TE AHO O TE KAHU CANCER CONTROL AGENCY

Complex Sarcoma Services in Aotearoa, New Zealand.

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FOREWORD

Te Aho o Te Kahu in partnership with the Sarcoma Guidelines Working Group take great pleasure to present this document describing complex sarcoma services for the management of both adult and paediatric sarcomas.

Sarcomas are a rare and complex cancer arising from bone, cartilage, or soft tissues such as fat, muscle, connective tissue, or blood vessels. Sarcomas are also a heterogenous group of cancers and can form anywhere in the body. Sarcoma affects both children and adults, accounting for 20% of all paediatric cancers

The complexity of sarcomas provides many challenges which necessitate a centralised approach. Currently, in New Zealand, there is a consistent and proactive national process to consider the distribution of sarcoma surgical services across the country. This is particularly evident in orthopaedic oncology services. However, the retroperitoneal sarcoma service has been less coordinated but is now encompassed within the two sarcoma multidisciplinary teams.

Te Aho o Te Kahu has developed a framework designed to align with the growing national and international evidence supporting a centralised approach for complex surgeries. A centralised approach ensures high quality, consistent care leading to better outcomes for people and their whānau.

Sarcoma processes have already undergone a degree of centralisation with the establishment of specialist sarcoma services in Auckland and Christchurch. This has enabled a wider focus on sarcoma services to cover all aspects of the sarcoma pathway including the complex surgical framework. The resulting work captures the criteria, rationale, and attributes of complex sarcoma services. This document supports the Sarcoma Optimal Cancer Care Pathways released by Te Aho o Te Kahu and together with the Complex Sarcoma Service document, gives a comprehensive overview of care required for sarcomas.

Te Aho o Te Kahu and the Sarcoma Guidelines Working Group would like to acknowledge all those across New Zealand who have been affected by cancer, either living with the disease, supporting others, or have lost loved ones.

We would also like to express our appreciation to all those who have contributed to the development of the current complex sarcoma services document and the substantial work carried out previously to establish the specialist sarcoma service.

Noho ora mai.

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The role and contribution of all those who took part in developing the Complex Sarcoma Service are acknowledged. The time, effort and expertise contributed by clinical experts have been invaluable in shaping the direction of this work by informing the key steps to achieve optimal and sustainable sarcoma services across New Zealand. The support of the membership of The **New Zealand Sarcoma Society** was invaluable in initiating and developing this document.

Also acknowledged are:

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This is also an opportunity to expressly acknowledge the work and contributions made by the 2013 National Sarcoma Tumour Guidelines Working Group. Members of the working group acknowledged are:

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TABLE OF CONTENTS

PURPOSE OF THIS DOCUMENT

The purpose of this document is to provide detail on the complex sarcoma pathway (refer appendix one), to improve quality of care, consistency, and outcomes for those diagnosed with sarcoma. Both adults and children may be affected by sarcomas, with paediatric sarcomas accounting for 20% of childhood cancers.

The complex sarcoma service document is designed to be used in conjunction with the Optimal Cancer Care Pathways (OCCPs), specifically the sarcoma OCCP[1], OCCP Principles and OCCP Supplementary Information. When used as a quality improvement tool the complex sarcoma service document and optimal cancer care pathway will promote nationally coordinated and consistent levels of service across New Zealand. They aim to ensure the efficient and sustainable best-practice management of sarcomas, with a focus on equity.

DEVELOPING THE COMPLEX SARCOMA SERVICE

For people and whānau, treatment closer to home is the ideal option. However, in the case of complex sarcomas, the many challenges necessitate a two-centre specialist service which can potentially lead to increased travel time for people and their whānau.

Complex sarcoma cases often use non-routine procedures and require:

- one or more specialities
- surgeons with significant subspeciality training (usually at least 1 year in an international fellowship post FRACS)
- additional supports e.g., level 1 Intensive Care Unit (ICU), interventional radiology.

This requires a broader range of infrastructure and resources compared to less complex conditions. Therefore, it is essential to use a well-resourced, multidisciplinary approach that is both nationally consistent and regionally focussed.

The retroperitoneal sarcoma service has been less coordinated and is now encompassed within the two sarcoma multidisciplinary teams (MDT), but clear pathways need to be laid out. Presently, most district hospitals offer cancer treatment, in particular less complex surgery, while the more complex, lower volume procedures are carried out over fewer sites, all without a national consensus for optimal care. This falls far short of international standards when it comes to the care of people with sarcoma.

Complex Surgery

One of the key issues debated internationally is how to manage the safe, high-quality provision of complex sarcoma cases. Inevitably, a degree of centralisation of resources (including staff, infrastructure, material, and experience) is considered necessary to have the best outcomes.

Te Aho o Te Kahu has developed a complex surgery framework to align to the growing national and international evidence that supports a centralised approach to sarcoma surgery. This approach ensures that with increased volumes and resources, centralised sarcoma surgery will support the development of highly experienced and skilled services, improve person and

[1] Optimal Cancer Care Pathway for People with Sarcoma, Te Aho o Te Kahu, 2025

whānau experiences, increase efficiency, promote training, reduce costs, and limit clinical variability.

The complex surgical framework outlines essential requirements to ensure high quality and consistent surgical care for complex cases. To accommodate the broader focus of sarcoma services, the complex surgery requirements have been included as its own section (refer section 6). The inclusion of specific requirements for complex cases is to:

- aid providers in determining the reason for specialist sarcoma centres
- improve the outcome for people with sarcoma by removing the number of sarcoma surgeries performed outside the Specialised Sarcoma Centres
- enable coordinated 'close-to-home' age-appropriate supportive care post operatively and other closer to home options where possible.

The Te Aho o Te Kahu complex surgery framework introduces a concept that provides an opportunity to embed Mātauranga Māori into service delivery as standard practice. Using a Te Ao Māori metaphor aids ambitions to disband a hierarchical system, system barriers and focus value on person-centred care. In traditional Māori carvings, manaia figures have three fingers – the ring finger (mānawa), the middle finger (tōroa) and the index finger (kōroa) making up the hand (ringaringa). The three fingers symbolize three functioning parts of the same hand, each equal and important but each representing a different set of functions. To lose any finger weakens the hand. Each finger is used to represent a surgical centre: mānawa, tōroa or kōroa, or a surgical function: pre-, post-, and/or peri-operative care. The concept focuses on coordinated, collaborative and high-quality care for the person with sarcoma and their whānau.

When considering the development of a complex surgery framework for sarcoma services it became evident that a degree of centralisation had already occurred with two specialist centres being based in Auckland and Christchurch. Effectively this provides a kōroa service as defined in the complex surgery framework. With two specialist sarcoma centres already established, this has allowed for the focus to be on developing a document reflective of a complete sarcoma service, not just the surgical component. It is the purpose of this document to bring together all requirements, current practices, and international guidelines.

TE TIRITI O WAITANGI AND DEVELOPING THE COMPLEX SARCOMA SERVICE

The New Zealand health system has obligations and aspirations under Te Tiriti o Waitangi. New Zealand's complex sarcoma service has been developed with Te Tiriti o Waitangi at the forefront of our considerations. This includes how the service functions to address bias and discrimination, how to balance leadership between providers and Māori communities, how to share decision-making and resources, and for providers to be accountable for Māori health equity. To ensure Te Tiriti principles were consistently considered, and prioritised, the following framework has been applied.

Te Tiriti o Waitangi Principles	The steps to achieve the future state in the Complex Sarcoma Service will enable commissioners and service providers to:
Tino Rangatiratanga Provides for Māori self-determination and Mana Motuhake in the design, delivery, and monitoring of health and disability services	Provide Māori whānau with the information and resources they need to exercise Tino Rangatiratanga over their treatment. Ensure services are designed sustainably and in partnership with appointed equity champions and Māori consumer representatives.

