TE AHO O TE KAHU
CANCER CONTROL AGENCY

Optimal Cancer Care Pathway (OCCP)

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Contents

Achieving Pae Ora, equity and whānau insights

The level of care that anyone engaging in any part of the cancer care system in Aotearoa New Zealand can expect is informed and guided by:

- *Te Pae Tata Interim New Zealand Health Plan 2022* (Health New Zealand | Te Whatu Ora 2022)
- *New Zealand Cancer Action Plan 2019–2029* (Ministry of Health | Manatū Hauora 2019)
- *Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer* (Te Aho o Te Kahu 2023).

The table below shows how each step in the OCCPs delivers on the goals of the health strategies.

Step 1. Wellness

Achieving Pae Ora Te Pae Tata Interim Health Plan (2022); New Zealand Cancer Action Plan (2019-2029).	**Equity Insights**	**Whānau Insights** Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer.
Te Pae Tata 2.1 Achieving equity in health outcomes: Establishing actions that ensure that equity in access and outcomes is a critical change in Te Pae Tata. Empower whānau to take charge of their own wellbeing.	The most common cancers affecting Māori are preventable and include breast, liver, lung, pancreatic, stomach and uterine cancers (Cancer Prevention Report 2022)	*"Cancer leadership hasn't been a priority – we don't just focus on one disease."* *"Golden egg solutions are not sustainable – consequences for our actions on current generations but also generations for come."*
NZ Cancer Action Plan Outcome 3: New Zealanders have fewer cancers | Te Huanga 3: He iti iho te mate pukupuku. Standardise care across Aotearoa so that whānau can expect the same high-quality level of care at any centre throughout Aotearoa.	Māori and Pacific people are more exposed to cancer risk factors (for example, tobacco, alcohol, poor nutrition) due to social, political, and economic influences, including colonisation and racism. These influences also drive poorer access to and through the health system, contributing to inequities in health outcomes. (Te Aho o te Kahu, 2022).	*"…the value of a 'Whānau Ora' approach as a 'complete package'."* Whānau look at prevention holistically. Preventing infectious illnesses is critical.
	Māori and Pacific peoples have poorer access to the resources that support good health (Te Aho o Te Kahu, 2021a).	More knowledge is needed on workplace carcinogens.

Step 2. Screening and early detection

Achieving Pae Ora Te Pae Tata Interim Health Plan (2022); New Zealand Cancer Action Plan (2019-2029).	**Equity Insights**	**Whānau Insights** Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer.
Te Pae Tata 2.1 Create flexible options for communities to access screening and early intervention services.	Pacific people have lower participation rates in cancer screening programmes. (Te Aho o Te Kahu, 2021a).	*"We went to screening as a group…we could awhi each other."* *"Education and screening at marae would be good."*
2.3 Deliver new equity-focused screening initiatives while sustaining those already developed and consideration of lung cancer screening.	Poorer access to early diagnosis and screening, the presence of comorbidities and poorer access to best-practice treatments have all been associated with disparities in the survival between Māori and non-Māori cancer patients. ((Te Aho o Te Kahu, 2021a).	Multiple barriers to participation in screening services. These include cost (travel, time off work, babysitters for children etc), a lack of trust in screening services, the lack of kaupapa Māori screening services, few Māori staff within the services, limited health

		literacy and a perception that screening is not a priority.
4.1 Take a pro-equity approach to age thresholds for access to screening and removing barriers to primary care to improve early detection.		Improvement is needed in early detection.
Standardise care across Aotearoa so that whānau can expect the same high-quality level of care at any centre throughout Aotearoa.		
Outcome 3: New Zealanders have fewer cancers | Te huanga 3: He iti iho te mate pukupuku		

