- Collaborate with multidisciplinary cancer teams, Aboriginal hospital liaison officers and Aboriginal community-based health services
- Facilitate two-way learning by providing mentorship, support, education and connection to Aboriginal hospital liaison officers and cancer care health professionals



First Nations Cancer Coordinator: Core Components

1. Strong connections with Aboriginal Health Units and multidisciplinary cancer teams
2. Continuous, between service coordination
3. Knowledge about cancer-specific needs AND cultural knowledge
4. Advocacy and education about cultural saftey in cancer care



Referral Pathways

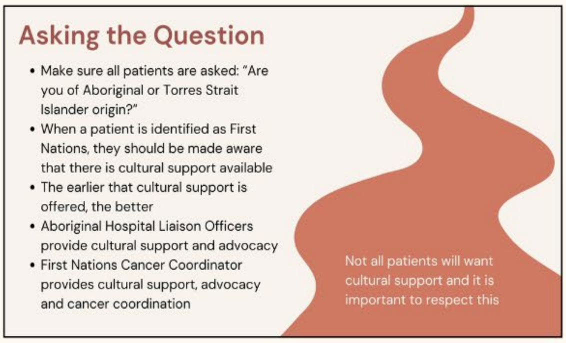
Patient identified as First Nations → Patient referred to First Nations Health Unit → Patient with cancer introduced to FNCC

Patient with cancer identified as First Nations → Cancer team offer cultural support → FNCC contacts interested patients directly

First Nations patient identified by ACCHO or GP → ACCHO or GP refers FNCC → FNCC contacts patient prior to hospital admission

FNCC identifies patient from MRO list → FNCC contacts patient prior to hospital admission

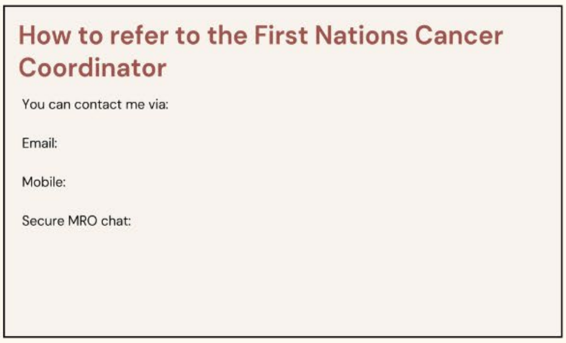
Patient hears about FNCC role (posters, word of mouth) → Patient self-refers to FNCC



Asking the Question

- Make sure all patients are asked: "Are you of Aboriginal or Torres Strait Islander origin?"
- When a patient is identified as First Nations, they should be made aware that there is cultural support available
- The earlier that cultural support is offered, the better
- Aboriginal Hospital Liaison Officers provide cultural support and advocacy
- First Nations Cancer Coordinator provides cultural support, advocacy and cancer coordination

Not all patients will want cultural support and it is important to respect this



How to refer to the First Nations Cancer Coordinator

You can contact me via:

