TE AHO O TE KAHU
CANCER CONTROL AGENCY

Optimal cancer care pathway for people with Sarcoma

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Whakataukī

Have a sense of the message in the winds...

Anei he taonga nō te mātanga nō Ahitereiria

Koutou maa I takoto te koha ki a mātou

Here is a treasure from the skilled and able specialist in Australia

Greetings for this treasure you have gifted us here in Aotearoa to explore and use

E ki ana te tangi o tatou manu

Ko te manu e kai ana ki te miro, nōnā te ngahere

Ko te manu e kai ana ki te mātauranga nōnā te Ao

It has been reiterated that when our manu cries, we sit up and listen

The bird that feeds upon local berries, local knowledge will prosper

The bird that feeds upon wisdom, our world knowledge will flourish.

It is an exciting time to feed off the wisdom of other cultures

Matua Tau Huirama

We would like to acknowledge The Voices of Whānau Māori Affected by Cancer (2023); He Ara Tangata – Te Aho o Te Kahu Consumer Group; the project team; clinicians; and national sarcoma service that contributed to the development of the Optimal Cancer Care Pathways.

Special acknowledgement is extended to the Cancer Council Australia, who generously shared their Optimal Care Pathways framework and provided permission for it to be adapted to support people and whānau across Aotearoa New Zealand experiencing cancer.

Contents

FOREWORD **5**

SUMMARY GUIDE OF SARCOMA OCCP INFORMATION **6**

PRINCIPLES OF THE OPTIMAL CANCER CARE PATHWAY **14**

OPTIMAL TIMEFRAMES **15**

OPTIMAL CANCER CARE PATHWAY **17**

STEP 1: WELLNESS 18
STEP 2: EARLY DETECTION 20
STEP 3: PRESENTATION, INITIAL INVESTIGATIONS, AND REFERRAL 23
STEP 4: DIAGNOSIS, STAGING AND TREATMENT PLANNING 28
STEP 5: TREATMENT 34
STEP 6: CARE AFTER TREATMENT 41
STEP 7: PALLIATIVE AND END-OF-LIFE CARE 46

For further information including:

- Achieving Pae Ora, equity and whānau insights
- Person/whānau questions
- Definitions
- Sarcoma references and bibliography

Refer to **Optimal Cancer Care Pathway (OCCP) supplementary information.**

Foreword

Kia ora,

On behalf of Te Aho o Te Kahu| Cancer Control Agency, the clinician community, and the people and whānau who contributed to developing this guidance, I am proud to present the sarcoma Optimal Cancer Care Pathway (OCCP) for Aotearoa New Zealand.

Almost everyone across Aotearoa has been affected by cancer in some way. This year over 28,000 people will be diagnosed with cancer, with thousands more supporting loved ones living with this disease. Sarcoma affects an increasing number of people with more than 360 diagnosed with sarcoma this year. We all believe that people and their whānau deserve the best cancer care available.

OCCPs are designed to guide the planning, coordination and delivery of best practice cancer prevention and care services across Aotearoa for different types of cancer. Each OCCP has been designed:

- with the needs of the person and their whānau at the heart
- to reflect the best capabilities available in Aotearoa
- to provide a national standard for high-quality cancer prevention and care that we expect for all New Zealanders.

While cancer control services are expanding and improving across the motu | country, there are often unwarranted variations in the risk of getting cancer and in the care experienced by people with cancer. Also, many continue to face barriers in accessing timely and effective cancer care because of where they live, their circumstances, or their ethnic background. Research shows that following best practice guidance like OCCPs, helps to reduce variations and disparities and improves cancer outcomes for people and their whānau. In turn, this will help our overall aim of reducing the burden of cancer on people and communities.

This resource reflects the expertise and experiences from many stakeholders across the country. Many thanks to everyone involved in this initiative, particularly Cancer Council Australia, who granted permission to adapt and adopt their Optimal Care Pathways framework to meet the needs of people in Aotearoa | New Zealand. We would also like to acknowledge the insights from The Voices of Whānau Māori Affected by Cancer (2023); He Ara Tangata – Te Aho o Te Kahu Consumer Group; the project team; clinicians; and national and special interest working groups.

Our thoughts are with the many people and whānau who are living with sarcoma, and those who have lost loved ones. Much of this guidance reflects the voices of those who have received cancer care. We are indebted to them for sharing their experiences to help improve cancer control outcomes and achieve equity.

Ngā mihi nui,

Rami Rahal
Tumuaki | Chief Executive
Te Aho O Te Kahu | Cancer Control Agency

Summary guide of sarcoma OCCP information

Quick reference guide of condensed tumour stream

The Optimal Cancer Care Pathways (OCCP) describe the standard of care that people and whānau across Aotearoa, New Zealand should expect the public health system to be striving for. They follow eight principles[1]: person and whānau-centred care; equity-led; safe, high-quality care; multidisciplinary care; supportive care; coordinated care; effective and timely communication; and knowledge-driven care.

The OCCP guides health providers in ensuring the person and their whānau receive optimal, supportive care at each stage of their cancer diagnosis and treatment.

Step 1: Wellness	Step 1: Checklist
Cancer prevention efforts should be part of all cancer control pathways. This step recommends actions the person/whānau can take to improve their wellbeing and reduce the overall risk of cancer. Evidence-based research shows that general cancer and wellbeing risks can be reduced by: • eating a nutritious diet • maintaining a healthy weight • taking regular, moderate to vigorous-intensity activity • avoiding or limiting alcohol intake • being sun smart • identifying pre-disposing infections such as, Hepatitis C • keeping up to date with immunisations or vaccines such as, Human Papilloma Virus (HPV) • avoiding smoking including marijuana and exposure to second-hand smoke ○ current smokers (or those who have recently quit) should be offered best practice tobacco dependence treatment and an opt-out referral to an intervention service such as Quitline • avoiding vaping • participating in screening services such as breast, cervical, bowel cancer screening • preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons.	☐ Carry out a health and wellbeing assessment including discussions around screening services and ways to reduce cancer risk. ☐ Assess the individual's risk of developing cancer. ☐ Encourage eligible people to participate in national screening programmes. ☐ Discuss recent weight changes and monitor weight. ☐ Discuss and record alcohol intake. Offer support for reducing alcohol consumption if appropriate. ☐ Record person's smoking status and offer stop smoking advice/support if appropriate. ☐ Record physical activity. ☐ Consider referral to a dietitian, physiotherapist, or exercise programme. ☐ Give the person education on being sun smart.

[1] Optimal Cancer Care Pathway Principles

Step 2: Early detection	Step 2: Checklist
This step recommends options for early detection for the person/whānau with suspected sarcoma. No screening programme exists for sarcoma. Persons with conditions that predispose to all cancer including sarcoma, such as Li Fraumeni, may be able to access additional surveillance. **Early detection** Sarcomas are rare and most are de novo. Early detection relies on raising awareness of the signs and symptoms with careful examination and investigation of suspected cases. For persons with a history of sarcoma, diligent surveillance is the most reliable way to ensure early detection of disease recurrence. Health care providers/professionals should be aware of pre-existing conditions and exposures that have been associated with an increased risk of sarcoma. Risk reduction measures for sarcoma can include: • limit exposure to radiation • although no evidence links smoking to sarcoma, some evidence suggests it can lead to higher risk of local recurrence or development of metastatic disease.	☐ Assess and discuss the individual's sarcoma and be aware of sarcoma and it's presenting features. ☐ Support the person and their whānau to follow surveillance guidance if they're at an increased risk of sarcoma. ☐ Refer to clinical genetic services where appropriate. ☐ Encourage participation surveillance programmes for those identified to be at high risk (e.g., persons with known Neurofibromatosis type 1, Li Fraumeni, Rothman-Thomson Syndrome etc). ☐ If signs and symptoms of sarcoma are present refer to 'Step 3: Presentation, initial investigation and referral' below. **Communication** Ensure the person and their whānau understands: ☐ the reason for concern for sarcoma ☐ when they should receive their results ☐ how to follow up if they don't receive their results ☐ why they need to be transferred to a specialist service.

Step 3: Presentation, initial investigations, and referral	Step 3: Checklist
This step outlines how to initiate the appropriate investigations and referrals to specialist/s in a timely manner for the person and their whānau with suspected sarcoma. The types of investigations undertaken will depend on many factors, including the type and location of the suspected sarcoma. Decisions around the nature and order of investigations is best made in the setting of an MDM discussion and expert review. A person and their whānau may present via primary care, an emergency presentation, physiotherapy, or incidental finding on scans done for other reasons.	☐ Record signs and symptoms. ☐ Complete all cancer assessments. ☐ Inform the person and their whānau of preliminary results. ☐ Discuss referral options of cancer care with the person and their whānau, including cost implications if private provider requested.

Signs and symptoms of sarcoma to investigate (see step 3.2) include:

- mass with a diameter exceeding 5 cm
- mass deep to fascia
- rapidly changing mass (over months)
- bone pain and difficulty bearing weight particularly in children and younger adults
- abdominal symptoms are typically vague and non-specific, such as early satiety, pain, bloating, unexplained weight loss and unexplained unilateral or bilateral leg swelling.

Sarcoma **assessment** includes:

medical history, including medications: pre-existing conditions and exposures that have been associated with an increased risk of sarcoma
physical examination: size and location of mass, depth, obvious bone swelling, palpable abdominal mass
investigations (laboratory, radiology): X Ray of effected area, MRI of mass, CT abdomen/pelvis for suspected abdominal/retroperitoneal lesions, relevant additional imaging including staging will be advised by the sarcoma centre, blood test as appropriate to diagnosis in bone masses, PSA, protein electrophoresis
family/whānau history: increased risk with first degree relative with sarcoma
social history of the person and their whānau specialist referral for a soft tissue lump.

Referral

Any clinical suspicion or laboratory/ imaging findings suggestive of sarcoma requires further investigation and a referral to specialist services.

If the person presents with one or more of the following red flags, the referral should be triaged as a high suspicion of cancer.

An unexplained soft tissue mass and one or more of the following:

- mass size > 5cm in size
- increasing in size
- deep to fascia
- painful
- radiology suspicious for malignancy
- a recurrence after previous excision.

An unexplained bony mass and one or more of the following:

- palpable mass fixed to bone
- increasing in size
- radiology suspicious for malignancy
- a recurrence after previous excision
- suspected spontaneous fracture.

☐ Complete and record supportive care needs assessment, refer to allied health services as required.

☐ Inform the person and their whānau of cultural services and relevant support groups available.

☐ Initiate referrals and arrange further investigation.