Te Tiriti o Waitangi Principles	The steps to achieve the future state in the Complex Sarcoma Service will enable commissioners and service providers to:
Equity Requires the Crown to commit to achieving equitable health outcomes for Māori	Put in place a range of priorities and resources to ensure that Māori have equitable access to services. Support the inclusion of indigenous remedies with other treatments where appropriate.
Active Protection Requires the Crown to act, to the fullest extent practicable, to achieve equitable outcomes for Māori. This includes ensuring that it, its agents, and its Treaty partner are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity	Be informed by key strategic documents and programmes focused on equitable health outcomes for Māori, including: • Government response to Hauora Manaaki Ki Aotearoa Whānui - the Health and Disability System Review • Government response to Komiti Whiriwhiri Take Māori - Māori Committee inquiry into Health Inequities • Whakamaua: Māori Health Action Plan 2020 - 2025 • He Pūrongo Mate Pukupuku o Aotearoa 2020 - The State of Cancer in New Zealand 2020 • Rongohia Te Reo, Whatua He Oranga – The Voices of Whānau Māori Affected by Cancer 2023 • Te Pae Tata – Interim New Zealand Health Plan 2022 • He Korowai Oranga: The Māori Health Strategy 2022 • Pae Tū: Hauora Māori Strategy 2023
Options To provide for kaupapa Māori health services and to ensure that all healthcare services are provided in culturally appropriate ways that recognise and support the expression of hauora Māori models of care	Strengthen relationships with kaupapa Māori health providers who in turn can support people and whānau to receive treatments in a mana enhancing manner. Incorporate insights and opinions from Kaupapa Māori health providers, Māori health professionals and Māori people and whānau to understand cultural sensitivity and opportunities for improvement. Recognise that kaupapa Māori health providers have a meaningful influence which they naturally incorporate in their daily work routines. Support all people working in cancer treatment services to develop their knowledge of and ability to deliver culturally safe care. This includes: • embedding cultural protocols and priorities into service designs • ensuring all staff members are familiar and comfortable with key concepts such as tapu, noa and tikanga practices • ensuring staff understand and can apply various Māori health models (Te Whare Tapa Wha, Te Wheke, Te Pae Mahutonga, and Te Waka o Meihana) • recognising and supporting any whānau Māori who may be disconnected from their cultural roots.
Partnership The principle of partnership, which requires the Crown and Māori to work in partnership in the governance, design, delivery, and monitoring of health and disability services. Māori must be co-designers, with the Crown, of the primary health system for Māori	Partner with Māori (including Hei Āhuru Mōwai, clinicians, health providers and whānau) to develop a robust clinical and operational governance structure that is consistent with: • Te Pae Tata, Interim New Zealand Health Plan • He Korowai Oranga: The Māori Health Strategy • Whakamaua: The Māori Health Action Plan • He Mahere Ratonga Mate Pukupuku • Pae Tū: Hauora Māori Strategy 2023

BEING EQUITY-LED AND WHĀNAU CENTRED

There has been a deliberate focus on how to improve the accessibility, availability, acceptability, and standardisation of service delivery.

Each step aims to address inequity and reflect a whānau-centred approach. The following questions have been developed to guide the analysis:

- who is most affected by this issue/work, and how are they affected?
- are Māori needs and aspirations identified?
- how will this work improve the experience of people and their whānau?
- what Māori and Pacific health gains will come from this work?
- will this work develop or progress kaupapa Māori initiatives?
- how do the wider determinants of health impact on this work?
- how are Māori, Pacific peoples and tāngata whaikaha involved in planning and decision-making?
- how will this work contribute to more equitable cancer outcomes for Māori, Pacific peoples and/or tāngata whaikaha?
- what unintended consequences might arise? Who will be impacted?
- are there risks for widening the equity gap? How could these be mitigated?

Te Tiriti o Waitangi principles have been consistently embedded across work by Te Aho o Te Kahu. Comprehensive and clear guidance for equity and whānau-centred care across the cancer pathway can be found in the Optimal Cancer Care Pathways.

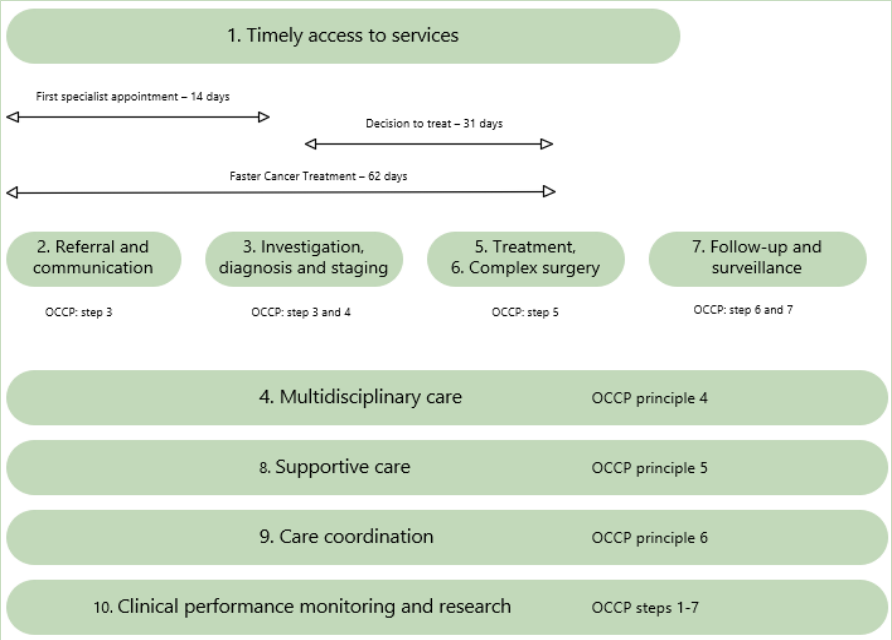
The proposed changes to the delivery of complex sarcoma services have considered any impact this may have on these other services.

HOW THIS DOCUMENT IS STRUCTURED

Each section (1-10) in the complex sarcoma service is focused on good clinical practice and should be read in conjunction with the sarcoma OCCP. Each section has a set of criteria, a rationale and a set of attributes required for achieving high level quality care.

Figure one below shows each section in the Complex Sarcoma Service, along with how these components fit together into the cancer continuum and where each section aligns to the steps in the sarcoma OCCP.

Figure 1. Diagram to show the sections within the Complex Sarcoma Service structure and alignment to OCCPs.



The attributes are supported by either national or international literature, good clinical practice or with consensus from New Zealand clinicians involved in providing care to people with sarcoma.

This document describes the Complex Sarcoma Service for the management of both adult and paediatric sarcomas:

bone sarcomas

- soft tissue sarcomas of the extremities, trunk, and retroperitoneum
- fibromatosis.
- benign, locally aggressive, soft tissue & bone neoplasms (e.g., Tenosynovial, Giant Cell Tumour)

Also described is the management of these conditions in all areas of the body including:

- upper & lower limbs
- pelvis
- spine
- chest
- abdomen & retroperitoneum
- head & neck.

Background

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 childhood 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.

While lifestyle factors play a role in the genesis of some cancers, this does not appear to be the case for sarcoma. There are some rare genetic conditions that can predispose the development of sarcoma such as Li-Fraumeni, neurofibromatosis and hereditary retinoblastoma. Exposure to previous radiation is another rare causative factor.

Because of the rarity of sarcoma, there is often a delay in diagnosis. This, especially if combined with inappropriate treatment, can lead to poorer outcomes. Early recognition and referral to specialist treatment centres to coordinate & guide treatments, can lead to improved outcomes in terms of both survival and a reduced need for disabling surgery.

In 2020, sarcoma accounted for 1% of the number of new cancer registrations, but 15% of paediatric cancers in Aotearoa (Te Whatu Ora, 2023).

Year	Registrations		
	Bone sarcoma	**Gastrointestinal stromal tumour**	**Soft tissue sarcoma**
2017	33	22	254
2018	34	30	312
2019	38	33	276
2020	50	82	311
2021	49	112	307
2022	60	115	310

Long-term survival of soft tissue sarcoma occurs in 50–60% of cases. It is dependent on several factors, including tumour size, histological grade, and the presence of metastases at the time of diagnosis/presentation.

Osteosarcoma has an overall survival rate of 60%. Local data[2] suggests that there is a trend toward poorer outcomes for Māori and Ewing's sarcoma. The 2000-2009 analysis showed

[2] Provided by New Zealand Bone Tumour Registry, Middlemore Hospital, Counties Manukau.

particularly poor survival for Māori diagnosed with bone tumours (37.0%) and while this improved to 52.1% for the 2008-2017 period it was still the lower than the survival rate reported for Pacific Peoples (79.6%) and non-Māori/non-Pacific Peoples (63.4%)[3] The factors behind this are unknown, as there does not appear to be an ethnic bias in incidence for this tumour. It is recognised that inequalities exist between Māori and non-Māori in exposure to the risk and protective factors for cancer (Ministry of Health 2004a), in cancer incidence and cancer outcomes (Ajwani, et al. 2003), and in access to cancer services (Ministry of Health 2004b).