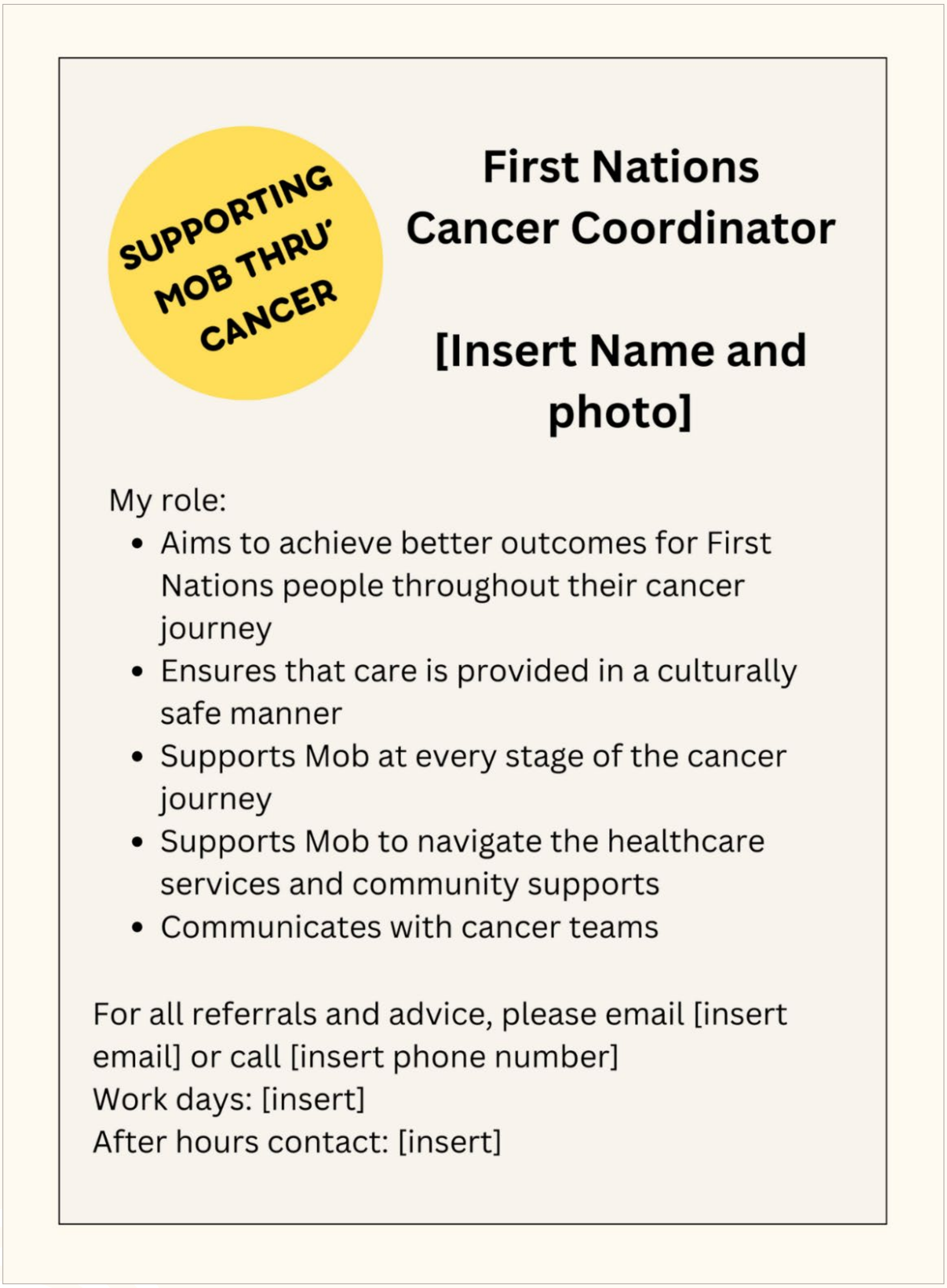
Email:

Mobile:

Secure MRO chat:

Appendix D

Sample First Nations cancer coordinator poster



SUPPORTING MOB THRU' CANCER

First Nations Cancer Coordinator

[Insert Name and photo]

My role:

- Aims to achieve better outcomes for First Nations people throughout their cancer journey
- Ensures that care is provided in a culturally safe manner
- Supports Mob at every stage of the cancer journey
- Supports Mob to navigate the healthcare services and community supports
- Communicates with cancer teams

For all referrals and advice, please email [insert email] or call [insert phone number]
Work days: [insert]
After hours contact: [insert]

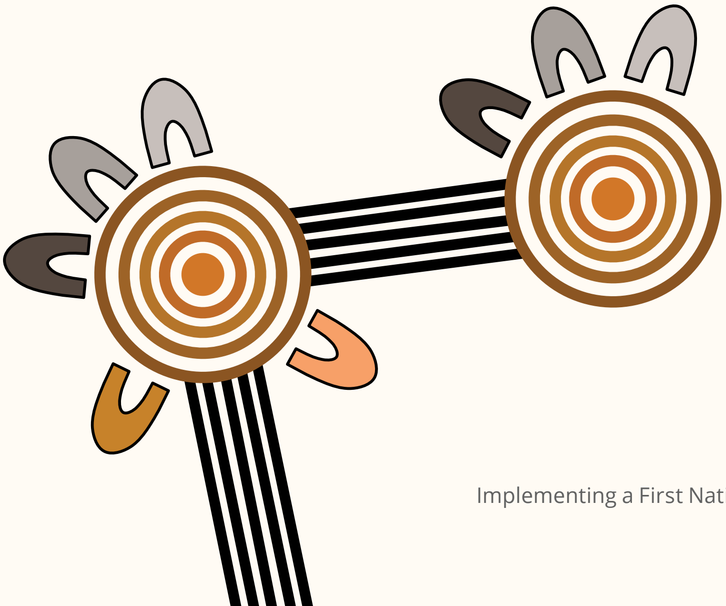
Appendix E

Optimal care pathways (pre and post implementation)