Timeframe

☐ If there is a high suspicion of sarcoma, submit referral immediately to hospital specialist services.

☐ High suspicion of cancer referral is triaged **within 1-2 working days** and referrer is notified.

☐ Confirm that the person referred urgently with a high suspicion of cancer will attend their first specialist assessment (FSA) clinic **within 14 days**.

☐ People referred urgently with a high suspicion of sarcoma after a local FSA are reviewed by a sarcoma treatment unit within **14 days.**

☐ Diagnostic investigations should be completed **within 2 weeks** of the initial specialist assessment.

Communication

☐ Explain to person and their whānau that they are being referred to a hospital specialist service and why, including:

- how long this may take
- who to contact if their symptoms change
- how to follow up if they do not receive their specialist appointment within the specified time.

An unexplained presence of one or more of the following: • increasing or persistent bone pain (especially at rest) • night pain • limp (for a child).	

Step 4: Diagnosis, staging and treatment planning	Step 4: Checklist
This step outlines the process for confirming the diagnosis and stage of cancer and the planning of subsequent treatment. **Sarcomas are a heterogeneous group of cancers.** **Diagnosis** for sarcoma may include all or some of: • radiology: ultrasound, CT scan, MRI, or PET-CT scan • pathology: image-guided core biopsy • laboratory: blood tests • no biopsy of a suspected sarcoma should occur prior to discussion by a sarcoma MDM or with one of the core sarcoma MDM team. **Staging** for sarcoma is: • specific to the subtype and will be advised by the Sarcoma Centre • it may include CT scan, PET-CT, Whole body MRI. **Performance status** • Should be recorded and forwarded with the referral if possible. **Multidisciplinary meeting** • Mandatory for all suspected cases of sarcoma. • All sarcoma cases should have a referral to one of the two sarcoma centres including retroperitoneal and gynecological sarcoma. **Familial cancer risk** • Is rare in sarcoma but should be considered for if multiple cancers within the family. **Clinical genetic testing** • Referral to clinical genetic services for sarcoma is considered if features of the cancer suggest a familial predisposition. **Treatment planning** Optimal cancer care requires a multidisciplinary approach and varies significantly based on subtype. Discussion at an MDM ensures treatment plans are tailored to an individual's needs in collaboration with the whānau and health care team.	☐ All people with a high suspicion of Sarcoma should have a Sarcoma CNS to coordinate care. ☐ Confirm diagnosis. ☐ Referral to a cancer care coordinator. ☐ Record staging, performance status and comorbidities. ☐ Discuss the person's diagnosis at a multidisciplinary meeting (MDM) and inform the person and their whānau of the treatment decision. ☐ Consider enrolment in clinical trial. ☐ Consider fertility consequences with treatment and refer to fertility specialist as required. ☐ Assess supportive care needs and refer to allied health services as required. ☐ Initiate primary or secondary prehabilitation to optimise overall well-being. ☐ Refer to age appropriate and sarcoma specific support services as required: ▪ psychology support ▪ social work ▪ dietician ▪ AYA Sarcoma CNS ▪ youth worker ☐ Begin prehabilitation where appropriate. Physiotherapy, dietician, and occupational therapy are useful prior to surgery. ☐ Give the person and their whānau information on Cancer Society, Canteen, Sarcoma Foundation New Zealand and/or relevant cultural services and support groups as available. **Timeframe** All suspected or confirmed sarcoma will be discussed in an MDM **within 2 weeks** from date of referral to MDM.

	Communication The lead clinician and team are responsible for: ☐ Discussing a timeframe for diagnosis and treatment options with person and their whānau. ☐ Explaining the role of the MDM team in treatment planning and ongoing care. ☐ Where appropriate, initiating discussions about the potential diagnosis, prognosis, advance care planning and palliative care while clarifying wishes, needs, beliefs, and expectations of the person and their whānau and their ability to comprehend the communication. ☐ Providing appropriate information and referral to support services as required. ☐ Communicating with the GP of the person and their whānau about the diagnosis, treatment plan and recommendations from the MDM. ☐ Ensuring the referring team understand the rationale and action the MDM recommendations.

Step 5: Treatment	Step 5: Checklist
This step describes publicly funded optimal treatments for sarcoma by trained and experienced clinicians and team members, in an appropriate environment. Establish the intent of treatment: • curative – to cure the cancer completely • tumour control – to stop the cancer growing and spreading • palliative – to manage symptoms caused by the cancer. **Treatment options** **Surgery** – Surgery at a sarcoma treatment centre is recommended for most people with sarcoma. **Systemic therapy** – people who may benefit from systemic therapy. • Osteosarcoma and Ewings Sarcoma people will routinely have both neo adjuvant and adjuvant systemic treatment as part of their care. People with soft tissue sarcomas may have chemotherapy, and some will have combined radiation and chemotherapy. **Radiation therapy** – people who may benefit from radiation therapy include: • most people with limb and truncal soft tissue sarcoma	☐ Health providers/professional, treating specialist has relevant qualifications, experience, and expertise. ☐ Discuss the intent of treatment and the risks and benefits with the person and their whānau. ☐ Provide the agreed treatment plan with the person, their whānau and keep GP informed. ☐ Assess supportive care needs and refer to allied health services as required. ☐ Give the person and their whānau information on available cancer non-governmental organisations (NGOs,) cultural services and support groups. ☐ Consider early referral to palliative care if appropriate. ☐ Discuss advanced care planning with the person and their whānau. **Timeframes** ☐ The eligible person triaged with a high suspicion of cancer receives their first cancer treatment **within 62 days** from the date of referral.

• some retroperitoneal sarcomas • Ewings sarcoma may be treated either as the main treatment for local control or as part of the treatment for local control. **Palliative care** – Early referral to palliative care can improve quality of life and in some cases survival. Referral is based on need, not prognosis.	☐ The person with a confirmed diagnosis of sarcoma receives their first treatment **within 31 days** of the decision to treat. ☐ Adjuvant chemotherapy should begin **within 31 days** of decision to treat unless there are clinical reasons to recommend otherwise. **Communication** The lead clinician and team are responsible for discussing these areas with the person and their whānau: ☐ treatment options including the intent of treatment, risks, and benefits ☐ advance care planning ☐ options for healthy lifestyle support to improve treatment outcomes such as exercise and nutrition.

Step 6: Care after treatment	Step 6: Checklist

The person and their whānau have access to appropriate follow up and surveillance care and are supported to achieve their optimal health after cancer treatment.
 	
Provide a summary of the treatment and follow-up care plan to the person, their whānau and their GP outlining:
• diagnosis, including tests performed and results
• treatment received (types and date)
• current toxicities (severity, management and expected outcomes)
• interventions and treatment plans from other health providers/professionals
• potential long-term and latent effects of treatment and care of these
• supportive care services provided
• a follow-up schedule, including tests required and timing
• a process for rapid re-entry to medical services for suspected recurrence ongoing assessments of the effects of treatment such as:
  ○ fatigue
  ○ nutrition
  ○ sexual function
  ○ bladder function
  ○ bowel function
  ○ peripheral neuropathy
  ○ paediatric late effects
  ○ fertility.
	☐ Provide a survivorship plan that includes a summary of the treatment and follow-up care plan to the person, whānau and their GP.
	
	☐ Assess supportive care needs and refer to allied health services as required.
	
	☐ Give the person and their whānau information on Cancer Society and/or relevant cultural services and support groups available.
	
	Communication
	
	The lead clinician and team are responsible for:
	☐ explaining the treatment summary and follow-up and surveillance care plan to the person and their whānau
	
	☐ informing the person and their whānau about secondary prevention and healthy living
	
	☐ discussing the follow-up care plan with the GP of the person and their whānau providing guidance for rapid re-entry to specialist services.

Step 7: Palliative and end-of-life care	Step 7: Checklist
Palliative and end-of-life care provides the person facing life-limiting conditions and their whānau with holistic support and coordinated services based on their specific needs. Palliative care may be provided through: • hospital palliative care • home and community-based care • community nursing, including access to appropriate equipment. Early referral, identification, correct assessment and treatment of pain and other symptoms prevent and relieves suffering. End-of-life care should consider: • appropriate place of care • person's preferred place of death • support needed for the person and their whānau. Awareness of and access to, assisted dying services should be available if the person raises this with the health care team. **Communication** A key way to support the person and their whānau is by coordinating ongoing, clear communications between all health providers/professionals involved in their providing their cancer care.	☐ Early referral to generalist/ specialist palliative care. ☐ Refer to specialist palliative care services as required. ☐ Refer to supportive care services as required. ☐ Make sure the person and their whānau are aware of the prognosis and what to expect when someone is dying. ☐ Discuss activation of advance care plan, directive, or enduring power of attorney.

How optimal cancer care pathways improve outcomes

Optimal Cancer Care Pathways (OCCPs) are critical tools for guiding the national delivery of consistent, safe, high-quality, evidence-based cancer care for people and whānau across Aotearoa New Zealand. Research shows OCCPs improve the outcomes and experiences of people and their whānau affected by cancer to guide the design and delivery of cancer care services that are systematic, equitable, connected, and timely (Cancer Council Australia).

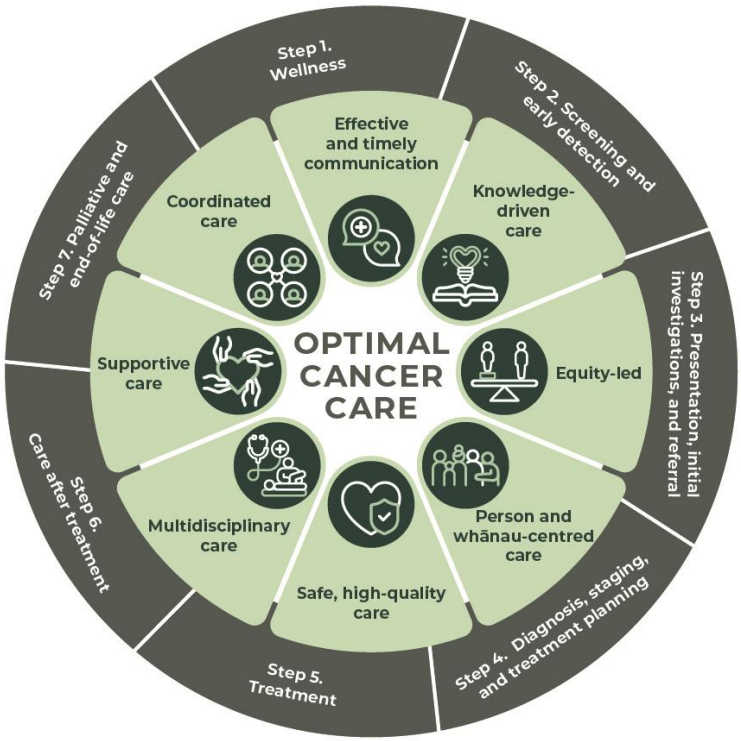
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- identify gaps in existing cancer services
- address barriers and unwarranted variations in accessing high-quality care
- identify opportunities for system improvements
- continually improve the way services are planned and coordinated.