One year survival rates (average 2017-2022)		
Bone sarcoma	**Gastrointestinal stromal tumour**	**Soft tissue sarcoma**
85.6%	89.1%	78.6%

Currently across Aotearoa New Zealand, sarcoma surgery is performed for both cancer and non-cancer conditions as well as some complex metastatic carcinomas, all of which may be carried out in the Auckland and Christchurch public hospitals.

Care is currently provided by six orthopaedic surgeons across Aotearoa New Zealand, all of which have subspeciality fellowship training in orthopaedic oncology. In addition, paediatric care is provided by surgeons with further subspecialty training in paediatric focussed sarcoma care. Spinal sarcoma surgery is also provided by surgeons with fellowship experience in spine tumour surgery and will attend the Sarcoma Multidisciplinary Meeting (MDM).

In addition, all retroperitoneal sarcoma care is delivered by four surgeons with specialist fellowship training in retroperitoneal sarcoma, who are core members of the MDM.

Other site-specific surgery for sarcoma such as head and neck, and cardiothoracic surgery is performed as combined work at the two sarcoma centres.

Plastics surgery is involved in combined cases where reconstruction is needed and in peripheral units for the management of conditions like Pleomorphic Dermal Sarcoma and Kaposi sarcoma.

[3] AYA incidence & survival 2008-2017

Complex Sarcoma Service

1. Timely Access to Services

Criteria

- People referred urgently with a high suspicion of a sarcoma receive their first cancer treatment within 62 days.
- People referred urgently with a high suspicion of a sarcoma have their FSA within 14 days.
- People referred urgently and categorised as a high suspicion of sarcoma after a local/regional FSA are reviewed by a sarcoma treatment unit (in person or via MDM) within 14 days.

Rationale

Timely access to quality cancer management is important to support good health outcomes for New Zealanders.

Key components of successful cancer management include early recognition and reporting of symptoms, expertise in identifying people requiring prompt referral and rapid access to investigations and treatment.

A suspicion of cancer or cancer diagnosis is very stressful for people and family/whānau. It is important that people, family/whānau and GPs know how quickly people can receive treatment. Long waiting times may affect local control and survival benefit for some people with a sarcoma and can result in delayed symptom management for those who are palliative.

Timely access to services ensures:

- people receive age-appropriate quality clinical care
- people are managed through the pathway and experience well-coordinated service delivery
- delays are avoided as far as possible.

Attributes

1.1 Imaging reports are received by the referrer within two working days of the examination being performed (expert opinion).

1.2 Reports are distributed electronically (expert opinion).

1.3 Systems are developed at a local level to manage the further investigation and treatment of incidentally found abnormalities suggestive of sarcoma on radiological imaging (expert opinion).

1.4 People with a bone sarcoma should receive their first cancer treatment within 62 days of a high suspicion of cancer referral or 31 days from date of decision to treat (Faster Cancer Treatment Indicators, Sept 2023, Achieving the Health Targets July 2024 – June 2027, Health New Zealand).

1.5 Primary health care providers refer to secondary care services within one working day of receiving an investigation suggesting the possibility of a sarcoma and refer to a sarcoma treatment unit if a positive diagnostic result is received (expert opinion).

1.6 Resources are provided to appropriate services (including radiology pathology, oncology, and surgery) to allow the triage, diagnosis, and treatment of people with a sarcoma within the timeframe specified in the guideline.

1.7 Referrers identify barriers to attendance at FSAs (such as mobility, cost, comorbidities, and compliance issues) and address them where possible.

Criteria

- People with a confirmed diagnosis of a sarcoma receive their first treatment within 31 days of the decision to treat.
- People needing radiation therapy or systemic anti-cancer therapy, as first treatment, receive their first treatment within 31 days of the decision to treat.

Rationale

The 31-day timeframe for radiation treatment is based on international best-practice guidelines and recommendations that have been endorsed by the Royal Australian and New Zealand College of Radiologists, Faculty of Radiation Oncology and the National Cancer Treatment Advisory Group, and the Faster Cancer Treatment Indicators (Sept 2023) and is a Health New Zealand Target for cancer treatment for 2030.

Attributes

1.8 Delivery of radiation therapy follows the Radiation Oncology Prioritisation Guidelines (Ministry of Health 2011a).

1.9 Delivery of systemic anti-cancer therapy follows the Medical Oncology Prioritisation Criteria (Ministry of Health 2012b).

2. Referral and Communication

Criteria

- People with a suspected sarcoma (usually following appropriate imaging) are directly referred to a sarcoma treatment unit for diagnosis and management following a clearly identifiable clinical pathway that is available to primary and secondary care clinicians.

Rationale

Prompt referral for expert diagnosis is crucial. The purpose of the referral pathway is to ensure that all people with a suspected sarcoma are referred to the most appropriate health care service, and that appropriate standardised information is available in the referral.

People and their families/whānau may want to discuss diagnosis and treatment with their GP. The GP needs access to key information, such as community clinical pathways or www.sarcoma.org.nz to support their people in the most appropriate way.

Attributes

2.1 All primary and secondary care clinicians are aware of 'red flag' signs of sarcoma, to enable earlier detection and intervention of sarcomas (Grimer, et al. 2010).

2.2 Referrals contain the words 'suspected sarcoma', to help with prioritisation (expert opinion).

2.3 Sarcoma treatment centres ensure that GPs are aware of, and comply with, the urgent referral criteria, and that primary and secondary care clinicians are aware of the diagnostic pathways (Grimer, et al. 2010).

2.4 All cancer services develop and implement a did-not-attend (DNA) reduction and follow-up strategy that entails equity-focused quality assurance.

2.5 People under the age of 30 years are offered referral to adolescent and young adult (AYA) cancer services to ensure developmentally appropriate assessment care & support.

Criteria

- People and their GPs are provided with verbal and written information about sarcoma, diagnostic procedures, treatment options (including effectiveness and risks), final treatment plan and support services.

Rationale

Good communication skills are fundamental to the development of an effective relationship between a person with sarcoma and health practitioners.

Good communication is likely to reduce anxiety and increase a person's trust and confidence in cancer care providers. This will increase the chance that they receive the treatment that is most appropriate for them. Good information may improve compliance with treatment, reduce complaints and enhance health outcomes.

Attributes

2.6 Information in an appropriate language and format and that meets Ministry of Health Guidelines (2012c) is offered to each new person with a sarcoma, and covers:

- general background information about the specific sarcoma
- details of treatment options, specific local arrangements, information websites, support services and whom the person should contact if necessary
- details of age-appropriate support groups that provide support and funding, including CanTeen, the Cancer Society the Child Cancer Foundation and The Sarcoma Foundation New Zealand.

2.7 Services ensure access to professionally trained interpreters for people with limited English proficiency.

Criteria	• Communications between health care providers include the person's name, date of birth, NHI number and contact details, and are electronic.

Rationale

Management of sarcoma requires a specialist MDT, often working across regions, and it is important that effective communication exists across all levels to ensure continuity of care and appropriate service developments.

Attributes

2.8 Proforma-based referrals are made electronically (expert opinion).

2.9 Primary, secondary, and tertiary care clinicians engage in two-way communication throughout the person's cancer journey (expert opinion).

2.10 GPs are informed when specialists downgrade an urgent suspected cancer referral to non-urgent.

2.11 Members of the Sarcoma Guidelines Working Group agree on an operational policy regarding:

- communication between the MDT and hospital referring teams
- communication between members of the team
- communication between members of the team, people with sarcoma, and carers.
- adequate time for people to consider treatment options.

2.12 When the referrer is not the GP, all correspondence is copied to the GP.

3. Investigation, Diagnosis and Staging

Criteria

- Imaging investigations for a bone and soft tissue sarcoma follows standardised imaging pathways agreed to and based on current National Comprehensive Cancer Network (NCCN)[4] guidelines, Sarcoma OCCP and the Royal College of Radiologists cancer imaging guidelines.
- Imaging for staging is performed and reported within two weeks of referral to radiology services.
- Imaging from people with a high probability of a bone or soft tissue sarcoma is reviewed at a regional sarcoma MDM by radiologists with expertise in bone and soft tissue sarcoma.