The following measures can be adapted for use in a medical record audit or structured and semi-structured interviews. The optimal care pathway checklist column has been structured according to the patient-facing and outward-facing (education and advocacy) aspects of the role.

Table 5: Checklists and measures associated with steps in the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* **and** *A guideline to implementing the optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*

Steps	OCP Checklist	Measure
Step 1. Prevention and early detection	Patient facing • Is there a protocol/guide in place for discussing cancer risk and family history in a culturally appropriate way? Outward facing • Working with ACCHOs and/or First Nations health and community groups to promote awareness of cancer risk and encourage early help seeking. • Increasing access and encouraging participation in population-based cancer screening programs.	• Relevant personal information recorded in patient medical records (e.g., family history of cancer, current or former smoking, increasing age) • Patients lost to follow up (Yes or No) • Source of referral: how many patients were diagnosed from pre-screening versus incidental finding?

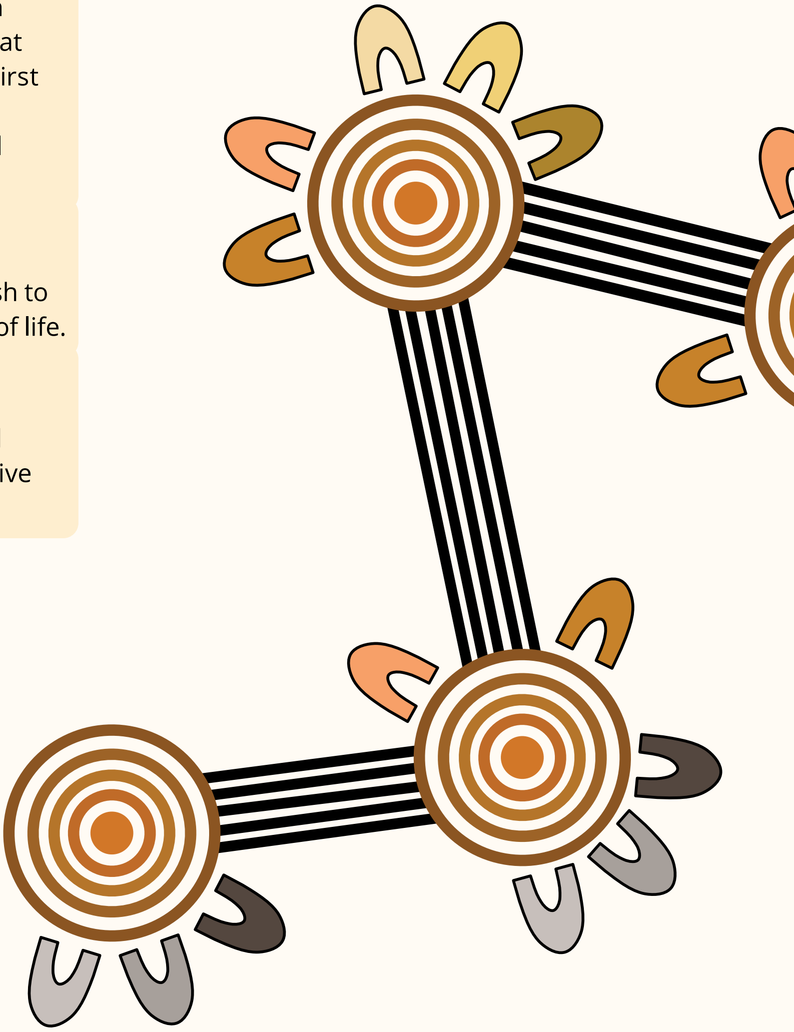


Steps	OCP Checklist	Measure
Step 2. Presentation, initial investigations and referral	Patient facing: • Understand and have strategies to address potential barriers to early presentation of cancer symptoms in First Nations people • E.g. implementing the SCNAT-IP tool • Provide culturally appropriate information about steps involved in the investigation of cancer symptoms? • Facilitate access for First Nations people to appropriate support to help with accessing and attending specialist appointments? • Implement strategies to facilitate timely follow-up on the status of tests or referrals for investigation of cancer symptoms in First Nations people? • Family members/carers involved in the decision making for optimal care timelines (this may be facilitated by communication technologies, additional discussions) Outward facing: • Run education sessions/ publish newsletter articles highlighting the importance of timely referral and investigation of cancer symptoms in First Nations people • Develop and participate in campaigns to increase community awareness of cancer signs and symptoms	• Potential barriers to treatment and follow-up recorded in patient medical record (e.g., financial issues, travel and accommodation requirements, caring arrangements for other family members) • SCNAT-IP tool used and recorded in patient medical records • Coordination of travel, accommodation and support needs recorded in patient medical record • Cultural support (FNCC) is available to help patients access and attend specialist appointments. Presence of cultural support recorded in patient medical records • Medical Record evidence of referrals made to other culturally appropriate services (e.g. local ACCHO) • Patients lost to follow up (Yes or No) • Timing of AHLO/ FNCC involvement (as evidenced in patient medical records) following patient admission • Medical Record recorded presence of family members/carers at appointments

Steps	OCP Checklist	Measure