As shown in Figure 1, the OCCPs map seven key steps in providing cancer care based on evidence-based practice, underpinned by eight principles to deliver the optimal level of care. While the seven steps appear linear, in practice, the care a person receives may not be. The steps provided will be tailored to their specific situation and needs, for example the type of cancer they have, when and how the cancer is diagnosed and managed, the person's decisions, and how they respond to treatment.

OCCPs are designed to be used alongside clinical guidelines. The OCCPs do not constitute medical advice or replace clinical judgement or guidance.

Figure 1: Optimal Cancer Care model

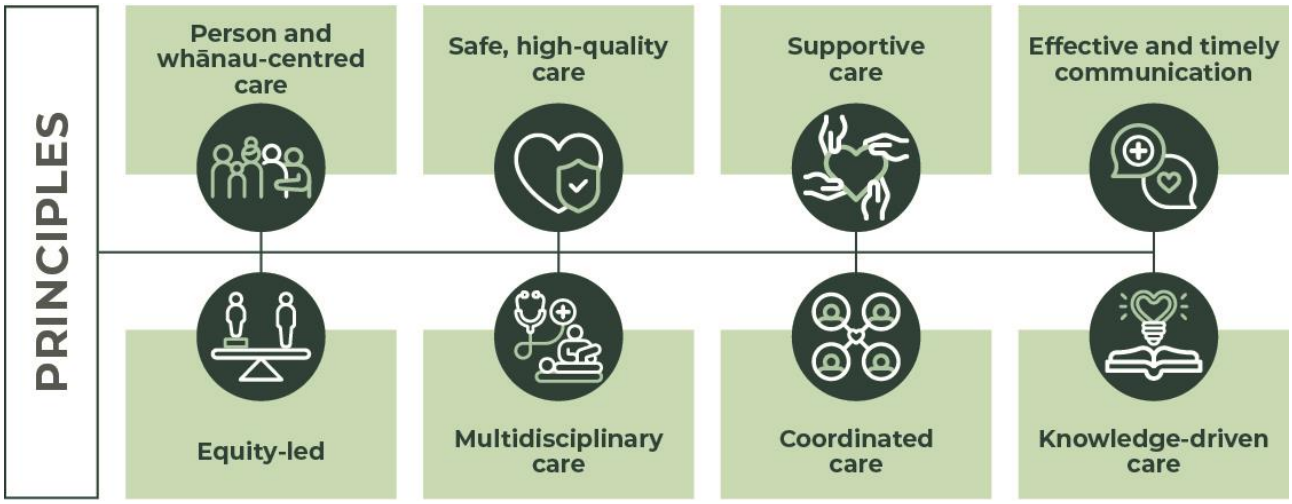


[2] Optimal Cancer Care Pathway Supplementary Information

Principles of the optimal cancer care pathway

The principles[3] underpinning OCCPs are essential to achieving the best cancer care, experience, and outcomes of the person and their whānau. OCCPs put the person and their whānau at the centre of care planning throughout their treatment/care and prompt the health care system to coordinate high-quality care. The person and their whānau are informed and involved in decisions throughout their cancer experience, according to their preferences, needs and values.

Figure 2: Principles of optimal cancer care



[3] Optimal Cancer Care Pathway Principles

Optimal timeframes

Evidence based guidelines, where they exist, are used to inform clinical timeframes. Shorter timeframes for appropriate investigations, consultations and treatment can provide an improved experience for people and their whānau and better cancer outcomes. The three steps shown below are a guide for health providers/professionals and the person/whānau on the optimal timeframes for being assessed and receiving treatment. These timeframes are based on expert advice and consultation with the National Sarcoma Service.

Figure 3: Timeframes for care

Step in pathway	Care point	Timeframes
Step 3: Presentation, initial investigations, and referral	Signs and symptoms	A person presenting with symptoms is promptly assessed by a health professional.
	Initial investigations started by GP	If symptoms suggest sarcoma, the person and their whānau are referred for Xray or Ultrasound scan **within 2 weeks** for urgent investigation.
	Referral to a hospital specialist	The person should see a specialist **within 2 weeks** of triage as high suspicion. The person referred urgently with a high suspicion of sarcoma after a local FSA should be reviewed by a sarcoma treatment unit **within 14 days**.
Step 4: Diagnosis, staging, and treatment planning	Diagnosis and staging	Investigations should be completed **within 2 weeks** of request. ***No biopsy*** should occur prior to MDM discussion or discussion with one of the two sarcoma MDT members.
	Multidisciplinary team meeting and treatment planning	All newly diagnosed people are discussed or registered with one of the two Sarcoma MDMs, before treatment begins. MDM takes place **within 2 weeks** of referral.
		The person referred with a high suspicion of sarcoma and triaged by a clinician, will receive their first cancer treatment **within 62 days.**

Step 5: Treatment	Neoadjuvant/ adjuvant chemotherapy, radiation therapy or surgery	The person begins their first cancer treatment **within 31 days** of the decision to treat, regardless of how they were initially referred. The person with sarcoma is presented in the sarcoma MDM after surgery **when results are available** for consideration of adjuvant therapy. Adjuvant chemotherapy should begin **within 31 days** of decision to treat unless there are clinical reasons to recommend otherwise.

Optimal cancer care pathway

Seven steps of the optimal cancer care pathway

Step 1: Wellness

Step 2: Early detection

Step 3: Presentation, initial investigations, and referral

Step 4: Diagnosis, staging, and treatment planning

Step 5: Treatment

Step 6: Care after treatment

Step 7: Palliative care and end-of-life care

Sarcomas are a rare form of cancer that can occur in any part of the body and in any age group. They arise from mesodermal tissue, including bone, cartilage, muscle, nerve, blood vessels and fat. They may be high-grade or low-grade lesions and are capable of local recurrence as well as regional and distant spread

Soft tissue sarcomas can occur in subcutaneous and deep tissues. They more commonly occur in adulthood, but can occur in any age group, and accounting for 20% of all paediatric cancer and 7% of all paediatric cancer-related deaths. The overall incidence in this country is about three cases per 100,000 population per year; incidence is not increasing significantly over time.

Bone sarcomas are less common: osteosarcoma has an incidence rate of 3–4 per 1,000,000 per year, and a peak incidence in children and adolescents. Ewing's sarcoma, another bone sarcoma, occurs in 2–3 people per 1,000,000 per year.

Step 1: Wellness

Cancer prevention efforts should be part of all cancer control pathways. This step recommends actions the person/whānau can take to improve their wellbeing and reduce the overall risk of cancer.

Health care providers and services such as primary care, public health units, hospitals and NGOs work collaboratively to prevent cancer (and other conditions) with the person and their whānau and communities. Te Aho o Te Kahu (2022) produced a report outlining evidence-based, best-practice interventions to prevent cancer. Reducing cancer risk factors addresses work to achieve the goals of fewer cancers, better survival, and equity for all.

1.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- culturally safe health care providers and practices embedded in all health services and steps of the cancer care pathway
- institutional and personal bias or racism within the health and disability system being acknowledged, identified, and addressed (Harris et al 2012)
- implementation of health and wellness approaches that support ritenga Māori (Māori customary rights) framed by te ao Māori (a Māori world view), enacted through tikanga Māori (Māori customs) and encapsulated with mātauranga Māori (Māori knowledges)
- meaningful partnerships with Māori communities and organisations that benefit Māori
- support and resource health promotion activities co-designed with Māori.
- prioritise achieving equity for screening participation rates in national cancer screening programmes (cervical, breast, bowel).

1.2 Modifiable cancer and wellbeing risks

Evidence-based research shows that general cancer and wellbeing risks can be reduced by:

- eating a nutritious diet
- maintaining a healthy weight
- taking regular, moderate to vigorous-intensity activity
- avoiding or limiting alcohol intake
- being sun smart
- identifying pre-disposing infections, such as hepatitis C
- immunisations – for example, HPV
- avoiding smoking including marijuana and exposure to second-hand smoke
    - current smokers (or those who have recently quit) should be offered best practice tobacco dependence treatment and an opt-out referral to an intervention service such as Quitline.
- avoiding vaping
- screening services, such as breast, cervical and bowel cancer screening
- preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons (Te Aho o Te Kahu 2022).

Most cancer risk factors are not unique to cancer and are shared by other chronic diseases such as diabetes, heart disease and strokes.

1.3 Communication with the person/whānau receiving care

Health providers

- Raise and discuss any modifiable risk factors.
- Provide information and education regarding access to wellness programmes, including kaupapa Māori services.
- Discuss advance care planning, advance directive and/or Enduring Power of Attorney (EPA) as required (refer principle 1)[1].

"Whānau look at prevention holistically."
Person/whānau insights

Communication between health services

- Inform the person and their whānau of any referrals between health care services and wellness programmes.

1.4 Measuring and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Smoking and vaping rates** (note: these measures apply to every step on the pathway).
    - The number of current smokers (aged 15 years and above) who smoke daily and have smoked more than 100 cigarettes their whole life as measured by the New Zealand Health Survey, by gender and ethnicity.
    - The number of vapers (aged 15 years and above) who have tried vaping and vape at least once a day as measured by the New Zealand Health Survey, by gender and ethnicity.

- **The New Zealand Heath survey** (NZHS) provides information about the health and wellbeing of New Zealanders.
    - Health status and behaviours.
    - Risk factors.
    - Access to health care.

Step 2: Early detection

This step outlines recommendations for early detection for the person with suspected sarcoma.

2.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- making sure early detection of cancer is provided in culturally appropriate ways that recognise and support the expression of hauora Māori models of care
- providing access to co-designed kaupapa Māori early detection for cancer programmes, where possible (Te Aho o Te Kahu 2022)
- implementing programmes that enhance access to cancer services.

Māori and Pacific peoples often present at an earlier age than the general population, so awareness and consideration of this needs to factor into assessment and review of signs and symptoms.

2.2 Early detection

There is no national sarcoma screening programme.

Early detection focuses on detecting symptomatic people as early as possible.

Some conditions with a predisposition to sarcoma may be undergo surveillance for early detection of sarcoma and other cancers and should follow guidelines for multiple predisposition syndromes.