Rationale

Successful treatment of a bone and soft tissue sarcoma requires accurate diagnosis and staging; and expertise in radiology and pathology is crucial. Specialist review of imaging of people with a suspected sarcoma reduces clinical error and delay in diagnosis. Delays in investigation, inappropriate/inaccurate imaging and biopsies can have a profound negative affect on prognosis.

Attributes

3.1 Adequate imaging of all soft tissue lesions with a reasonable chance of malignancy is undertaken, using magnetic resonance imaging (MRI) with or without computed tomography (CT) with plain films where appropriate to identify calcification and bone involvement (NCCN 2012a).

3.2 Adequate imaging of all bone lesions with a reasonable chance of malignancy is undertaken, using plain radiographs in two orthogonal planes (including whole-bone views) followed by MRI with or without CT (NCCN 2012a).

3.3 CT chest staging is performed in all people with a sarcoma, entailing ≤1 mm or less axial images with lung reconstruction algorithm and (5–10mm) axial Maximal Intensity Projection (MIP) images to aid nodule detection.

3.4 Ultrasound has a limited role in assessment of soft tissue lesions, confined to initial primary care confirmation/exclusion of a superficial mass and assessment of periarticular lesions (i.e., solid versus cystic (expert opinion).

3.5 Positron emission tomography and computed tomography (PET-CT) is carried out in the work-up of bone and soft tissue sarcomas where appropriate and follows the latest evidence-based guidelines from the Royal College of Physicians and Royal College of Radiologists (RCP and RCR 2012; Central Cancer Network 2010; RCR 2006). New Zealand PET-CT guideline for sarcoma groups indications to SA1 (Staging of people with localised, intermediate, or high-grade sarcoma) and SA2 (Re-staging of residual masses in people with Ewing's sarcoma or rhabdomyosarcoma)

[4] www.nccn.org

3.6 All images are available for electronic transfer and review by specialist sarcoma radiologists and discussion at the sarcoma MDM (expert opinion).

3.7 Magnetic resonance imaging includes at least two planes (axial/transverse) T1 and T2 (or PD) fat-saturated images of slice thickness ≤5mm and post-gadolinium images with at least one plane (axial) with fat saturation (RCPA[5] 2011; NICE[6] 2006). These should include the entire compartment involved (expert opinion).

3.8 Bone sarcoma MRI includes T1 with or without STIR large field of view images through the whole affected bone (NCCN 2012a).

3.9 Radiologists with special expertise in bone and soft tissue sarcoma report images (NICE 2006).

3.10 Regional sarcoma MDMs monitor and review imaging processes and provide feedback to referring parties.

Criteria

- Biopsy of a suspected sarcoma is carried out under the advice and recommendation of a specialist sarcoma surgeon who is responsible for the definitive tumour resection.

Rationale

The definitive diagnostic test for a sarcoma is a core or open biopsy. A poorly performed or planned biopsy can irreversibly compromise the chance of limb salvage or even cure.

Attributes

3.11 Biopsy is only carried out after appropriate local imaging of the lesion (Grimer, et al. 2010a).

3.12 Core needle biopsy is considered for bone and soft tissue lesions as appropriate; ultrasound or CT guidance is carried out as indicated (Grimer, et al. 2010a; 2010b).

3.13 For soft tissue sarcomas, fine needle aspiration is not recommended, although it may be useful in confirming disease recurrence or nodal involvement. (Grimer, et al. 2010b).

3.14 The regional MDM (Auckland or Christchurch) will advise on which region/service is appropriate to perform the biopsy.

Criteria

- All people with a provisional histological diagnosis of a bone or soft tissue sarcoma have their diagnosis reviewed and confirmed by a specialist sarcoma pathologist affiliated to a sarcoma MDM.
- The histology of excised sarcoma specimens is recorded in a synoptic format.

3.15 For people with previous diagnostic or technical challenges, or whenever the referring team or MDM requests it, should have their biopsy performed in one of the two sarcoma centres.

[5] Royal College of Pathologists of Australasia (RCPA)

[6] National Institute for Health and Care Excellence (NICE)

Attributes

3.16 A specialist sarcoma pathologist regularly reports bone and soft tissue tumours and is a core member of the sarcoma MDT.

3.17 A specialist paediatric pathologist reviews and confirms diagnoses in the paediatric setting, where appropriate (expert opinion).

3.18 Sarcomas are reported in accordance with the current World Health Organization classification, and the report includes the minimum data set for pathological staging based on the most recent American Joint Committee on Cancer (AJCC) *Cancer Staging Manual* (Edge, et al. 2010; NCCN 2012b; NICE 2004).

3.19 The synoptic report is based on the Royal College of Pathologists of Australasia (RCPA) structured reporting protocols for soft tissue sarcomas (RCPA 2011). (Only soft tissue tumour protocols are currently available. Until the RCPA publishes protocols on bone sarcomas, its data set for histopathology reports on primary bone sarcoma (RCPA 2010) is recommended.)

3.20 Specialist sarcoma pathologists have access to ancillary diagnostic techniques, including immunohistochemistry and cytogenetic and molecular genetic analysis.

3.21 Results of ancillary testing are incorporated into the final histopathology report.

3.22 Specialist sarcoma pathologists provide appropriate feedback to the original reporting pathologist (expert opinion).

3.23 Appropriate resources are available to allow the ongoing training and up-skilling of the pathology service.

4. Multidisciplinary Care

Criteria

- All people with the following confirmed sarcomas are presented at a sarcoma MDM:
  - bone sarcoma
  - soft tissue sarcoma of extremities, trunk, and retroperitoneum.

Rationale

International evidence shows that multidisciplinary care is a key aspect to providing best-practice treatment and care for people with cancer. Multidisciplinary care involves a team approach to treatment planning and care provision along the complete cancer pathway.

Cancer Multidisciplinary meetings (MDMs) are part of the philosophy of multidisciplinary care. Effective MDMs result in positive outcomes for people receiving the care, for health professionals involved in providing the care and for health services overall. Benefits include improved treatment planning, improved equality of outcomes, more people being offered the opportunity to enter relevant clinical trials, improved continuity of care and less service duplication, improved coordination of services, improved communication between care providers and more efficient use of time and resources.

Attributes

4.1 Core membership of a sarcoma multidisciplinary team (MDT) includes the following: a specialist sarcoma radiologist, a specialist sarcoma pathologist, a specialist sarcoma surgeon, a radiation oncologist, a medical oncologist, a clinical nurse specialist/cancer nurse and a sarcoma service admin coordinator. Paediatric oncologists, AYA key workers, a palliative care specialist and Kaitiaki ō Tūroro Māori / Māori Patient Guardian would also be included where applicable. Allied health practitioners such as physiotherapists, orthotists, psychologists, and occupational therapists should be encouraged to be involved when clinically indicated.

4.2 The agreed terms of reference governing the Multidisciplinary Meetings (MDM) are based on standards for high-quality MDMs in Aotearoa New Zealand[7]. Written protocols should describe the organisation and content of the meeting, including agreed criteria outlining which people should and should not be discussed.

4.3 Hospitals should support members of the MDT and referring clinicians to attend MDMs either virtually or physically.

4.4 The MDM records information in a database that can be collated and analysed locally, regionally, and nationally.

4.5 The local MDM database should be able to collaborate with the National Sarcoma Registry.

4.6 Referring clinicians, people and their whānau and their GPs receive the MDT's recommendations on diagnosis, treatment options and treatment care plans in writing within two working days of the MDM.

[7] *Standards for High-Quality Multidisciplinary Meetings (MDMs) in Aotearoa New Zealand* (Te Aho o Te Kahu 2024)

4.7 The lead clinician is responsible for discussing the MDM recommendation(s) with the person and their family/whānau within 2 weeks of the MDM. Final decisions on treatment and care plans are made by people and their family/whānau, in consultation with members of the treating team (expert opinion).

4.8 Treating clinicians record reasons for not following a treatment plan recommended by the MDT (expert opinion).

4.9 A clear pathway exists for people with a sarcoma who require management under a site-specific MDT (such as those for head and neck, gastrointestinal stromal, gynaecological, or skin cancers) or paediatric services (NCCN 2012a).

4.10 Specific cultural services and expertise are involved through the MDT where appropriate.

4.11 MDMs formally audit their operations and review complications outside the routine MDM at regular intervals and nationally coordinated, as deemed appropriate by the members of the group.

Criteria	• People with fibromatosis are managed by a sarcoma MDT.