Step 3. Presentation, initial investigations, and referral

Achieving Pae Ora Te Pae Tata Interim Health Plan (2022); New Zealand Cancer Action Plan (2019-2029).	**Equity Insights**	**Whānau Insights** Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer.
Te Pae Tata 2.3 Develop new, joined-up pathways to facilitate rapid diagnosis of suspected cancer, beginning in primary care to support equitable access to cancer diagnostic and treatment options.	Māori adults are more than 1.5 times as likely as non-Māori adults to have experienced an unmet need for a general practitioner (GP) due to cost (Manatū Hauora Ministry of Health, 2019).	There is a perception that primary care providers are often racist and/or biased, dismissing or ignoring signs and symptoms, or assuming the symptoms are due to comorbidities.
3.1.4 Develop health pathways that support equity, incorporating Mātauranga Māori, Te Ao Māori approaches, and integrating whānau perspectives to reduce the burden on whānau to navigate health services, particularly for complex care.	Cost is the main barrier to accessing primary healthcare.	System barriers (pg. 67). Access - Primary care is not accessible to whānau. Trust - whānau struggle to trust primary care professionals. Mindset - Impact of whānau beliefs and experiences.
NZ Cancer Action Plan Outcome 1: New Zealanders have a system that delivers consistent and modern cancer care | Te huanga 1: He punaha atawhai. Outcome 2: New Zealanders experience equitable cancer outcomes | Te huanga 2: He taurite nga huanga.	Lack of transport is more than twice as likely to be a barrier to accessing GP services for Māori adults as it is for non-Māori adults (Manatū Hauora | Ministry of Health, 2019).	Multiple visits, sometimes over several years presenting with the same symptoms before their primary health provider would order a diagnostic test. Whānau face multiple barriers to primary care. *"That safety net had been taken away."*

Step 4. Diagnosis, staging, and treatment planning

Achieving Pae Ora Te Pae Tata Interim Health Plan (2022); New Zealand Cancer Action Plan (2019-2029).	**Equity Insights**	**Whānau Insights** Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer.
Te Pae Tata 2.3 The leadership focus will be on addressing unwarranted variations in care, so that everyone can access high-quality cancer care, regardless of who they are or where they live. This includes cancer prevention, improved diagnostic pathways and access to timely best-practice treatment once cancer is diagnosed.	Māori and Pacific peoples encounter multiple barriers and delays along the diagnostic pathway, contributing to poorer outcomes (Te Aho o Te Kahu 2021a).	*"Every time I needed a biopsy, that meant a whole day off work. Plus, another day each time the results came through." "Having a support person is really important to advocate, look and learn."* *"A lot of people need to travel hours to get to an appointment and don't have vehicles or family support."*

2.3 Develop new, joined-up pathways to facilitate rapid diagnosis of suspected cancer, beginning commencing in primary care, to support equitable access to cancer diagnostics and treatment options.	Māori are less likely to access staging procedures in a timely manner than non-Māori. As a result, they are less likely to have their stage information recorded (Cormack et al 2005).	They want all available treatment options explained to them, so they can make informed decisions for their whānau. This also includes treatment options that may be costly.
3.1.4 Standardise pathways across Aotearoa to remove differences in eligibility criteria and access to Health Pathways, including diagnostics.		The trauma of the cancer experience hung over them and they often did not know how to deal with the physical, psychosocial, and emotional consequences.
NZ Cancer Action Plan Outcome 1: New Zealanders have a system that delivers consistent and modern cancer care. | Te huanga 1: He punahi atawhai		
Outcome 4: New Zealanders have better cancer survival, supportive care, and end-of-life care | Te huanga 4: He hiki aki I te oranga.		