Risk reduction measures for sarcoma can include:

- limit exposure to radiation
- although no evidence links smoking to sarcoma, some evidence suggests it can lead to higher risk of local recurrence or development of metastatic disease.

2.3 Sarcoma risk factors

Persons may have no apparent risk factors, but there are a few pre-existing conditions and exposures that have been associated with an increased risk of sarcoma.

Risk factors for bone sarcoma:

- family history (slight increased risk)
- history of retinoblastoma
- history of paediatric cancer
- genetic and precursor conditions
- past treatment with chemotherapy or radiation therapy
- exposure to certain chemicals (for example, vinyl chloride and dioxin).

Genetic conditions associated with bone sarcoma

Persons with certain rare inherited cancer syndromes may have an increased risk of developing osteosarcoma, for example in Li–Fraumeni syndrome (mutation of *TP53*).

Precursor conditions associated with bone sarcoma
There are several precursor conditions that are associated with an increased risk of bone cancer. For example, Paget's disease of bone, a benign condition mostly affecting people older than 50 years, causes formation of abnormal bone tissue. Bone sarcomas (usually osteosarcoma) develop in about 5–10% of persons with severe Paget's disease. Prior radiotherapy can also cause late development of bone sarcomas.

Risk factors for soft tissue sarcoma include:

- familial syndromes
- history of cancer
- past treatment with radiation therapy
- exposure to certain chemicals (for example, vinyl chloride and dioxin)
- age (over 50 years).

Genetic conditions associated with soft tissue sarcoma
In most cases of soft tissue sarcoma, it is not possible to identify a specific aetiological agent. Some genetic conditions including Li–Fraumeni syndrome and neurofibromatosis carry an increased risk for soft tissue sarcoma.

Precursor conditions associated with soft tissue sarcoma
Lymphoedema is associated with lymphangiosarcoma, most often after radical lymphadenectomy, but also in primary lymphoedema. Prior radiation therapy can also cause late development of soft tissue sarcomas.

2.3. Familial cancer risk

Some people may have an increased risk of developing sarcoma. An individual's family cancer history is reviewed and the person and their whānau are advised of the risks of developing a familial cancer. Health providers encourage and support the person and their whānau to follow surveillance guidance if an increased risk of familial cancer is identified. Refer to clinical genetics where appropriate if the person and their whānau have known genetic predispositions or a familial history.

For further information visit the Genetic Health Service New Zealand website **(geneticheathservice.org.nz).**

2.4 Communication with the person/whānau receiving care

Health providers/professionals

- Promote health checks.
- Raise and discuss any cancer risk factors.
- Provide information and education regarding early detection and surveillance.
- Promote and monitor participation in surveillance programmes, if eligible.
- Discuss any investigation results and follow up care as required.
- Discuss available supports, such as funding for travel and accommodation, one-stop clinics, and same-day access to a chest x-ray.

We went..... as a group...we could awhi each other". "Education and ..... at a marae would be good."
Person/whānau insights

Communication between health services

- Share results and further tests or referrals required with the appropriate service/specialty.

2.5 Measurement and monitoring

Monitoring and measuring are key components of contemporary best practice. Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Faster Cancer Treatment**

Early detection through primary care that identifies a high suspicion of cancer and requires an urgent referral to specialist will be seen **within 2 weeks**. The following FCT business rules will apply:

  - **31-day Health Target -** All people will receive their first cancer treatment (or other management) within 31 days from decision to treat. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 31 days from the decision to treat. (**FCT business rules**, 2023).
  - **62-day indicator** – All people with a high suspicion of cancer (without a confirmed pathological diagnosis of cancer at referral) will receive their cancer treatment within 62 days from date of referral. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 62 days from date of referral to first treatment.

Step 3: Presentation, initial investigations, and referral

This step outlines the process for initiation of the right investigations and referral to the appropriate specialist in a timely manner for the person with suspected sarcoma.

The types of investigations undertaken will depend on many factors including the preferences of the person and their whānau.

Community HealthPathways provide a source of relevant detailed information for a prostate cancer assessment from a person's primary care presentation and referral to secondary care to specialist services (Community Health Pathways. 2024). You can read more in **Community HealthPathways** .

The Community-referred radiology (CRR) Referral Criteria are criteria to provide nationally consistent access to imaging. The criteria set out a mandatory minimum level of radiology access to help primary care manage imaging in the community. Refer to: **National Community Referral Criteria for Imaging » Radiology**.

3.1 Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- prioritising Māori with a 'high suspicion of cancer' referral pathway until symptoms are proven otherwise
- engaging with kaupapa Māori services that are equipped to provide holistic Whānau Ora services in the community
- supporting Māori with access to diagnostics, investigations, and referrals through to the appropriate secondary services.

3.2 Signs and symptoms

Signs and symptoms suspicious of cancer that prompt initial investigations may be via primary care, elective care, or an acute admission. Primary care services work with the person and their whānau to assess, investigate, review, and refer to appropriate services within recommended timeframes (see Optimal Timeframe section). These timeframes are indicated by national FCT high suspicion of cancer pathways and the indicator data dictionary.

Timeframe for general practitioner consultation

A person with signs and symptoms that may suggest sarcoma should be seen by a general practitioner **within 2 weeks.** Delayed diagnosis of sarcoma is common. There needs to be a high index of suspicion, as early detection and referral are crucial to achieving timely treatment and best prognosis. The diagnosis is often not suspected before biopsy or excision. This leads to delay in diagnosis, further operations, increased morbidity, and the potential loss of curative intent.

Any unexplained and/or persistent signs and symptoms lasting more than three weeks (or sooner for people with known risk factors) should be investigated. The presence of multiple signs and symptoms, particularly in combination with other underlying risk factors, may indicate an increased risk of sarcoma.

The following suspicious signs and symptoms of **bone sarcoma** include:

- persistent non-mechanical or mechanical pain in any bone lasting more than a few weeks
- mechanical/functional pain may indicate impending pathological fracture
- pain that is unremitting and unresponsive to analgesics
- nocturnal bone pain
- a mass
- swelling
- fractures with minimal trauma.

The symptoms of bone sarcomas can vary, but the most common are pain and swelling or tenderness in the affected area. The sarcoma can cause weakness of the bone leading to a fracture. Presence of these symptoms should lead to referral for an X-ray, which may lead to the suspicion of bone malignancy.

Suspicious signs and symptoms of **soft tissue sarcoma** include:

- mass deep to fascia
- mass with a diameter exceeding 5 cm
- rapidly changing mass (over months)
- mass with atypical physical characteristics – for example, hardness, firmness, irregularity.

Note some soft tissue sarcoma, for example synovial sarcoma, can have benign characteristics, small slow growing and be present for years.

Suspicious signs and symptoms of **retroperitoneal sarcoma** include:

- abdominal mass
- early satiety
- unexplained unilateral or bilateral leg swelling
- loss of appetite
- unexplained weight loss, especially in presence of increasing abdominal distension
- urinary symptoms including retention, incomplete emptying, and frequency
- DVT
- inguinal, groin or scrotal mass without a clear non-sarcoma diagnosis
- incidentally discovered mass during treatment or investigation of another condition.

3.3 Assessment

Sarcoma assessment includes relevant:

- medical history, including relevant medications:
- physical examination: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight: assessment of the physical characteristics of the mass and regional lymph nodes
- investigations (laboratory, radiology): plain x-ray (especially if there is bone pain)
- familial cancer history: increased risk with first degree relative with sarcoma
- social history: important to understand impact of treatment and support network.

3.4 Initiate investigations, including referrals

- Simple investigations can be helpful in either bone or soft tissue sarcoma. Ultrasound (USS) in the case of soft tissue lumps and plain X-ray in the case of bone are quick and safe investigations which can be accessed by general practitioners or allied

health professionals, helping to diagnose sarcoma early (Sarcoma Foundation New Zealand).

- Indicate if there is a high suspicion of cancer and/or it is urgent, and the person needs to be seen **within 2 weeks.**
- Primary care should arrange the referral for x-ray or USS in conjunction with referral for specialist assessment to avoid delays.

Timeframe for completing investigations for the person with suspected sarcoma

Optimally:

- a suspected sarcoma should have simple investigations completed, and a referral sent to a specialist **within 2 weeks**
- no biopsy should be done without discussion with the sarcoma multidisciplinary team (MDT).

Referral options are clearly communicated with the person and their whānau, including details of expected timeframes, who to contact if they don't hear from the service referred to within the timeframe given, and any costs for accessing services.

When referring a person for investigation or procedures, referrers must ensure that:

- the person is aware and encouraged to have a support person with them
- the procedure or investigation is explained to them in a way that they can understand, including in different formats and with a translator, as required
- Māori are referred to kaupapa Māori services if they choose and as available
- an investigation assessment is undertaken to identify if an individual can tolerate the preparation, procedure, or investigation
- assessment and support are given to address any possible barriers of accessing services – for example:
    - transport
    - financial
    - family situation that may impact on the decision to consent to a procedure
    - coordinating appointments and/or offering the person and their whānau, whānau focused bookings.

To support accurate triage, referral information must include the following information:

- signalled as high suspicion of cancer or urgent
- medication and allergies
- past medical history and current comorbidities
- results of relevant investigations
- notification if an interpreter service is required
- concerns that may require support or affect ability to attend appointments, undergo investigations or treatment.

Timeframe for referring to a specialist

Any person with symptoms suspicious of sarcoma is referred to a specialist following guidelines in Community HealthPathways. The specialist should see the person with proven or suspected sarcoma and their whānau **within 2 weeks** of diagnosis or a high suspicion of cancer. If necessary, prior discussion should facilitate referral (Community Health Pathways 2024).

- The first specialist assessment should occur **within 2 weeks** of referral.
- People referred urgently with a high suspicion of sarcoma after a local FSA are reviewed by a sarcoma treatment unit **within 14 days**.

To meet the 62 day indicator (FCT Business Rules) high suspicion of cancer referrals should be triaged in a timely manner **within 1–2 working days** by an appropriately trained person (nurse specialist or doctor).

If symptoms are concerning and the referral is not accepted, primary care 'safety netting' for re-assessment is recommended.

3.5 Supportive care and communication

All people who are managed by a sarcoma MDT should be allocated a Sarcoma CNS (NICE guidelines).

Assess the supportive care needs of the person and their whānau. Where appropriate, give them:

- support during investigations and care following referral, such as financial, transport and personal support
- help for dealing with psychological and emotional distress – for example, anxiety/depression, interpersonal concerns, and adjustment difficulties to a potential diagnosis of cancer
- information regarding supportive services that they can engage with at a time suitable to them.
- referrals to kaupapa Māori and Whānau Ora services at their request.