Rationale

Although a benign tumour, fibromatosis may be locally aggressive, and often appears similar to soft tissue sarcomas. Histological differentiation is crucial. Treatment of this disease is challenging and involves multiple modalities, and often differs on a case-by-case basis.

Attributes

4.12 Systemic therapy and/or radiation therapy are considered in selected cases.

4.13 The role of surgery is limited in treatment.

5. Treatment

Criteria	• People with a sarcoma have access to sarcoma treatment centres with appropriate resources and facilities to deliver the best standard of care.

Rationale

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 centres based in Auckland and Christchurch.

Attributes

5.1 Surgical departments have access to intensive care units, high-dependency units, and after-hours medical cover.

5.2 Appropriate surgical expertise in post-resection reconstruction is available when required.

5.3 The regional sarcoma treatment centres work collaboratively to ensure similar standards of care.

5.4 People have support from their local clinical team to access specialist facilities most appropriate to their need.

Criteria	• There is a formal working relationship between the regional sarcoma treatment centres and associated providers of systemic therapy and radiation therapy detailing pathways for specialist surgery, specialist pathology, adjuvant therapies, allied health, and nursing care coordination.

Rationale

Communication between the specialist sarcoma treatment centres and local treatment providers outside the two centres is essential for ongoing high-level care and should be coordinated in a manner that provides the best outcome for individual people.

Attributes

5.5 People may be offered adjuvant treatments closer to home. All treatment units offering these adjuvant therapies will have medical and radiation oncologists specialising in sarcoma management and have oversite/guidance/involvement from the coordinating sarcoma MDT.

5.6 Medical and radiation oncologists work closely with surgeons in planning adjuvant and neo-adjuvant treatment (NHS Wales 2009).

Criteria	• Treatment for sarcoma is based on histological subtypes, and people are offered a combination of surgery, systemic therapy and radiation therapy where indicated.

Attributes

5.7 People receiving radiation therapy and/or systemic therapy are offered treatment according to a documented policy as agreed by the national sarcoma MDM or in a formal clinical trial where indicated (NCCN 2012a).

5.8 Oncologists treating people with sarcoma have a specific interest in radiation therapy and/or systemic therapy for sarcoma and are affiliated to the sarcoma MDT (NICE 2006).

5.9 Cancer centres providing curative radiation therapy and/or systemic therapy for children and young people with sarcoma meet the criteria detailed in the Ministry of Health's *National Plan for Child Cancer Services in New Zealand* (2010b).

5.10 All people undergoing surgery are consulted about final disposal of remaining tissue or body parts surgically removed following appropriate pathological examination. (Some tissue may be retained for future histological reference.)

Radiation therapy

5.11 All radiation therapy centres meet the current Radiation Oncology Practice Standards set by the Radiation Oncology Alliance (Radiation Oncology Alliance 2023).

5.12 All radiation therapy centres treat those with sarcoma using modern techniques and have access to equipment capable of delivering 3D conformal radiation therapy and intensity modulated radiation therapy (Tripartite Committee 2011).

5.13 After jointly agreeing on definitions, radiation therapy centres monitor long-term morbidity rates following radical radiation therapy through a recognised quality system accredited by an external standards institution to a recognised standard (NHS Wales 2009).

Systemic therapy

5.14 People with chemo sensitive subtypes are considered for adjuvant chemotherapy, and those that are borderline resectable are considered for neo-adjuvant chemotherapy or radiation therapy (NCCN 2012b).

5.15 Systemic therapy is only delivered in a centre with a systemic therapy policy that covers generic issues pertinent to systemic therapy, such as staff grading, training, and competencies; prescribing, preparation, and dispensing; administration; and disposal of waste and spillage (NHS Wales 2009).

5.16 People with a sarcoma are treated according to detailed and evidence-based written systemic therapy protocols that include regimens and their indication, drug doses and scheduling, pre- and post-treatment investigations, and dose modifications (NHS Wales 2009). In Aotearoa New Zealand the Anti-Cancer Therapy-Nationally Organised Workstreams (ACT-NOW) programme is about identifying these opportunities within the context of chemotherapy.

5.17 Major morbidity following systemic therapy with curative intent is monitored (NHS Wales 2009).

Criteria

- People who have a primary bone sarcoma have access to surgery performed by an oncology fellowship-trained orthopaedic surgeon who is a core member of a sarcoma MDT, and at one of the two sarcoma centres.

Rationale

Primary bone sarcomas are rare tumours, and specialist surgical management is vital to the outcome for the people. Inappropriately performed surgery can lead to poor outcomes and significant morbidity.

Attributes

5.18 Surgery for a primary bone sarcoma is only performed after adequate preoperative staging.

5.19 Decisions about the optimal surgical procedure are made with reference to the tumour type, extent, and response to neoadjuvant therapy if appropriate.

5.20 The type of reconstruction is determined by the person and surgeon after an appropriate discussion of the risks and benefits of different options.

5.21 Most people are considered as candidates for limb salvage, but surgical margins are not compromised to achieve this.

5.22 Close discussion takes place between the surgeon and the reporting pathologist, to enable adequate description of surgical margins and areas of particular interest.

Criteria

- People who have a soft tissue sarcoma have access to surgery performed by, or under the direct supervision of, a soft tissue sarcoma fellowship-trained consultant surgeon affiliated who is a core member of a sarcoma MDT, and at one of the two sarcoma centres.

Rationale

Surgery is the standard treatment for a soft tissue sarcoma and must be performed by an appropriately trained specialist surgeon (Grimer et al 2010b).

Attributes

5.23 The aims of surgical resection and reconstruction are to minimise the risks of local recurrence and optimise function by way of limb salvage where possible.

5.24 Appropriate vascular and plastic surgical reconstructive options are available when required.

5.25 Surgery of truncal soft tissue sarcomas and fibromatosis is undertaken by a team involving multiple specialties where appropriate.

5.26 People presenting with metastatic soft tissue sarcoma are presented at the sarcoma MDM for consideration of metastasectomy and/or systemic therapy.

Criteria	• People with a suspected retroperitoneal sarcoma are treated by a soft tissue sarcoma specialist who is a core member of a sarcoma MDT, and at one of the two sarcoma centres

Rationale

Retroperitoneal tumours are rare, and there is a high degree of morbidity associated with their treatment. An assessment and treatment plan should be determined collaboratively by the members of the sarcoma MDT, and the surgery must be performed by an experienced surgeon with a subspecialty interest in these tumours.

Attributes

5.27 Appropriate investigations are performed prior to the initiation of treatment and include a chest/abdomen/pelvis CT with contrast with or without MRI (Grimer et al 2010b).

5.28 A decision on pre-treatment biopsy is made by the treating sarcoma surgeon and is based on the degree of suspicion and the need for preoperative radiation therapy or systemic therapy.

5.29 In people with positive surgical margins, the requirement for adjuvant radiation therapy is discussed at a sarcoma MDM (expert opinion).

Palliative Care

Criteria	• People are offered early access to palliative care services when there are complex symptom control issues, when a curative treatment cannot be offered or if curative treatment is declined.

Rationale

A diagnosis of cancer and its subsequent treatment can have a significant impact on the quality of a person's life, as well as on the lives of families/whānau and other carers. A person may face new fears and uncertainties and may have to undergo unpleasant and debilitating treatments. People should expect to be offered optimal symptom control and psychological, cultural, social, and spiritual support. They may want to be assured that their families/whānau and carers will receive support during illness and, if they die, following bereavement.

Palliative care is the care of people who have higher grade symptoms or emotional impacts from active, progressive diseases or other conditions that are not responsive to conventional treatments or have a guarded prognosis. Palliative care embraces the physical, social, emotional, and spiritual elements of well-being – tinana, whānau, hinengaro and wairua – and enhances a person's quality of life while they are dying. Palliative care also supports the family/whānau (Ministry of Health 2001).

The objective of palliative care is to alleviate suffering and provide compassionate care for the person and their family/whānau. Competence in palliative medicine and sensitivity to people's beliefs and values are two key prerequisites for a provider of palliative care.

Clinicians should form a care plan for palliative people with a view to ensuring that pain and other potentially distressing symptoms are relieved, dignity is preserved and there is engagement with family/whānau (Ministry of Health 2001).

Attributes

5.30 People are screened for palliative care needs at their initial visit, at appropriate intervals and as clinically indicated (NCCN 2012b; Palliative Care Australia 2005).