Step 3. Diagnosis, staging and treatment planning	Patient facing • Routinely identify First Nations patients during MDMs • Have expertise in culturally appropriate care on the multidisciplinary team (FNCC) • Use culturally appropriate care coordination to support timely diagnostic work up appropriate to the cancer type • Consider suitable clinical trials and provide culturally appropriate information about clinical trials • Collect and use patient-reported outcome and experience measures relevant to First Nations people affected by cancer? Outward facing: • Work with national clinical trial organisations about ways to increase access to and participation in cancer clinical trials by First Nations people	• Presence of cultural support (FNCC/ AHLO) recorded in MDM notes for First Nations patients • The timeframe for diagnosis and treatment aligns with the patients and carers needs. I.e., if rural, can patients manage accommodation and travel expenses to access treatment? • Appointment flexibility noted in Medical Record, i.e. do rural patients have access to telehealth appointments? • Medical Record recorded discussions around potential treatment costs with the patient and/or carer • Patients informed about, and offered access to the process of clinical trials • Number of “did not attends” (DNAs) versus total number of appointments, per patient • “DNAs” followed up in a timely manner (date of missed appointment, date of follow up call) • Reason for “DNA” recorded in Medical Record • Patients lost to follow up (Yes or No) • Co-morbidities measured and recorded in Medical Record

Steps	OCP Checklist	Measure
Step 4. Treatment	**Patient facing** • Routinely engage input from an identified health professional or other health professional with expertise in culturally appropriate and responsive care to provide support for people after completion of active treatment for cancer? • Discuss patient beliefs and definition of living well to ensure health services are working towards the patient's ideal outcome? • Provide culturally appropriate information to help First Nations people understand plans for follow-up care and how to access support once initial treatment has been completed? **Outward facing** • Include specific survivorship considerations for First Nations people as part of programs of work exploring shared care/survivorship care	• Patients lost to follow up (Yes or No) • Supportive care needs assessment (SCNAT-IP) completed and recorded • Regular and timely recalls and follow up appointments recorded • Cultural considerations recorded in follow-up care plan • A follow-up schedule (including tests required and timeframes) established with patient and/or carer
Step 6. Managing recurrent, residual or metastatic disease	**Patient facing** • Have agreed strategies and information to help patients understand their situation at the point of recurrence or diagnosis of residual or metastatic disease? • Are the rehabilitation outcomes culturally appropriate and reflective of the patient's preferences?	• Patients lost to follow up (Yes or No) • A process for rapid re-entry to medical services for suspected recurrence • Cultural considerations recorded in advanced care directive • Patients whose medical records show evidence of advance care planning or palliative care referrals made to culturally appropriate services