3.5.1 Communication with the person/whānau receiving care

Health providers/professionals

- Provide information regarding their role in the health care team.
- Explain who the person and their whānau is being referred to, the reason for the referral and the expected timeframes for appointments.
- Explain the need for the person and their whānau to return to the GP if signs and symptoms change while waiting for investigations and/or assessment.
- Request that the person notify the delegated clinic or their own GP practice if the specialist has not been in contact within the expected timeframe.
- Discuss the range of services available (including private), referral options, and any costs associated with accessing these services.
- Inform the person and their whānau that they can contact or request a referral to NGOs that provide supportive care, including local Māori health service providers/professionals.
- Give written and verbal information regarding planned investigations and referral services.
- Clarify that the person and their whānau understands the information that has been communicated.

"Whānau face multiple barriers to primary care". "That safety net had been taken away." Person/whānau insights

Communication between health services

- Include relevant information in referrals, as identified in Steps 3.3 and 3.4.

- Notify the referrer of the acceptance of referral and expected timeframes to be seen or decline of referral and reasons for decline.
- Notify changes in referral status (either changes to symptoms or wait time changes).
- Ensure roles and responsibilities are understood, including GP/lead clinician responsible for checking and notifying results to the person and their whānau.
- Acknowledge receipt of referrals.

3.6 Measurement and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

For a high suspicion of cancer and where the triaging clinician believes the referral is urgent, the person will begin the 62 FCT day pathway.

Early detection through primary care that identifies a high suspicion of cancer and requires an urgent referral to specialist will be seen **within 2 weeks**. The following FCT business rules will apply:

- **31-day Health Target -** All people will receive their first cancer treatment (or other management) within 31 days from decision to treat. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 31 days from the decision to treat. (**FCT business rules**, 2023).
- **62-day indicator** – All people with a high suspicion of cancer (without a confirmed pathological diagnosis of cancer at referral) will receive their cancer treatment within 62 days from date of referral. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 62 days from date of referral to first treatment.

Step 4: Diagnosis, staging and treatment planning

This step outlines the process for confirming the diagnosis and stage of cancer and the planning of subsequent treatment in discussion with the person and their whānau.

Health services work with the person and their whānau to diagnose and stage the cancer, provide treatment options and recommendations, and help meet any identified needs. This generally occurs in secondary or tertiary health care services. Assessment and investigation results, including discussions between the appropriate multidisciplinary team members and the person and their whānau, will help to determine the treatment options recommendations and plan.

4.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- prioritising access for Māori to diagnostics, staging, and treatment planning
- supporting the person and their whānau to access holistic care, including mātauranga Māori traditional practices and emotional and spiritual support to complement medical treatment
- talking with the person and their whānau and clinicians about current or intended use of rongoā or other complementary therapies to understand the potential benefits, risks and/or other implications
- consultation with the person and their whānau regarding what they would like to happen to any bodily tissue or organs removed as part of their diagnostic workup and treatment.

4.2 Specialist investigations (diagnostic work up for sarcoma)

Biopsy of suspected sarcoma should be guided by the Sarcoma MDM team as this may influence the diagnostic outcome and subsequent management, therefore all people with suspected sarcoma should be referred to a specialist sarcoma multidisciplinary team before biopsy (Cancer Council Australia Sarcoma Guidelines Working Party 2014, ESMO 2014a, ESMO 2014b, NICE 2010).

All people with a provisional histological and/or radiological diagnosis of bone or soft tissue sarcoma must have their diagnosis reviewed by a specialist sarcoma pathologist and/or radiologist who are part of a sarcoma MDT. A formal system for second opinions and review of difficult cases, including molecular pathology and cytogenetic facilities should be made available **(NICE guideline).**

Suspected soft tissue sarcoma should be referred to the local orthopaedic unit for further assessment and discussion with the sarcoma treatment centre (Step 5). All people with a probable bone sarcoma (usually following X-ray examination) should be referred directly to a sarcoma treatment centre for diagnosis and management.

Where possible the diagnosis of sarcoma is established or confirmed before treatment is planned. The sarcoma specialist, either before or after taking a medical history and making a medical examination of the person, may request additional investigations.

This may include:

- radiology: ultrasound, CT scan, MRI, or PET-CT scan
- laboratory: blood tests
- pathology: image-guided core biopsy (FNA is not appropriate or helpful for sarcoma diagnosis).

Timeframe for completing investigations

Diagnostic investigations should be completed **within 2 weeks** of the initial specialist assessment.

4.3 Staging

Accurately staging cancer helps guide treatment decisions and is a significant contributor to providing a cancer prognosis (Te Aho o Te Kahu 2021a). When cancer is diagnosed, additional investigations are often conducted to establish how much the cancer has grown and if, and how far, it has spread. The following additional tests may be required for staging:

- local – MRI, thallium scan, or PET-CT scans
- systemic – bone scan, PET-CT, CT whole body (including limbs) Turbo STIR MRI
- staging for soft tissue sarcoma uses:
    - American Joint Committee on Cancer (AJCC) Staging System, Tumour size, nodal status, metastasis, histological grade (TNMG).
    - French Federation of Comprehensive Cancer Centres (FNCLCC) for prognostic stage grouping

Note, pathological staging may occur after surgery for some sarcomas.

4.4 Performance status

Performance status is assessed to inform prehabilitation and treatment recommendations and documented using the Eastern Cooperative Oncology Group (ECOG) Performance Status Scale (ECOG-ACRIN Cancer Research Group). The degree of benefit of treatment for an individual may vary according to diagnostic, staging and prognostic factors and performance status.

In older people with cancer, a geriatric assessment measures their level of fitness and treatment tolerability. People over the age of 70 years should undergo some form of geriatric assessment (COSA 2022). Screening tools can be used to identify those who will benefit most from these comprehensive assessments.

Geriatric assessments help tailor the treatment plan, address any issues found with the multidisciplinary team, and provide interventions to optimise te person's general health status (Seghers et al 2023).

4.5 Clinical genetics

Referral to clinical genetic services for sarcoma is considered if features of the cancer suggest a genetic predisposition, such as:

- early age onset
- family history
- physical features which raise the possibility of a recognised genetic syndrome
- multiple primary cancers.

For further information see the Genetic Health Service New Zealand website **(geneticheathservice.org.nz).**

4.6 Multidisciplinary meeting

Optimal cancer care requires a multidisciplinary approach to tailor treatment plans to the person's needs in collaboration with their whānau and the health care team.

All cases of sarcoma or suspected sarcoma must be referred to one of the two Sarcoma Multidisciplinary Meetings (MDM) which are hosted in Auckland and Christchurch.

All sarcoma MDTs should participate in national audit, data collection and training. This ensures both MDT's maintain a consistent and high standard of care and are sufficiently resourced to meet targets.

The person with suspected sarcoma should be referred early to a specialised sarcoma centre for management.

- Referral to a sarcoma MDM following nationally agreed referral criteria is undertaken to inform treatment recommendations or further assessment and investigation.
- All suspected or confirmed sarcoma will be discussed in a MDM within two weeks from date of referral to MDM.
- The multidisciplinary team discusses complex cancer cases and recommends a treatment plan.
- Results of all relevant tests and access to images must be available for the MDM.
- Information about the person and their whānau, their overall condition, co-morbidities, personal preferences, and social and cultural circumstances must be available for the MDM.
- The level of discussion may vary, depending on the person and clinical and supportive care factors.
- The proposed treatment plan will be recorded in the person's medical record and MDM database, and communicated to the referrer and primary care provider **within 2 days** of the MDM.
- The referring clinician and/or team discusses the recommendations from the MDM with the person and their whānau immediately after the MDM, enabling the sarcoma centre to contact the person directly.
- The sarcoma lead clinician will discuss the treatment plan with the person and whānau and introduce them to their sarcoma CNS.

MDMs are managed and guided by the following standards:

- ***Standards for High-Quality Multidisciplinary Meetings (MDMs) in Aotearoa New Zealand*** (Te Aho o Te Kahu 2024)
- ***HISO 0038.4:2021 Cancer Multidisciplinary Meeting Data Standard*** (Te Aho o Te Kahu 2021b)

4.6.1 Treatment options and recommendation

Following MDM, treatment intent is discussed with the person and their whānau. Treatment intent ranges from curative, non-curative, symptom management and palliative care.

Treatment, referral options and recommendations are discussed with the person and their whānau to enable informed decision making in accordance with their rights and ability to exercise independence, choice, and control.

The advantages and disadvantages of recommended treatments and associated potential side effects are discussed in plain language with interpreter support as required. Other support may be required for this discussion such as kaumātua/kuia, chaplain and nursing staff as required.

Further discussion between health services (primary care and specialists) and the person and their whānau will ensure comorbidities are well managed. This optimises the person's health to be able to cope with the proposed cancer treatment and its effects.

4.6.2 Fertility preservation

A referral for fertility preservation alongside a contraception assessment and advice should be discussed with the person and their whānau dependent on age, type of sarcoma and the treatment planned. An early, collaborative, and multidisciplinary approach with the person is undertaken, which maximises the opportunity for best practice contemporary care and consideration for future fertility. Further information on fertility preservation can be found at the **AYA Cancer Network Aotearoa**.

4.6.3 Prehabilitation

Prehabilitation is the process of optimising a person's overall wellbeing prior to undergoing cancer treatment. Ideally, prehabilitation should begin as early as possible after a cancer diagnosis to allow adequate time for interventions to take effect. A nominated service provider is tasked with coordinating prehabilitation. Prehabilitation (preparing for treatment) is initiated and assessed by primary or hospital services and may require referral to additional services or management of:

- smoking cessation
- rongoā
- psychosocial support
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for person and their whānau preparing for surgery
- nutrition.

4.6.4 Clinical trials

Where eligible, the person with sarcoma is offered and supported to participate in research or clinical trials. Many emerging treatments are only available as clinical trials and may require referral to specific trial centres.

4.7 Supportive care and communication

4.7.1 Care coordination

Care coordination supports the navigation through diagnosis, staging, and treatment planning. The person and their whānau receive tailored education and are enabled to ask questions, seek further clarity around treatment options and recommendations, and gain support around the potential next steps in the pathway. The care coordinator will assist in the coordination and navigation of care, support the person and their whānau, and complete any additional referrals that may be required.

People and their whānau who have someone coordinating their care are often more satisfied with the opportunities provided to them and the decision-making process about their care (Cancer Institute NSW 2010).

The person and their whānau will have a clear understanding of what to expect at each step of the cancer pathway, with a clear point of contact should they require support or further information (refer Principle 6).