Step 5. Treatment

Achieving Pae Ora Te Pae Tata Interim Health Plan (2022); New Zealand Cancer Action Plan (2019-2029).	**Equity Insights**	**Whānau Insights** Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer.
Everyone will have equitable access to high quality emergency and specialist care when they need it, wherever they live.	Once diagnosed with cancer, Māori continue to experience poorer survival rates than non-Māori for nearly all the most common cancers.	*"You have no idea where you sit in the queue [for treatment]".* Treatment doesn't feel fair.
Ensure access to timely best-practice treatment once cancer is diagnosed, with auditing to ensure deviations are justified.	Māori wait longer for curative treatment (surgical or radiotherapy) compared to non-Māori (pg.165) – from OCCP equity analysis spreadsheet.	Effective supportive care models reflect the te ao Māori worldview.
Simplify access to national and regional specialist services and address unwarranted variation in the quality-of-care people experience.		Cancer creates many financial barriers for whānau.
Implement national pathways to access transport and accommodation to support the equitable completion of cancer treatment.		Whānau need to have a choice of services including rongoā, mirimiri etc and know how to access tohunga, particularly for whānau who may be disconnected from te ao Māori.
NZ Cancer Action Plan Outcome 1: New Zealanders have a system that delivers consistent and modern cancer care | Te huanga 1: He punahi atawhai. Outcome 2: New Zealanders experience equitable cancer outcomes | Te huanga 2: He taurite nga huanga. Outcome 4: New Zealanders have better cancer survival, supportive care, and end-of-life care | Te huanga 4: He hiki ake I te orange.		*"More training and support for the next generation of rangatahi Māori to pursue careers in cancer or health generally."*

Step 6. Care after treatment

Achieving Pae Ora Te Pae Tata Interim Health Plan (2022); New Zealand Cancer Action Plan (2019-2029).	**Equity Insights**	**Whānau Insights** Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer.
Te Pae Tata We will focus on the delivery of equitable care across the cancer continuum, from prevention to palliative end-of-life care and survivorship.		Whānau feel forgotten when treatment ends. Draw on the lived experience of patients. We've been there, we know what it's like.
NZ Cancer Action Plan Outcome 1: New Zealanders have a system that delivers consistent and modern cancer care | Te huanga 1: He punahi atawhai. Outcome 2: New Zealanders experience equitable cancer outcomes | Te huanga 2: He taurite nga huanga. Outcome 4: New Zealanders have better cancer survival, supportive care, and end-of-life care | Te huanga 4: He hiki ake I te orange.		*"The need for care doesn't stop when treatment finishes."* *"It can't be just bureaucrats who design the systems. You must co-design with patients and whānau. "*

Step 7. Palliative and end-of-life care

Achieving Pae Ora Te Pae Tata Interim Health Plan (2022); New Zealand Cancer Action Plan (2019-2029).	**Equity Insights**	**Whānau Insights** Rongohia Te Reo, Whatua He Oranga: The voices of whānau Māori affected by cancer.
Te Pae Tata The delivery of high-quality end of life care that is culturally responsive to the needs and aspirations of Māori.	Currently, not all New Zealanders have equal or early access to palliative care (State of Cancer report, 2020).	More conversation is needed on palliative care and end-of-life care.
NZ Cancer Action Plan Outcome4: New Zealanders have better cancer survival, supportive care, and end-of-life care | Te huanga 4: He hiki ake I te orange.	Evidence reveals gaps and inconsistencies in the provision of appropriate palliative care services to Māori. Gaps are exacerbated for whānau who have limited resources and poor access to information. (Māori and Palliative Care: Lit review Te Ohu Rata Aotearoa Feb 2018).	*"Palliative care is a tapu space and requires a careful, holistic approach."* *"What about having kaimahi in the palliative care space? They don't seem to cover this part of health, whānau are passed over to the Pākehā system when they reach palliative care."*

Person/whānau questions

Questions to support the person/whānau	
Step	**Questions**
1. Wellness	What can I do to improve my health? If others in my whānau have cancer, do I need to be concerned about my health?
2. Screening and early detection	What is screening? How do I access the national screening services? Who gets notified of my result and what happens next?
3. Presentation, initial investigations, and referral	Could this be cancer? Why? Could this be something else? Can I choose whether I go to a public hospital or private practice? Can I choose the specialist I see? Will there be any costs for me? What tests am I being referred for? How much time will this take? Do I need to go to different places for these? Is there transport available to these services?
4. Diagnosis, staging, and treatment planning	Have I got cancer? What is this type of cancer? What tests will I have? How much will tests/appointments cost? What are my options? Where should I be treated? What stage is my cancer? What does this mean? What support services are available to me?
5. Treatment	Are there other treatment options available? What treatment do you recommend? Where will I have to go to have treatment? What will treatment cost and how much will I have to pay myself? What activities/exercise will help me during and after treatment? Can I still work? Can I use complementary therapies such as rongoā Māori? How will the treatment affect my day-to-day life? Who are the people in my team and who is my main contact person? What side effects could I have from treatment? Who do I contact if I am feeling unwell or have any questions? Will treatment affect my ability to have a child?
6. Care after treatment	Who should I contact if I am feeling unwell? What can I do to be as healthy as possible? Where can I get more help? Where is the cancer and has it spread? What are my treatment options? What are the chances that the treatment will work this time? Is there a clinical trial available? Where else can I get support?
7. Palliative and end-of-life care	What can you do to reduce my symptoms? What extra support can I get if my whānau care for me at home? Can you help me to talk to my whānau about what is happening? What support is available for my whānau or carer? Can I be referred to a community support service? What are the options available to me?