Steps	OCP Checklist	Measure
Step 7. End of life care	Patient facing • Use culturally appropriate language and strategies to discuss death and dying with First Nations people • Have culturally appropriate strategies and pathways to identify and respond to the needs and preferences of First Nations patients at the end of life? • Support and facilitate provision of cultural practices for First Nations people, their families, carers and community at end of life? Outward facing • Develop and distribute information resources on advance care planning that is culturally relevant for First Nations people, tailored, if possible, to reflect local services and context. • Develop and implement pathways and services to support patients who wish to return to country at end of life. • Empower First Nations communities to provide input into messaging and information about palliative and end-of-life care.	• Advance care directive in place • Cultural considerations recorded in advance care directive • The most appropriate place of care and preferred place of death established with patient and recorded in advance care directive/ Medical Record • Location of death recorded • Requirements for cultural ceremonies and practices recorded



Appendix F

First Nations cancer coordinator evaluation — example interview guide

Staff and stakeholder interview guide (post-implementation)

1. What would you say are the core components of a First Nations cancer coordinator role and how it interacts with your team, hospital or organisation?
2. Can you describe how the role may have been helpful in the work of your team and/or organisation?
3. Can you think of any challenges that the implementation of this role has introduced for you / your team / the wider organisation?
4. What might be some ideas or strategies that we could use to further improve cancer care for First Nations people?
5. Prompts
   - Ideas/recommendations for the cancer coordinator or navigator role in the future?
   - Ideas/strategies/recommendations for improving cancer and palliative care?
6. Is there anything else you want to share about the coordinated care of First Nations people that I haven't asked you about today?

Patient and family interview guide (post-implementation)

Interview introduction

We're delighted to meet with you today and grateful to you for agreeing to share with us about your experiences and thoughts about your own cancer or your family member's cancer journey. We'd also like to talk to you about your cancer care and the support you may need or have received.

What you share today is really important. There are no right or wrong answers — we are simply interested in your experience and views. If at any time you feel distressed, please feel free to pause, stop, come back to or choose not to answer any questions.

We'll have about 30 to 45 minutes to talk today. With your permission we'll be audio recording this interview, just so we can carefully think through and understand the things you bring up. Once recorded, your name will not be associated with the things you say — we'll allocate you a separate ID number instead. What you share will not have any bearing on your relationships with the hospital or the healthcare staff you see. All data will be securely stored in our research office at [location]. Does that sound OK?

Guiding questions

1. Can you tell me about what has been happening for you leading up to your cancer diagnosis, treatment or surgery? What was going through your mind during this time?

2. Have you had, or do you have support from First Nations health staff and services in your cancer care?
   - In the primary health care and/or First Nations community services?
   - In the hospital — AHLO and/or FNCC?
   - As part of your care, have you met the FNCC? How were you referred to the FNCC? In what ways have they provided support to you?
   - In what areas do you see they are helpful for First Nations people affected by cancer and their families?

3. What has been most helpful with your treatment or care?
   - In the primary health care and/or First Nations community services?
   - In the hospital — AHLO and/or FNCC?

4. Are there things that are missing with your treatment or care?
   - What could we do better? (what has been unhelpful? what are unmet needs?)
   - In the primary health care and/or First Nations community services?
   - In the hospital — AHLO and/or FNCC?

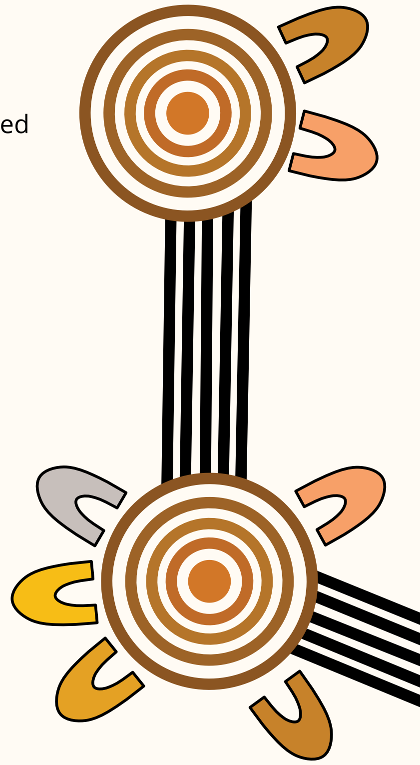
5. Have the needs of your family, caregiver or support person(s) been met?
   - What has been most helpful in meeting their needs? (for example, information resources, someone to talk to, AHLO and/or FNCC services)
   - Is there anything else that we need to do to better support them?