4.7.2 Supportive Care

Assess the supportive care needs of the person and their whānau, including:

- care coordinator is in place
- prehabilitation
- contraception and fertility support
- early referral to palliative care
- information and education needs are met (for further information refer to Step 3.5).

4.7.3 Communicating with the person/whānau receiving care

Health providers/professionals

> ***"A lot of people need to travel hours to get to an appointment and don't have vehicles or family support."***
> Person/whānau insights

- Ensure the person and their whānau have the option to have additional support people with them when having discussions.
- Explain and discuss with the person their diagnosis, staging, treatment options and recommendations in plain language.
- Discuss the advantages and disadvantages of treatment options and associated potential side effects.
- Provide information on the sarcoma treatment centre, consultants/nurses who will be involved in treatment and the key worker for the person.
- Provide information and assistance on travel and accommodation for those travelling for treatment.
- Provide information and resources in a format that is useful to the person and their whānau (and that they can share with others as they wish).
- Identify any barriers or challenges that may prevent the person and their whānau from accessing services or attending treatment.
- Discuss with the person and their whānau ways to improve health outcomes and wellbeing prior to and during treatment.
- Advise the person and their whānau of their lead clinician and care coordinator.
- Clarify that the person and their whānau have understood the information that has been communicated.
- The person and their whānau may require time to process the information that has been relayed, prior to consenting to treatment.
- Coordinate scheduling of appointments with the person and their whānau to ensure access barriers are minimised and attendance is supported.
- Discuss with the person and their whānau the need to update or complete their advance care planning and/or advance directive.

Communicating between health services

- Coordinate appointments among health services, in discussion with the person and their whānau to make best use of their time and resources and to support access.
- Communicate the diagnosis, MDM recommendations and treatment plan between health services.
- Ensure the referring team understand the rationale and action the MDM recommendations.

- Discuss and agree shared care arrangements, in symptom and co-morbidity management, supportive care and referral to local services.
- Confirm the lead clinician and provide handover details as necessary.

4.8 Measuring and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Te Aho o Te Kahu Quality Performance Indicator**
    - Route to diagnosis: Proportion of people who are diagnosed with cancer within 30 days of an emergency or acute (unplanned) hospital admission (Te Aho o Te Kahu, 2024).
- **Faster Cancer Treatment**
    - **31-day Health Target -** 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat. (**FCT business rules**, 2023)
    - **62-day indicator** – 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.
- **MDM Standards**

For audit compliance with standards and standards audit tool the following may be used:

- ***Standards for High-Quality Multidisciplinary Meetings (MDMs) in Aotearoa New Zealand*** (Te Aho o Te Kahu 2024)
- ***HISO 0038.4:2021 Cancer Multidisciplinary Meeting Data Standard*** (Te Aho o Te Kahu 2021b)

Step 5: Treatment

This step describes publicly funded optimal treatments for sarcoma by trained and experienced clinicians and team members, in an appropriate environment.

- Sarcomas are rare cancers, and treatment is often complex, in the form of radical treatment and challenging surgery. The limited numbers of personnel with relevant training and expertise in sarcoma treatment and care means that not all treatments can be offered in all cancer centres.
- There is strong evidence to demonstrate that people treated within specialist centres have better overall rates of survival (NICE 2006). In New Zealand, these specialist centres are regional sarcoma treatment units based in Auckland and Christchurch.
- All people with a confirmed diagnosis of bone or soft tissue sarcoma (except children with certain soft tissue sarcomas) should have their care supervised by or in conjunction with a sarcoma multidisciplinary team (MDT) (NICE Manual).
- All people with sarcoma are entitled to access sarcoma treatment units with appropriate resources and facilities to deliver the best standard of care
- Treatment for sarcoma is based on histological subtypes, and persons are offered a combination of surgery, systemic therapy, and radiation therapy.
- Sarcoma surgery occurs at the two sarcoma centres (Auckland and Christchurch) unless otherwise directed by the relevant sarcoma MDM.

The treatment of sarcoma is informed by the following guidelines:

- Australian and New Zealand Sarcoma Association (2022). **Clinical Practice Guidelines** for Management of Sarcoma
- European Society for Medical Oncology (2021). Soft tissue and visceral sarcomas: ESMO **clinical practice guidelines** for diagnosis, treatment, and follow-up
- National Comprehensive Cancer Network. NCCN **clinical practice guidelines** in oncology: soft tissue sarcoma
- National Comprehensive Cancer Network. NCCN **clinical practice guidelines** in oncology: bone cancer
- National Comprehensive Cancer Network. NCCN **clinical guidelines** in oncology: gastrointestinal stromal tumors (GIST)
- National Comprehensive Cancer Network. NCCN **clinical guidelines** in oncology: Kaposi sarcoma
- **Guidance on Cancer Services Improving Outcomes for People with Sarcoma**
- **UK BSG Guidelines for the Management of Soft Tissue Sarcomas – 2024 Update**
- **UK BSG Guidelines for the Management of Bone Sarcomas**

5.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through ensuring that:

- services achieve equity of access and outcomes irrespective of where treatment occurs
- equity in access to treatment is facilitated through active and coordinated support of financial and social barriers to treatment
- tikanga Māori and rongoā is integrated and applied in discussion with treating clinicians

- a referral to the Kia Ora E Te Iwi (KOETI) programme (Cancer Society) occurs as required
- the person and their whānau have all the information and resources to support their mana motuhake (empowerment).

5.2 Treatment intent

The treatment intent should be established in a multidisciplinary meeting/setting (see Step 4.6), documented in the person's medical record, and shared with the person and their whānau as appropriate. Discuss the advantages and disadvantages of recommended treatments and associated side effects in plain language to support the person and their whānau to make an informed decision. If there is more than one suitable treatment option, services could facilitate the decision making of the person and their whānau by having all specialties involved in the single appointment.

Timeframes for starting treatment are informed by evidence-based guidelines where available. The treatment team recognises that shorter timeframes for appropriate consultations and treatment often provide a better experience for people.

Confirm decisions, and consent for treatment. If treatment is agreed, develop a treatment care plan that includes:

- what the treatment and intent is, alongside likely impacts
- ways to improve health outcomes and wellbeing during treatment, this includes where they can receive support and information
- expected timeframes.

5.2.1 Additional considerations

Undertake a needs assessment and address any possible barriers or challenges (such as financial, social, care coordination and cultural obligations) that may prevent the person from accessing treatment. Formally involving the palliative care team/service early can benefit the person receiving care, so it is important to know and respect each person's preference.

The person's current or intended use of any traditional or complementary therapies, including rongoā, will need to be discussed. Information resources should be provided so the person and their whānau can review and take these away for further reflection and sharing, including contact information for services and key care coordinators.

Initiate advance care planning discussions with the person and their whānau before treatment begins (this could include appointing a substitute decision-maker and completing an advance care directive).

Ensure prehabilitation is underway (as appropriate) to optimise treatment outcomes, and manage any comorbidities, prior to treatment. Depending on the treatment decided, additional prehabilitation activities may need to be initiated.

If initial treatment is declined, discuss next steps fully with the person and their whānau. This includes the option to re-engage with initial treatment if they change their minds, with the understanding it may no longer be viable and/or suitable.

Ensure an escalation plan with key contact people is developed if the person becomes unwell before treatment begins.

5.3 Treatment options

The type of treatment recommended for sarcoma depends on the type, stage and location of the cancer and the person's age, health, and preferences. Treatment may include a combination of the treatment options listed below, concurrently, or sequentially, to maximise outcome.

The person may also be supported to participate in research or clinical trials where available and appropriate. Many emerging treatments are only available as clinical trials and may require referral to certain trial centres.

- **Surgery** is the main treatment option for bone sarcomas. The treatment of soft tissue sarcomas is usually a combination of surgery and radiation therapy but may include systemic therapy in some subtypes. Surgery alone may be the treatment for low grade sarcoma.

Timeframes for starting treatment

  - Surgery should be completed within 62 days of referral triage or 31 days of decision to treat if no neoadjuvant therapy is required (depending on FCT eligibility).

If neo-adjuvant surgery is required, time to surgery is dependent on the treatment regime.

- **Radiation therapy**

People suitable for radiation therapy please refer to The Radiation Oncology Model of Care (Te Aho o Te Kahu 2024).

  - For soft tissue sarcoma, radiation therapy (external beam, brachytherapy, intensity-modulated radiation therapy, particle beam) must be considered before or after surgery.
  - In general, radiation therapy for bone sarcomas is mainly used for palliation (ESMO 2014a).
  - In Ewing's sarcoma, radiation therapy may be considered as part of the treatment protocol as it can be a key part of curative treatment for some.
  - Radiation therapy is a valuable part of palliative therapy for other persons with bone sarcoma. For persons with large and high-grade soft tissue tumours, radiotherapy will also usually be used (NICE manual).

Timeframes for starting treatment

  - The timing of radiation therapy needs to be individualised dependent on resection and reconstructive considerations.
  - If radiation is a first treatment, treatment should occur within 31 days of decision to treat.

- **Systemic anti-cancer therapy**

People suitable for systemic anti-cancer therapy (SACT) please refer to The Model of Care for Adult Systemic Anti-Cancer Therapy Services in Aotearoa, New Zealand (Te Aho o Te Kahu 2024).

- People with sarcoma should be treated with pre- and/or postoperative SACT by a medical oncologist with experience in treating sarcoma and is involvement in multidisciplinary care.
- For persons with other forms of localised soft tissue sarcoma, chemotherapy is not the current standard of care, and persons should be treated as per the multidisciplinary team's treatment plan.
- Chemotherapy and radiotherapy are important components of the treatment of some people and should be carried out at designated centres by appropriate specialists as recommended by a sarcoma MDT.

Timeframes for starting treatment

- If chemotherapy is a first treatment, treatment should occur **within 31 days** of diagnosis of the decision to treat.
- Adjuvant chemotherapy should begin **within 31 days** of decision to treat unless there are clinical reasons to recommend otherwise.

- **Palliative care**

Palliative care is an integral part of cancer treatment and care. It offers specific assessments, supportive care programmes, and services focused on living with and dying from cancer. Early referral and access to palliative care is a critical aspect of best practice. The person and their whānau who cannot be offered curative treatment, or declines curative treatment, as well as those with a significant symptom burden, should be offered prompt access to palliative care services.

Treatment includes managing the impact of cancer therapy, including the management of physical symptoms, distress, and other clinical issues a person and their whānau may experience.

Early referral to palliative care and other health services is recommended to help manage:

- pain management in the community
- psychological support
- nutritional support
- sexual dysfunction
- peripheral neuropathy
- fatigue.