Definitions

Advance care directive: A voluntary person-led document that focuses on an individual's values and preferences for further health and medical treatment decisions, preferred outcomes, and care. They are completed and signed by a competent person. Advance care directives focus on the future health care of a person, not on the management of their assets. They come into effect when an individual loses decision-making capacity.

Advance care planning: A process of discussion and shared planning for future health care. Focused on the individual, it involves the person and the health care professionals responsible for their care. It may involve the person's family/whānau and/or carers if that is the person's wish. Advance care planning provides individuals with the opportunity to develop and express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.

Cancer coordination: The services that support the person and their whānau to successfully navigate the cancer pathway. Key elements of cancer coordination include:

- holistic needs assessment
- liaison with clinical and non-clinical services
- supporting the person and their whānau to access spiritual, cultural, and social support
- providing financial advice and support, including for travel and accommodation.

Care coordinator: The health provider nominated by the multidisciplinary team to coordinate the care of the person and their whānau. The care coordinator may change over time depending on the person's stage in the care pathway and the location in which care is being delivered.

Complementary therapies: A supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life and help people deal with the side effects of cancer.

End-of-life care: This type of care includes physical, spiritual, and psychosocial assessment and care and treatment, delivered by health professionals and ancillary staff. It also includes support of whānau and care of the body after death.

Indicator: A documentable or measurable piece of information regarding a recommendation in the optimal cancer care pathway.

Interdisciplinary team of palliative care: A group of individuals with diverse training and backgrounds who work together as an identified unit or system. Team members collaborate to solve problems too complex to be solved by one discipline alone, or several disciplines in sequence.

High suspicion of cancer: If a person presents with one or more red flags, then the referral will be triaged as high suspicion.

Holistic care: Comprehensive care that considers the physical, emotional, social, economic, and spiritual needs of the person; their response to the health condition; and the effect of the condition on their ability to meet self-care needs.

Last days of life: The period of time when a person is dying, which may be measured in hours or days.

Lead clinician: The clinician who is nominated as being responsible for an individual's care. The lead clinician may change over time.

Kaimahi: Worker, employee, clerk, staff.

Kaupapa Māori: Māori approach, Māori topic, Māori customary practice, Māori institution, Māori agenda, Māori principles, Māori ideology – a philosophical doctrine, incorporating the knowledge, skills, attitudes, and values of Māori society.

Mātauranga Māori: The body of knowledge originating from Māori ancestors, including the Māori world view and perspectives, creativity, and cultural practices.

Mirimiri: To rub, soothe, smooth, stroke, fondle, smear, massage, rub on, rub in.

Multidisciplinary approach: An integrated team approach that involves all the relevant health professionals (including doctors, nurses, allied health staff, scientific and technical staff, not-for-profit staff, and community-based staff) as well as the person and their whānau, discussing treatment, care options and recommendations.

Multidisciplinary meeting: The cancer multidisciplinary meeting (MDM) is a forum for collaboration between health professionals with expertise in the diagnosis and management of cancer. At these meetings, participants collectively review all clinical, psychosocial, and cultural information pertinent to each patient's care, and recommend personalised treatment and care options.

Optimal cancer care pathway (OCCP): The key principles and actions required at each step of the cancer continuum to deliver consistent, equitable, safe, high-quality, evidence-based care for all people affected by cancer.