5.31 Access to palliative care, decision-making and care planning is based on a respect for the uniqueness of the people and their family/whānau, independent of their current health status, diagnosis, age, gender, cultural background, or geography. Their needs and wishes guide decision-making and care planning and are integrated into care plans (Palliative Care Australia 2005).

5.32 People and carers have access to spiritual care, either from their MDT or from community spiritual care resources (NICE 2004).

5.33 People and their family/whānau are offered free high-quality, developmentally appropriate, plain-language information in a variety of formats about cancer and palliative care services. Information materials need to ensure they are culturally, developmentally, and educationally appropriate (NICE 2004).

5.34 Systems are in place to ensure the views of people and their family/whānau are considered when developing and evaluating cancer and palliative care services. All such services support people to participate in their own care by offering a range of informal opportunities, such as self-help activities and peer support schemes in community settings (NICE 2004).

5.35 Formal mechanisms are in place to ensure that people, their caregivers and family/whānau have access to age-appropriate emotional support, information, and support services (NICE 2004; Palliative Care Australia 2005).

5.36 Interdisciplinary palliative care teams, including New Zealand Medical Council specialist registered palliative care physicians and skilled palliative care nurses, are readily available to provide consultative or direct care (NCCN 2012b).

5.37 All health care professionals take part in educational programmes to develop effective palliative care knowledge, skills and attitudes, protocols for the management of cancer pain, neuropathic pain, and the route of referral to palliative care services (NCCN 2012b).

5.38 All health care professionals should recognise those dying in a timely manner and discuss advance care planning and end-of-life goals of care with people and their family/whānau using an end-of-life care pathway.

5.39 Palliative care services are consulted at any stage if a person's symptoms are complex and/or prove difficult to treat.

6. Complex surgery

Criteria	• All people with a sarcoma requiring complex surgical procedures will have access to a specialist sarcoma centre where surgery is performed by, or under the direct supervision of, a fellowship-trained consultant surgeon affiliated to a sarcoma MDT.

Rationale

High complexity surgery requires a higher level of resourcing, including multiple specialities, have higher morbidity, longer stays in hospital, longer recovery times including rehabilitation, and show higher rates of mortality.

Centralisation of complex surgical procedures, in cancer treatment, is an applied strategy to optimise safety and quality of care to improve people outcomes. This strategy results in the reorganisation of services into fewer more specialised centres. The rationale for centralisation is that by increasing volume and types of surgeries, it will support the development of highly specialised services, improve experience and efficiency, facilitates training, reduced costs, and limits clinical variability (Sheetz, Dimick, Nathan, 2019).

Attributes

6.1 Referral pathways will be streamlined, with clear and visible connections.

6.2 Timely access is key to good outcomes and therefore will continue to be tracked and reported as with the current faster cancer treatment indicators.

6.3 A system for rapid transfers to a specialist sarcoma centre from district services should be available with National 24/7 on-call support.

6.4 The specialist sarcoma centre will provide the triage service for elective sarcoma surgeries and will be responsible for clear and timely communication with the district of domicile.

6.5 Pre-admission clinic, or similar arrangement, will have specialist sarcoma knowledge to appropriately assess people for elective surgery.

6.6 The specialist sarcoma centre will participate in regular multidisciplinary team meetings (at least once a week) attended by orthopaedic oncologist, retroperitoneal sarcoma surgeons, spine tumour surgeons, plastic surgeons, medical oncologists, radiologists, pathologists, radiation oncologists, sarcoma clinical nurse specialists, MDM coordinators. Referring clinicians from other units should attend for continuity of care.

6.7 The potential risk for post-surgical complications must be assessed prior to discharge and relayed to receiving clinician and or sarcoma skilled staff.

6.8 The specialist sarcoma unit will have a dedicated sarcoma outpatient clinic (half day or greater) at a minimum of once per week where those with sarcoma can be seen.

6.9 All sarcoma providers will operate within a shared service, forming partnerships with referring and other specialist providers.

6.10 The specialist sarcoma centre will perform a minimum of 50 surgeries per year.

6.11 The specialist sarcoma centre will have regularly scheduled elective theatre list (on average one day per week), as well as 24-hour emergency theatre access.

6.12 All providers will ensure the availability of coordinated plans for pre-surgical optimisation. A referral process for the required pre-optimisation, including prehabilitation services and/or support services will be available.

6.13 There will be a named liaison for both palliative care and clinical psychology made available to people and their whānau as required.

6.14 All providers to ensure staff involved in the care of the person are trained and skilled in complication management with specific sarcoma complications incorporated into Enhanced Recovery After Surgery (ERAS) protocols.

6.15 Prior to complex surgery a holistic needs assessment should be undertaken and assessment of home circumstances to ensure there is appropriate support for discharge planning.

6.16 The specialist sarcoma centre will provide a consultative on-call service during normal working hours, 5 days a week for outpatient and inpatient advice. Out of these hours the local hospital will treat the person as appropriate, via the standard acute hospital services.

6.17 A regional (North and South Island) sarcoma advice roster is established utilising surgeons from specialist sarcoma centres. The roster would be available to all surgeons in Aotearoa New Zealand to allow timely advice and transfer of people as appropriate.

6.18 There should be dedicated administrative support to facilitate and monitor the sarcoma pathway and outcomes enabling support for clinical staff to review complexity, timely access, protocols, and all other business related to the provision of complex sarcoma cancer care. This should include a designated clinical lead and opportunities for all staff involved with sarcoma work to contribute.

6.19 The specialist sarcoma centre will have access to at least one ward, or part thereof. This ward will be staffed with a dedicated Nurse Manager and staff with sarcoma knowledge, to serve people admitted to the specialist sarcoma centre.

6.20 Nationally consistent protocols will be available for emergency management of those with sarcoma. These protocols will be readily accessible in all units and include pathways and contacts for support to hospitals outside of the specialist sarcoma centre.

6.21 There will be available a 24/7 level III intensive care unit. Staff will have Enhanced Recovery After Surgery (ERAS) experience for sarcoma complications.

6.22 All providers with an anaesthetic department supporting sarcoma surgery will have at least one member of the anaesthetic team with advanced expertise and interest in sarcoma surgery.

6.23 Operating theatre nursing and technical staff will have at least one team with a specific interest in sarcoma surgery.

6.24 The specialist sarcoma centre will support Clinical Nurse Specialists (CNS) and/or Nurse Practitioners (NP). These skilled nurses should be informed and aware of on-going clinical research projects, audits, and clinical trials.

6.25 The specialist sarcoma centre will regularly review mortality and morbidity meeting, at least 6 monthly with a yearly national review.

6.26 A FIHR[8] compliant Sarcoma Surgical Database to be established. Quality assurance programs with clinical indicators and/or quality projects will be planned and updated annually. This will become standard practice and reviewed at the weekly sarcoma service meetings and/or audit meetings.

6.26 The specialist sarcoma centre will have an affiliation with one of the University Medical Schools and be involved in Undergraduate Teaching Programs. In addition, the specialist sarcoma centre will be an accredited training site for both non-SET and SET trainees in Orthopaedic and General Surgery as applicable.

6.27 Clinical research and trials will work across all hospitals for those with sarcoma. All MDMs should have a research and trials lead and research coordinator, with all people assessed at the MDM for trial suitability.

[8] Fast Healthcare Interoperability Resource (FIHR) Standards

7. Follow up and Surveillance (follow up details refer to appendix two)

Criteria

- People are offered follow up under the direction of the specialist sarcoma treatment unit responsible for their treatment.
- Follow-up plans include clinical review by appropriate members of the MDT, working in conjunction with the person, their family/whānau and their GP.

Rationale

Follow up promotes recovery and maximises a person's quality of life. It is also designed to detect either local recurrence or metastatic disease at a time when early treatment is still possible and potentially effective. Follow up is best carried out by the surgeon who was responsible for the initial treatment, and with whom people and their family/whānau have often developed a rapport.

There is an absence of published research to specify an optimal follow-up schedule. Regardless of management, those treated for sarcoma generally need long-term follow up, as there is a significant chance of recurrence over time. Surveillance can lead to the early detection of local or systemic disease and enable other treatments to improve outcome (Grimer, 2010a; 2010b).

Attributes

7.1 Follow up follows an agreed plan for surveillance, and includes investigations of symptoms reported by the person, a physical examination of the tumour site and a check for possible complications of any reconstruction, as well as the presence or absence of local tumour recurrence (Grimer, 2010a; 2010b).