6. What might be some ideas/strategies that we could use to improve cancer care for First Nations people?
   - What are your ideas and recommendations for improving culturally responsive and safe care for you, your family and community (your mob)?

7. Is there anything else you want to tell us about your cancer care that we haven't asked about today?

Thank you for your time. You have been very generous with your thoughts and reflections.

Sometimes talking about these things can make things come up for us. Perhaps there might be someone who you can call or have a cup of tea with today? Or if you would like to talk with someone else, we've included some helpful contacts in your information sheet for you to reach out to.



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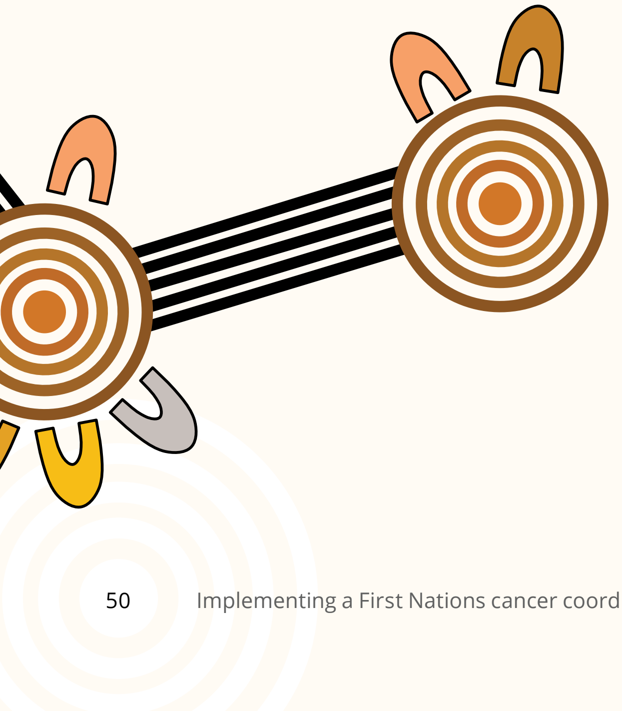