Palliation: Alleviation of symptoms when the underlying medical condition or pathological process cannot be cured. The goal of palliation is to help a person feel more comfortable, and to improve quality of life. Palliation is a key goal of care for both end-of-life and palliative care.

Palliative care: Care for people of all ages with a life-limiting or life-threatening condition that aims to:

- optimise an individual's quality of life until death by addressing their physical, psychosocial, spiritual, and cultural needs
- support the individual's family, whānau and other caregivers where needed, through the illness and after death.

Performance status: An objective measure of how well a person and their whānau can carry out activities of daily life. It identifies any functional impairment and compares the effectiveness of therapies and prognosis. The ECOG Performance Status Scale and the Karnofsky Performance Status Scale are two widely used methods to assess the functional status of a patient.

Person: In the OCCPs, 'person' refers to the individual undergoing cancer investigations and care.

Primary and community health care providers: Primary and community health care includes a very wide range of services based in the community, including Māori and Pacific providers, mātanga rongoā and rongoā service providers, general practitioners, pharmacists, midwives, allied health professionals, dentists and dental therapists, aged care and home care workers, disability support service providers, nurse practitioners, community and practice nurses, the non-clinical workforce, district nurses, community mental health and addiction services, public health nurses, NGOs, and in some cases rural hospitals.

Rangatahi: The younger generation, youth.

Relative survival rate: The probability of being alive after a given amount of time after the diagnosis of cancer. It is often presented as one- and five-year survival.

Red flags: Identify symptoms in primary care that may be suspicious for cancer and indicate a referral to a specialist for triaging.

Rongoā: A holistic approach to oranga and wellbeing. A traditional healing practice grounded in te ao Māori.

Safety netting: Safety netting advice is a proactive approach used by health care professionals to provide the person and their whānau or their caregivers with clear instructions and information to ensure their safety and wellbeing after an initial medical encounter. It involves educating and empowering people to recognise potential signs of deterioration, manage symptoms, and take appropriate actions until further medical attention can be obtained. Safety netting advice aims to prevent adverse outcomes, improve outcomes, and promote self-care.

Specialist palliative care: Palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospice or hospital-based palliative care services.

Spirituality: Spirituality is the aspect of humanity that refers to the way people seek and express meaning and purpose by connection to nature, significant experience, or the sacred and is the essence of the human experience.

Supportive care: Care that aims to improve the quality of life for those with cancer, their family and whānau through support, rehabilitation, and palliative care. Supportive care services include the essential services required to meet a person's physical, social, cultural, emotional, nutritional, informational, psychological, spiritual, and practical needs throughout their experience with cancer.

Survivorship: An individual is considered a cancer survivor from the time of diagnosis, and throughout their life. The term includes 'Living with, through and beyond cancer | Te noho ora me te matepukupuku, eke panuku noa'.

Survivorship care plan: A formal, written document that provides details of a person's cancer diagnosis and treatment, supportive care assessments, the range of services including health and social support, potential late and long-term affects arising from the cancer and its treatment, recommended follow-up, surveillance, and strategies to remain well.

Targeted therapy: Targeted therapy uses a drug that attacks specific characteristics of the cancer to try and stop the cancer cells from growing and spreading.

Te ao Māori: The Māori world.

Te Whare Tapa Whā: The Māori model of health, which compares health to the four walls or cornerstones of a house. When one of the cornerstones becomes damaged or is missing, the person may become unbalanced or unwell. The four cornerstones are:

- Taha Tinana – physical health
- Taha Hinengaro – psychological health
- Taha Wairua – spiritual health
- Taha Whānau – family health

Tikanga: The appropriate procedure, custom, habit, lore, method, manner, rule, way, code, meaning, plan, practice, convention, protocol – the customary system of values and practices that have developed over time and are deeply embedded in the social context.

Tohunga: A skilled person, chosen expert, priest, healer. A person chosen by the agent of an atua and the tribe as a leader in a particular field because of signs indicating talent for a particular vocation.