7.2 For people with a high-grade bone sarcoma, follow up (Telehealth or Face-to-Face as appropriate) occurs at intervals of three months for the first three years post-treatment, every six months for year four and five, and annually thereafter. Local X-ray and chest imaging occurs at each visit (Grimer, 2010a)

7.3 For people with a low-grade bone sarcoma, follow up occurs six monthly for two years post-treatment and annually thereafter. Local X-ray and chest imaging is carried out at each visit (Grimer, 2010a).

7.4 For people with a high- or intermediate-grade soft tissue sarcoma, follow up occurs at three-monthly intervals for the first three years, every six months for year four and five, and annually thereafter. A chest X-ray is carried out at each visit to exclude pulmonary metastases (Grimer, et al. 2010b).

7.5 For people with a low-grade soft tissue sarcoma, follow up occurs at six monthly intervals for the first two years, and annually thereafter. A chest X-ray is carried out at each visit to exclude pulmonary metastases (Grimer, et al. 2010b).

7.6 Travel and accommodation costs for ongoing follow up are paid by the person's regional health service.

7.7 The person's GP receives written copies of the follow-up care plan within one day of the person receiving the same information.

7.8 People receive information on accessing appropriate support from the Cancer Society and other relevant special interest groups.

7.9 Referral to a psychologist is considered to promote more effective coping strategies and improve self-esteem and mood, where appropriate.

7.10 People and their family/whānau receive information on positive lifestyle factors, including smoking cessation, exercise, nutrition, and psychological support.

8. Supportive Care

Criteria

- People with a high suspicion or diagnosis of sarcoma and their family/whānau have equitable access to appropriate medical, allied health and supportive care services, which will be coordinated by their Sarcoma/AYA CNS in accordance with *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand* (Ministry of Health 2010a).

Rationale

The psychological, social, physical, and spiritual needs of cancer people are many and varied. These needs can be mostly met by allied health care teams in hospitals and in the community. Adults with cancer enjoy improved quality of life following needs assessment and provision of supportive care.

Non-government organisations, including the Cancer Society, perform an important role in providing supportive care.

Attributes

8.1 All people and their family/whānau have access to appropriate supportive care and spiritual services (Ministry of Health 2010a).

8.2 Supportive care assessments and interventions are undertaken in suitable facilities and locations that take into consideration a person's needs for privacy, comfort, and mobility.

8.3 All staff responsible for engagement with people and their families/whānau undertake and complete cultural competency training.

8.4 People and their families/whānau take an active role in advance care planning and end-of-life care planning where appropriate.

Criteria

- People who have had a limb amputated to treat their sarcoma are offered rapid and easy access to prosthetic services, and a prosthesis that suits their needs.

Rationale

In some cases, surgery for sarcoma may mean an affected limb is amputated. The person may need to be fitted with an artificial (prosthetic) limb or other device and undergo specialist physiotherapy, and as such often require lifelong support. The extent to which this disability affects a person's quality of life will vary considerably.

Attributes

8.5 People have timely access to appropriate orthotic and prosthetic services (NICE 2006).

5.5.1 People and their family should have the opportunity to meet the orthotic/prosthetic team prior to surgery.

8.6 Formal links to specialist centres that provide prosthetic services are established by the sarcoma MDT (NICE 2006).

Criteria	• People have access to appropriate rehabilitation services, including physiotherapy, occupational therapy, and chronic pain and lymphoedema specialist services.

Rationale

Surgery for sarcoma may result in long-term issues such as disfigurement. People treated for sarcoma must have access to a full range of age-appropriate support and rehabilitation services, to help them achieve the best possible quality of life.

Attributes

8.7 The sarcoma MDT coordinates support and rehabilitation (NICE 2006).

8.8 People will have care coordinators to arrange ongoing rehabilitation and supportive care in the persons local area wherever possible (NICE 2006).

8.9 People have equitable access to integrated services for rehabilitation (including physiotherapy, occupational therapy, psychosocial support, education, housing, welfare, and Whānau Ora services) using a coordinated approach. Specialist sarcoma physiotherapy and occupational therapy from the two sarcoma centres will help with advice and coordination for those outside the main sarcoma centres.

8.9.1 This equitable access needs to remain available post-treatment as people often have prolonged recovery & follow-up even after their sarcoma has been treated/removed.

8.10 People have access to lymphoedema services if symptoms occur following treatment.

8.11 Physical activity after treatment is encouraged for the significant positive impact it can have on a persons' quality of life, outcomes, and sense of control and wellbeing.

8.11.1 This should be facilitated by the provision of funded physiotherapy interventions from specialist physiotherapists experienced manging those with sarcoma.

9. Care Coordination

Criteria

- People with a sarcoma have access to a clinical nurse specialist who is a member of the MDM to help coordinate all aspects of their care.

Rationale

The cancer journey is complex, and it is not uncommon for a person to be seen by many specialists within and across multiple regions, across both the public and private sectors.

'Care coordination' refers to a system or a role primarily intended to expedite access to services and resources, improve communication and the transfer of information between services, address peoples' information needs and improve continuity of care throughout the cancer continuum. The **New Zealand Health Targets**[9] for improving faster cancer treatment.

- *Action One* aims to address unwarranted variation using national standards, operating models, and consistent national clinical pathways.
- *Action Four* aims to strengthen the cancer workforce with a national workforce plan to improve recruitment & retention of the cancer workforce.

People and caregivers should be able to access care coordination through a single point of contact and through all stages of the sarcoma cancer journey.

Attributes

9.1 All regional cancer centres have access to a cancer nurse specialist with specialist knowledge of sarcomas (Ministry of Health 2010a).

9.2 People are introduced to their care coordinator at their sarcoma FSA and no later than seven days of their initial presentation to the sarcoma unit and are provided with their contact details.

9.3 All people have their supportive care and psychosocial needs assessed utilising validated tools and documented at each stage of their cancer journey and are given access to services appropriate to their needs (expert opinion).

9.4 People who travel long distances to regional treatment services have access to information on the Ministry of Health's National Travel Assistance Scheme (Ministry of Health 2006).

9.5 People and their family/whānau have access to support services, including cancer psychological support services appropriate to their needs. Those experiencing significant distress or disturbance are referred to health practitioners with the requisite specialist skills (Ministry of Health 2010a).

9.6 Māori people and their family/whānau are offered access to Whānau Ora assessments, which can be used to inform people of treatment plans, care coordination and access to cultural support services.

[9] Achieving the Health Targets: High Level Implementation Plan July 2024-June 2027

9.7 Care coordinators have the following roles:

- supporting people to increase their communication skills, including the ability to ask questions regarding treatment programmes
- facilitating communication between health care providers and people and their family/whānau
- identifying and addressing barriers to accessing treatment for their sarcoma
- increasing a persons' experience of and ability to become more involved in their care (e.g., a persons' confidence in their own or their family's abilities to manage certain situations)
- providing or sourcing appropriate advocate support for people (Northern Cancer Network 2011).

9.8 All clinicians acknowledge the rights of people unable legally to consent, to refuse investigation or treatment, and that any discussions about the refusal are recorded in the persons' notes. Guidance on this topic follows the Health and Disability Commissioner Act 1994.

10. Clinical Performance Monitoring and Research

Criteria	• Data relating to sarcoma beyond the fields required by the Cancer Registry, including treatment data, are reported to existing and planned national repositories using nationally agreed data set fields.

Rationale

There is currently no national cancer database other than the New Zealand Cancer Registry, which is a population-based register of all primary malignant tumours diagnosed in New Zealand. The Sarcoma Guidelines Working Group is working towards the development of a National Sarcoma Registry. The importance of improving data collection, collation and analysis is also recognised in the Health New Zealand Health Targets which aims to improve data and digital tools specifically collection, standardisation, and visibility as well as improved operation frameworks.

Attributes

10.1 Where data is collected, it is governed by the cancer data standards (HISO 10038.0:2017, HISO 10038.1:2011 and HISO 10038.3:2011).

10.2 People are informed that their information is being recorded in a sarcoma database to help the MDT propose a treatment plan and to monitor and evaluate access to services.

10.3 Multidisciplinary teams are responsible for collecting and managing information on people with a sarcoma.

10.4 Clinicians working in sarcoma treatment and care will be able to request information from the database to help inform disease management.