5.3.1 Clinical Trials

The person is supported to participate in research or clinical trials where available and appropriate. Many emerging treatments are only available as clinical trials and may require referral to certain trial centers (refer Principle 8[2]).

5.4 Treatment summary

A treatment summary will be provided by the treating service for the person and their whānau and clinicians involved in their follow up care, including primary care. The summary includes:

- relevant diagnostic tests performed and results
- cancer diagnosis, characteristics, stage, and prognosis
- treatment received
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health providers/professionals

- potential long-term and late effects of treatment
- supportive care services provided
- recommended follow up and surveillance.

5.5 Supportive care and communication

Supportive care needs for the person and their whānau are assessed for all cancer treatment modalities, including surgery, chemotherapy, radiation, and palliative care.

Assess challenges and changes in health status that may arise for the person and their whānau due to their treatment, including:

- access to expert health providers/professionals with specific knowledge about the psychosocial needs of people undergoing sarcoma care
- potential isolation from normal support networks, particularly for rural people who are staying away from home for treatment
- general health care issues (such as smoking cessation and sleep disturbance), which can be referred to a general practitioner
- altered cognitive function due to chemotherapy or radiation therapy, which requires strategies such as maintaining written notes or a diary and repetition of information
- loss of fertility, sexual dysfunction or other symptoms associated with treatment or surgically or chemically induced menopause, which requires sensitive discussion and possible referral to a clinician skilled in this area
- decline in mobility or functional status
- management of physical symptoms such as pain, arthralgia, and fatigue
- early management for acute pain postoperatively to avoid chronic pain
- side effects of chemotherapy such as neuropathy, cardiac dysfunction, nausea, and vomiting – managing these side effects is important in protecting the person's quality of life
- managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications – referral to a pharmacist may be required
- disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic) – referral to a specialist psychologist, psychiatrist or social worker may be required
- weight changes – may require referral to a dietitian before, during and after treatment
- hair loss and changes in physical appearance – referral to Look Good Feel Better
- assistance with beginning or resuming regular exercise – referral to an exercise physiologist or physiotherapist.

Persons with functional disabilities as a consequence of their sarcoma should have timely access to appropriate support and rehabilitation services.

- Decline in functional status (particularly with limb reconstruction or amputation) may affect the person's mobility and ability to take part in everyday activities.
- Referral to an occupational therapist, orthotist/prosthetist and a physiotherapist or exercise physiologist for assessment, education, intervention, and compensatory strategies may assist with maintaining mobility.
- The person may require prolonged periods of rehabilitation.

- Healing of underlying structures, infection and other complication risks relating to skeletal implants may require input from wound nurse specialists and infection control specialists.
- The person who has had a limb amputated to treat their sarcoma requires rapid and easy access to prosthetic services, ideally preoperatively where possible.

The person and their whānau may also need to manage:

- financial issues related to loss of income (through reduced capacity to work or loss of work) and additional expenses as a result of illness or treatment
- advance care planning, which may involve appointing a substitute decision-maker and completing an advance care directive
- legal issues (completing a will, care of dependent children) or making an insurance, superannuation or social security claim based on a terminal illness or permanent disability.

5.5.1 Care coordination

Care coordination will support the person and their whānau through treatment. The care coordinator supports the implementation and activation of supportive care needs through the provision of information, education and referral regarding the concerns and issues that have been raised by the person and their whānau (refer Principle 5[2]).

5.5.2 Communication with the person/whānau receiving care

Health providers/professionals

- Confirm lead clinician and other treatment teams/members involved in care.
- Advise the person and their whānau of the expected timeframes for treatment and ensure they have a key contact person.
- Clarify that the person and their whānau understand the information that has been communicated.
- Refer the person to supportive care and other health care services to optimise wellbeing.

Communication between health services

- Confirm the lead clinician and handover as necessary.
- Confirm the diagnosis, treatment intent, recommendations, and plan, including potential side effects.
- Communicate supportive, treatment plan and referrals between health services.
- Advise of any enrolment in clinical trial as appropriate.
- Advise of changes in treatment or medications.

"A 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"
Person/whānau insights

5.6 Measuring and monitoring

Monitoring and measuring are key components of contemporary best practice. Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- A national sarcoma database will be used to monitor outcomes and targets.

For those who have started on the FCT pathway, the FCT wait time indicators will apply. FCT applies to a person's first cancer treatment of a new cancer.

- **Faster Cancer Treatment**
    - **31-day Health Target** – All people will receive their first cancer treatment (or other management) within 31 days from decision to treat.
      As a minimum, 90% of persons will receive their cancer treatment (or other management) within 31 days from the decision to treat.

    - **62-day indicator** – All first treatment will be started within 62 days from triage or 31 days from decision to treat (includes surgery, chemotherapy, and radiation therapy). As a minimum, 90% of persons will receive their cancer treatment (or other management) within 62 days from triage of referral to first treatment. (Ministry of Health | Manatū Hauora. 2023.)

- **Medical oncology treatment timeframes**
    - Category A – urgent within 48 hours
    - Category B – semi-urgent within 2 weeks
    - Category C – routine within 4 weeks
    - Category D – combined modality treatment (determined by scheduling of the two treatment modalities).

- **Radiation oncology treatment timeframes**[4]
    - Category A – treat within 24 hours.
    - Category B – treat within 10 working days.
    - Category C (palliative intent) – treat within 10 working days
    - Category C (curative intent) – treat within 20 days.
    - Category D – combined modality treatment (determined by scheduling of the two treatment modalities).
    - Category E (benign disease) – treat within 80 working days.

[4] Radiation Oncology Waitlist Data Business Rules – Te Whatu Ora

Step 6: Care after treatment

The person accesses appropriate follow up and surveillance and is supported to achieve their optimal health after cancer treatment.

The transition from active treatment to care after treatment is critical to supporting long-term health. Survivorship care planning is the umbrella term for care described in this step, and whilst aspects of this care begin at diagnosis (prehabilitation, supportive care, etc) the term itself is not often used until this part of the pathway.

In some cases, people will need ongoing specialist care, and in other cases a shared follow up care arrangement with their general practitioner may be appropriate. This will be informed by the type and stage of a person's cancer, the treatment they have received and the needs of the person and their whānau (refer Principle 5).

All sarcoma follow up should be guided be the Sarcoma MDM.

6.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- offering options for holistic recovery and wellness care within hauora Māori models of care
- providing access to clinical, psychological, social, financial, and cultural support to transition back into recovery and life after cancer treatment.
- offering options for holistic recovery and wellness care within hauora Māori models of care
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6.2 Survivorship care planning

After completing initial treatment, a designated member of the multidisciplinary team (most commonly nursing or medical staff involved in the person's care) should undertake survivorship care planning with the person and their whānau.

The survivorship care plan should cover, but is not limited to:

- the provision of a treatment summary
- information on what medical follow up and surveillance is planned
- how care after treatment will be provided, including by whom and where, and contact information
- inclusion of care plans from other health providers to manage the consequences of cancer and cancer treatment
- information about wellbeing and primary and secondary prevention health recommendations that align with chronic disease management principles (Step 1)
- rehabilitation recommendations and any referrals
- available support services, including cancer NGO survivorship programmes/services (these may be tumour specific)
- signs and symptoms to be aware of that may indicate the cancer has recurred
- monitoring for, and treatment of, long-term side effects of treatment
- the process for rapid re-entry to specialist medical services.

As people are often followed up for five or more years after treatment, this plan needs to be regularly reviewed and updated to reflect changes in the person's clinical and psychosocial status. All health providers involved in the follow up care are responsible for updating the care plan.

6.3 Treatment summary

A treatment summary will be provided by the treating service(s) to the person and their whānau and to those clinicians involved in follow up care.

The summary includes:

- the diagnostic tests performed and results
- cancer diagnosis, characteristics, stage, and prognosis
- treatment received (types and dates)
- current toxicities (severity, management and expected outcomes), including who to contact should they have any concerns about these
- interventions and treatment plans from other health providers
- potential long-term and late effects of treatment.

6.4 Rehabilitation and recovery

Rehabilitation may be required at any point in the care pathway. Issues that may need to be dealt with at this stage include managing cancer-related fatigue, coping with cognitive or physical changes, returning to study or work, and ongoing adjustment to cancer and its sequelae.

Sarcoma limb salvage is complex and with case-by-case variation in expected function post operatively. All persons undergoing sarcoma treatment should have access to specialist sarcoma physiotherapy and occupational therapy, who are part of the sarcoma service. This should begin preoperatively, and the teams should see the persons for follow up of functional outcomes and rehabilitation. The dedicated sarcoma services teams should communicate with local teams to advise and guide care.

People with sarcoma, should be considered for referral to the following rehabilitation or recovery services should be undertaken:

- physiotherapy
- dietician
- lymphoedema specialist
- occupational therapist
- orthotist/prosthetist
- psychologist.

6.5 Follow up and surveillance

Follow up and surveillance can have multiple functions, including:

- evaluation of treatment response
- early identification of recurrence
- early detection of new primary tumours
- monitoring and management of complications
- recording of person reported outcomes
- optimisation of rehabilitation

- functional outcome assessment
- provision of support to the person and their whānau.

Care after treatment is driven by predicted risks and an individuals' clinical and supportive care needs.

Care may include regular physical examinations, medical tests, and imaging. Specific plan will be based on the medical guidelines for the specific type and stage of cancer, the treatment that's been received, and the needs and wishes of the person and their whānau.

People are offered follow up under the direction of the specialist sarcoma treatment unit responsible for their treatment.

Specialist team surveillance should include:

- regular clinical examination and routine surveillance for local recurrence
- assessing function and possible complications from any reconstruction
- imaging (includes chest X-ray, MRI, CT, and functional imaging such as PET-CT, thallium, or technetium bone scans).

Long-term follow up will be needed for many people, especially those who have received a prosthetic replacement and those who had a childhood cancer, because of the risk of late complications.

If there are no guidelines to inform follow up and surveillance, then planning needs to include:

- who will be providing follow up care for example, their specialists, their primary care provider (including palliative care) or if there will be a shared care approach (refer Principle 1). Generally, people will have at least one clinic visit with the specialist(s) involved in a person's treatment and care to date
- what tests (such as blood or radiological tests) need to be carried out, who is responsible for ordering them, how frequently they need to be done, and who will discuss the results with the person and their whānau
- the frequency people should be seen and for what timeframe
- follow-up appointments are more frequent initially, becoming less frequent as time goes on
- who the person and/or their whānau should contact if they have any concerns.

Note that for some people follow-up appointments are reassuring; however, for others this may be anxiety-inducing, this should be discussed with the person and the surveillance can be tailored to meet individual person needs.