Traditional therapies/practices: Māori traditional healing, which is based on indigenous knowledge. It encompasses te ao Māori and a Māori view of being. Māori traditional healing practices include mirimiri (massage), rongoā (herbal remedies) and acknowledging te wairua (spiritual care). For Māori, the unobservable (spiritual, mental, and emotional) elements are as relevant as the observable or physical elements.

Whānau: The extended family, family group, a familiar term of address to a number of people – the primary economic unit of traditional Māori society. In modern day the term is sometimes used to include friends and carers who may not have any kinship ties to other members.

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OCCP Tumour Volumes

The data, as detailed below, and used to inform tumour stream OCCPs was provided by the Data and Analytics team at Te Aho o Te Kahu. Additional data was also sourced from the Health New Zealand Cancer Web Tool (https://www.tewhatuora.govt.nz/for-health-professionals/data-and-statistics/cancer/data-web-tool.

	Number of cases[1]	% of total cancers[1]
Bowel	15497	11.7
Breast[2]	17435	13.2
Lung	10635	8.0
Prostate	20804	15.7
Pancreatic	3118	2.4
Total	46685	35.3
Head and neck (C00-C14, C30-C32)[3]	3407	2.6
[including eye and thyroid (C69, C73)]	[5406]	[4.1]
Sarcoma	1842	1.4
Cervical (C48.1-2 & C57-70)[2]	864	0.7
Endometrial (C54.1)[3]	3118	2.4
Ovarian, Fallopian tube and peritoneum (C48.1-2 & C56-C570)[3]	1585	2.0
Melanoma	13492	10.2
Hepatocellular	2008	1.5
Oesophagogastic	1592	1.2
Neuroendocrine	3822	2.9
Multiple myeloma (C90.0-C90.1)[4]	2077	1.6
Chronic myeloid leukaemia (C92.1-C92.2)	282	0.2
Low grade lymphoma (C82.0-C83.1, C84.8, C88.0, C88.4), Hodgkin (C81.0-C81.9), and diffuse large b-cell (C83.3)	4761	3.6
Non-Hodgkin lymphoma (C83.5-84.7, C84.8-C86.6)[5]	1111	0.8
Myelodysplasia syndrome (D46.1-D49.9)	1181	0.9

	Number of cases[1]	% of total cancers[1]
Acute leukaemia (adults only) (C91-C95 excluding chronic leukaemia)	1282	1.0
Chronic lymphocytic leukaemia (C91.1)	1559	1.8
Low grade lymphoma (C820, C821, C822, C823, C824, C825, C826, C827, C829, C830, C831, C848, C8800, C8840)	2284	1.7
Diffuse large B-cell lymphoma (C833)	1900	1.4
Hodgkins lymphoma (C810, C811, C812, C813, C814, C817, C819)	577	0.4
Acute myeloid leukaemia[6]	1030	0.8
Chronic lymphocytic leukaemia[7]	1558	1.2

[1] Source NZCR, data for the five years from 2017-2021 for patients 18 and over.

[2] Breast cancer data is for female patients only.

[3] Excludes NETs and Sarcoma.

[4] Excludes plasmacytoma

[5] Non-Hodgkin lymphoma numbers exclude low grade and diffuse large b-cell Non-Hodgkin lymphomas to avoid double counting.

[6] Some acute myeloid leukaemia cases do not have registrations in NZCR as they have an existing Myelodysplastic syndrome registration that was latter transformed into acute myeloid leukaemia cases. Acute myeloid leukaemia: ICD-10 C92.0, C92.5, C92.7, C92.8, C94.0, C94.2, C92.3, C92.4, C92.6, C93.0 and morphology 9861/3, 9866/3, 9867/3, 9865/3, 9871/3, 9869/3, 9872/3, 9873/3, 9874/3, 9877/3, 9878/3, 9879/3, 9891/3, 9895/3, 9896/3, 9897/3, 9910/3, 9911/3, 9912/3, 9920/3, 9930/3

[7] Chronic lymphocytic leukaemia: ICD-10 C91.10 and morphology 9823/3.