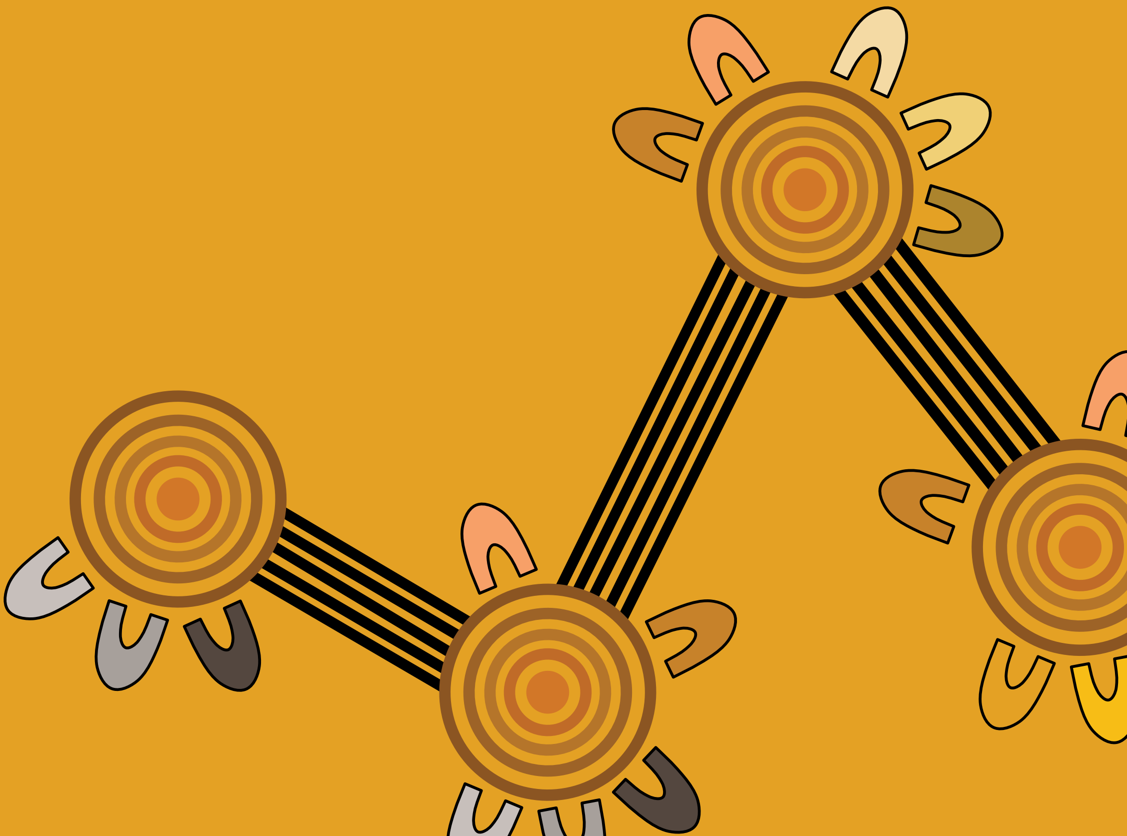

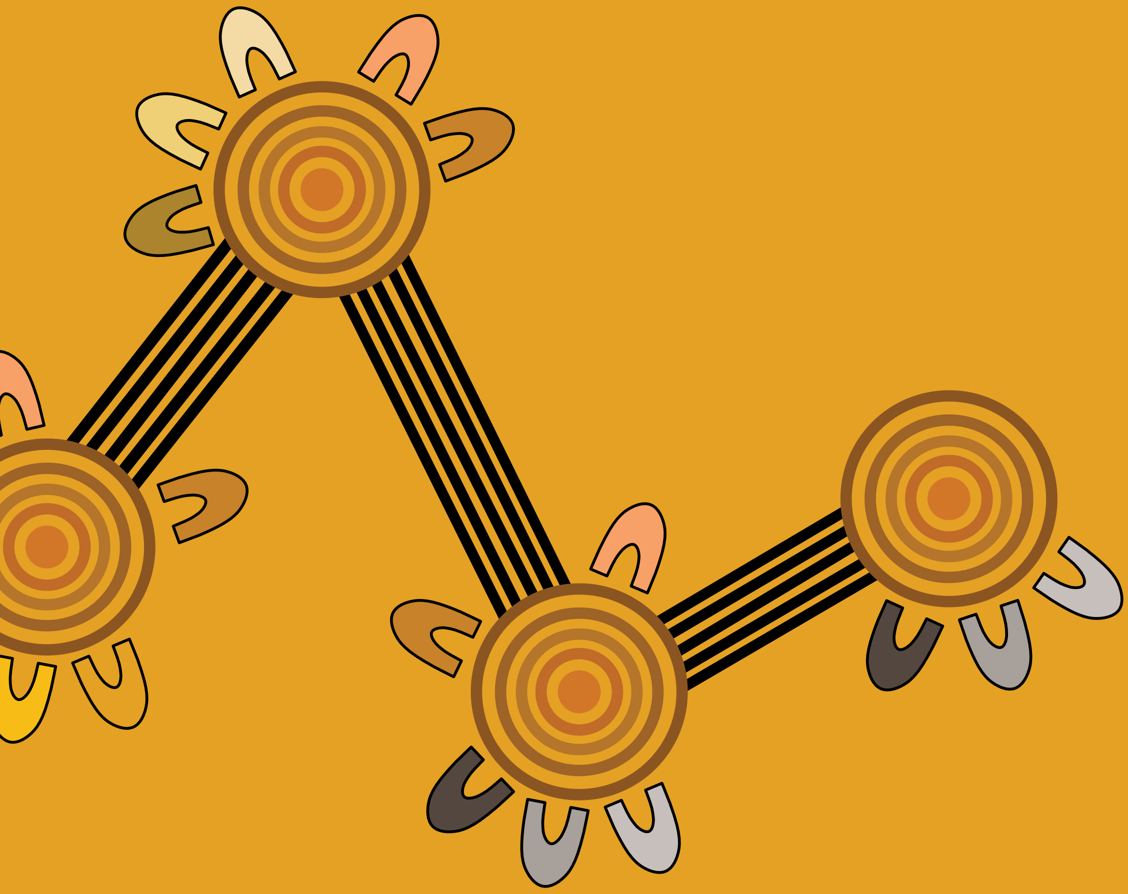

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