6.6 Signs and symptoms of recurrent disease

The likelihood of recurrence depends on many factors usually related to the type of sarcoma, the stage of sarcoma at presentation and the effectiveness of treatment. Educating the person and their whānau about potential symptoms of recurrence is critical for timely management.

The person and their whānau, and primary care givers can play an integral role in ongoing sarcoma surveillance:

- the person should regularly check the area of surgery for evidence of new mass indicating potential local recurrence

- the person should be alert to other lumps appearing elsewhere, but particularly in the same limb or close to the previous surgery
- the person should be aware of pain in other areas of the skeleton
- although chest imaging is part of the regular follow up, persistent chest symptoms should be reported
- people should be encouraged to report any recurrence of the initial symptoms they may have experienced at the time of initial diagnosis.

6.6.1 Rapid re-entry to specialty services

Service providers have a process for rapid re-entry to specialty services for suspected recurrence and advise the person and their whānau of how to do this if required. All service providers should raise concerns via the relevant sarcoma MDM office or directly to the responsible sarcoma CNS.

All people with sarcoma are provided an email and the name of their sarcoma CNS as a key contact.

6.7 Clinical trials

Where eligible, the person with cancer is offered and supported to participate in research or clinical trials. These might include studies to understand survivor's issues, to better manage treatment side effects, or to improve models of care and quality of life.

6.8 Supportive care, care coordination and communication

As the person transitions from active treatment, their needs often change, and health providers need to support people and their whānau to cope with life beyond treatment. (refer Principles 5, 6 and 7).

Health providers work with the person and their whānau to assess and address their needs, including:

"The need for care doesn't stop when treatment finishes."
"Whānau feel forgotten when treatment ends."
Person/whānau insights

supportive care

Health providers undertake a needs assessment to inform the survivorship care plan and make appropriate referrals.

coordinated care

Follow up care is provided closer to home and appointments coordinated to make access easier for the person and their whānau, where possible.

Continuity of care is provided where possible and appropriate – for example, people and their whānau should have the ability to continue to be supported by members of the care coordination team who they have developed a relationship with during their journey. All sarcoma follow up will be coordinated by the treating sarcoma MDM.

effective and timely communication

The person and their whānau are provided with a copy of their survivorship care plan, including information on any referrals that have been made.

Health providers involved in the follow up care of an individual have access to the up-to-date care plan, especially if primary care is involved, and can update the plan as required.

Specific needs that may arise at this time include the following:

- upper and lower limb lymphoedema may require referral to a trained lymphoedema practitioner
- long-term phantom limb pain may require ongoing pain management
- decline in functional status (particularly from limb reconstruction or amputation) may affect the person's mobility and ability to take part in everyday activities. Referral to an occupational therapist, orthotist/prosthetist and a physiotherapist or exercise physiologist for assessment, education, intervention, and compensatory strategies may assist with maintaining mobility. These may require prolonged periods of rehabilitation
- healing of underlying structures, infection and other complication risks relating to skeletal implants may require input from wound nurse specialists and infection control specialists
- people require ongoing nutritional screening, assessment, and management. Reduced oral intake and/or swallowing difficulties and weight loss require referral to a dietitian and speech pathologist (for swallowing difficulties)
- occasionally where treatment requires creation of a stoma, persons may require ongoing stoma-specific supports
- people may need treatment for other physical symptoms such as pain, fatigue, and musculoskeletal dysfunction.

6.9 Measuring and monitoring

Currently there are no national indicators for this step.

The measuring and monitoring of outcomes and achievement of targets will be monitored through the national sarcoma database/registry. These will include but are not exclusive to:

- FCT targets
- overall numbers of sarcoma and other mesenchymal tumours treated
- breakdown of sarcoma subtype numbers
- numbers of metastatic bone disease treated
- 30- and 90-day mortality
- unexpected deaths
- 5-year survival data.

Step 7: Palliative and end-of-life care

Palliative and end-of-life care provides the person facing life-limiting conditions with holistic support and coordinated services based on their specific needs.

Palliative and end-of-life care is an essential health service to optimise the person's quality of life until they die. This involves supporting the person's physical, psychosocial, spiritual, and cultural needs, and supporting their whānau with bereavement support. It is appropriate at any stage in a serious illness.

> **"You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only die peacefully, but also to live until you die."**
>
> Dame Cecily Saunders

7.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through ensuring that:

- the person and their whānau have the choice to access Kaupapa Māori support services for living with cancer (stable, progressive or end-stage)
- rurality does not restrict access to critical clinical, social, cultural and resource support for the person and their whānau
- palliative and end-of-life care is integrated across health services.

7.2 Palliative care

Palliative care prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other symptoms, whether physical, psychosocial, or spiritual, and improves the quality of life (World Health Organisation 2020).

Palliative care should be provided by all health professionals. Palliative care uses a team approach with non-specialist services (primary care, community care and generalist hospital services) supported by specialist palliative care services (hospitals, hospices). Palliative care services must be integrated with primary, community and secondary care, responsive and locally appropriate.

In many cases the whānau are the primary caregivers, and it is the responsibility of health providers/professionals to support the whānau. Health and social service providers/professionals will work together to ensure that the care for the person and their whānau is seamless, and that resources are used efficiently and effectively.

Primary, secondary, and palliative care services work alongside the person and their whānau to decide an appropriate place of care and the support required to implement the advance care plan.

Palliative care is provided in different settings, depending on availability and the needs and preferences of the person and their whānau. Settings include:

- in the community/a person's own home
- aged residential care
- hospice care
- hospital care.

Palliative care is most effective when considered early in the course of an illness. Early palliative care not only improves quality of life for the person and their whānau but also reduces unnecessary hospitalisations and use of health care services.

Referral to specialist palliative care services will be appropriate for those with a level of need that exceeds the resources of the generalist palliative care provider. Referral criteria for adult palliative care services in New Zealand are available on the Ministry of Health | Manatū Hauora website.

Clinical trials may improve palliative care and support the management of a person's symptoms of advanced cancer (Cancer Council Australia, nd; Cancer Council Victoria, nd). The treatment team should support the person and their whānau to participate in research and clinical trials where available and appropriate.

7.3 End-of-life care

The person with advanced cancer may reach a time when active treatment is no longer appropriate, symptoms are increasing, and functional status is declining. Dying is a normal part of every person's life course and every person has the right to die well.

Te Ara Whakapiri: Principles and guidance for the last days of life (Ministry of Health | Manatū Hauora 2017b) defines the essential components (baseline assessment, ongoing assessment, after-death care) and considerations required to provide quality end-of-life care for adults. This covers all care settings, including the home, residential care, hospitals, and hospices.

The multidisciplinary team needs to share the principles of a palliative approach to care when making end-of-life decisions with the person and their whānau. Honest communication is essential to ensure they have time to prepare and appropriate support is in place.

If the person does not already have an advance care plan or advance directive in place, a designated member of the team should encourage them to develop one in collaboration with their whānau.

It is essential for the treatment team to consider the appropriate place of care, the person's preferred place of death, and the support needed for the person and their whānau.

The treatment team should also ensure that whānau receive the information, support, and guidance about their role according to their needs and wishes.

7.4 Assisted dying

The person requesting assisted dying information are supported to access this service. Health providers/professionals are required to be aware of their rights and responsibilities regarding assisted dying services should the person raise this with the health care team. For more information visit: **www.health.govt.nz/our-work/regulation-health-and-disability-system/assisted-dying-service**.

7.5 Supportive care and communication

An essential component of palliative and end-of-life care is assessing and ensuring the needs of the person and their whānau are met. A number of supportive care needs may arise, including:

- assistance for dealing with emotional and psychological distress from grief and fear of death and dying
- specific support for the person and their whānau where a parent is dying and will leave behind bereaved children or adolescents
- facilitating conversations with the person and their whānau regarding an advance care plan, an advance directive and appointing an EPA
- access to appropriate equipment
- supporting whānau with carer training
- information and education around 'What to expect when someone is dying'
- identifying a key contact person.

7.5.1 Care coordination

Palliative care services must be integrated, responsive and well-coordinated. The person receiving palliative/supportive and end-of-life care may require several different types of care from different services and/or providers. The primary care team/palliative care team assists in coordinating care with the wider heath care team. It is important that the different providers and services are aware of and responsive to the various facets of care that the person and their whānau require.

7.5.2 Communicating with the person/whānau receiving care

Health providers/professionals

- Encourage the person and their whānau to designate a lead person(s) to communicate with care providers.
- Encourage discussions about the expected disease course, considering personal and cultural beliefs and expectations.
- Discuss shared goals of care.
- Discuss palliative care options, including community-based services as well as dying at home.
- Empower the person and their whānau to determine the care that they may want to provide, with or without support services.
- Refer the person to palliative care in the community according to their wishes.
- Discuss supportive care options available.

"The difference in his wellbeing after rongoā was huge. He was still dying, but he didn't look sick anymore."
Person/whānau insights

Communicating between health services

Clear communication between all providers/professionals involved in coordinating care is essential. This includes:

- confirming the lead clinician and handover as necessary
- providing updates on the person's prognosis
- initiating supportive and palliative care referrals
- advising on end-of-life care planning.

"Palliative care is a tapu space and requires a careful, holistic approach."
Person/whānau insights

7.5.4 Palliative care and end of life key national guidelines

- *Advance care planning.* (Te Tahu Hauora | Health Quality & Safety Commission New Zealand. 2022.) **hqsc.govt.nz**
- *A Guide For Carers. (***Hospice New Zealand** 2019).
- *Mauri Mate: A Māori palliative care framework* (**Hospice New Zealand**.2019)
- *Te Ara Whakapiri: Principles and guidance for the last days of life* (**Ministry of Health** | Manatū Hauora 2017b)
- *The Palliative Care Handbook* (**Hospice New Zealand** 2019b)

Information on assisted dying for the public (**Health New Zealand** | Te Whatu Ora, nd)

7.6 Measuring and monitoring

- *Ngā Paerewa Pairuri Tāngata | Standards for Palliative Care* (Hospice New Zealand 2019a) **Standards for palliative care.**
    - Standard 1: Assessment of needs
    - Standard 2: Developing the care plan
    - Standard 3: Providing the care
    - Standard 4: Supporting and caring for the family, whānau and carers
    - Standard 5: Transitions within and between services
    - Standard 6: Grief support and bereavement care
    - Standard 7: Culture of the organisation
    - Standard 8: Quality improvement and research
    - Standard 9: Staff qualification and training

- **National palliative care outcomes and reporting framework** (under development).