Criteria	• Data on clinical outcomes and a persons' satisfaction are regularly monitored and reported as part of a national audit.

Rationale

Accurately recorded and high-quality data is essential for monitoring outcomes, comparing clinical services, and ultimately improving care for people with sarcoma. Audits will identify inequalities in service along the sarcoma pathway, including timely access to services and those based on ethnicity. As sarcomas are uncommon, data need to be collated nationally before any meaningful analysis can be carried out.

Attributes

10.5 Data are reported according to an agreed system of quality improvement guidelines and standards of practice.

10.6 All parts of the sarcoma pathway are investigated and audited, including referral, investigations, management of treatment and outcomes. These will be audited and presented regularly by the Sarcoma Guidelines Working group (NICE Sarcoma Guidelines, 2006).

10.7 Data are routinely collected and published by ethnicity to monitor ethnic inequalities and reflect the high-level goal of reducing inequalities.

10.8 Audit results are presented at a national sarcoma MDM audit review, and are available to clinicians within referring units, regional cancer networks and to the public (NICE Sarcoma Guidelines, 2006).

10.9 Service providers consider the role of differential access to timely and appropriate cancer services, which leads to inequalities in cancer outcomes.

10.10 Data will be collected in a fashion that facilitates international collaboration regarding these rare conditions.

10.11 National data will be audited and reviewed with the Sarcoma Guidelines Working Group & the wider sarcoma healthcare provider community, every 12 months or when deemed necessary.

Criteria	• All people with a sarcoma are offered the opportunity to participate in research projects and clinical trials where these are available.

Rationale

The rarity of sarcomas means that international collaborative trials are the norm. People from New Zealand should be offered the chance to enrol in international studies when they are eligible.

One of the key findings of *Access to Cancer Services for Māori* (Ministry of Health 2005) was the limited nature of information on access to cancer services for Māori, including discussion of interventions. Several areas that arise from the project as priorities for further research.

Attributes

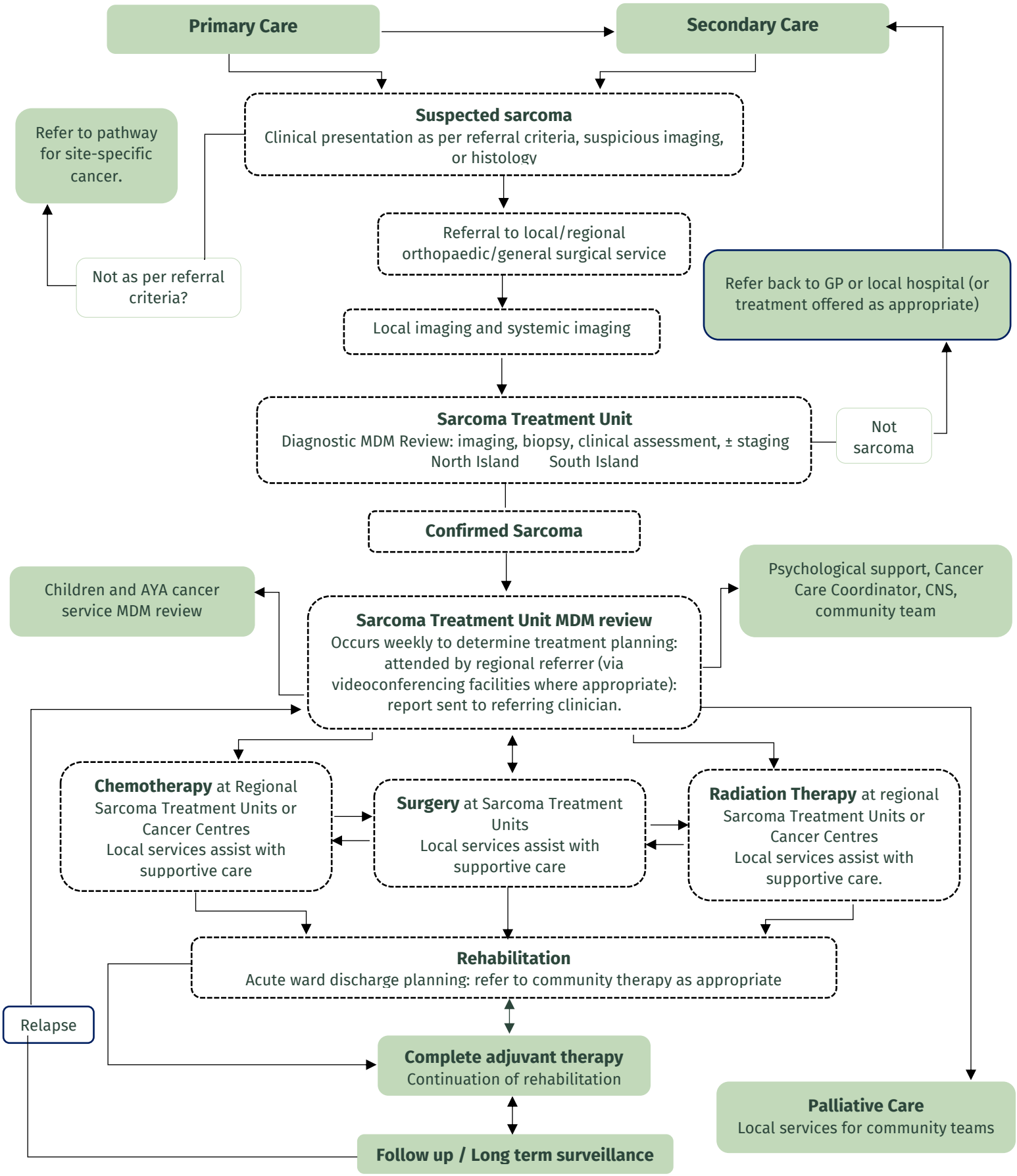
10.10 People receive full written information to help inform their decision about whether to participate in a clinical trial (NICE 2006).

10.11 Sarcoma treatment centres maintain a listing of clinical trials to which people are being recruited and make this available for collation on a national basis.

10.12 Research with the high-level goal of reducing inequalities in cancer care is prioritised.

10.13 All people are offered the option of tissue banking to enable potential future research and therapies.

APPENDIX 1: THE SARCOMA PATHWAY



APPENDIX 2: SARCOMA FOLLOW-UP

Follow up for soft tissue sarcomas	
Stage of disease	**Disease monitoring**
1. Localised extremity post-surgery ± radiotherapy	
Benign tumours/atypical lipomatous tumours	
Year 1	• post-operative visit in first 6 weeks • supported discharge
Low grade	
Year 1	• post-operative visit in first 6 weeks • 3-month clinical examination (to check function if necessary • 6 monthly clinical examination[1], CXR
Year 2	• 6 monthly clinical examination, CXR
Years 3+	• annual clinical examination, CXR
Discharge at 10 years after surgery	
Intermediate and high grade	
Year 1	• post-operative visit in first 6 weeks • 3 - 4 monthly clinical examination, CXR • image prosthesis at 6 months and 1 year
Year 2	• 3 - 4 monthly clinical examination, CXR • image prosthesis annually
Years 3 – 4	• 6 monthly clinical examination, CXR • image prosthesis annually
Years 5 – 10	• annual clinical examination, CXR • image prosthesis annually
Discharge at 10 years after surgery unless: - Patient has had radiotherapy with toxicity that requires long term follow-up - Patient has a prosthesis *in situ* (follow-up evaluation by orthopaedic team) - Teenage and young adult patients (<25 years at diagnosis) - will require long term follow-up in a late effect service - Clinical trial patients on active follow-up	
1. Abdominal/retroperitoneal/gynaecological sarcomas post-surgery (excluding GIST)	*Comment*: Because of the uncertainty about the timing and benefits of intervention for recurrent disease, surgical or otherwise, in this group of sarcomas follow up can take twoforms: radiologically directed follow-up, or clinically directed follow-up. The choice of follow-up protocol is a clinical decision between clinician and patient, taking into account biological factors of the particular histological sub-type.
Radiologically directed follow-up	
Low grade	

Year 1	• post-operative visit in first 6 weeks • 3 - 6 monthly clinical examination • baseline CT chest/abdo/pelvis[2] post-surgery, then at 6 and 12 months
Year 2	• 6 monthly clinical examination
	• CT scan chest/abdo/pelvis[2] at 18 and 24 months
Year 3+	• annual clinical examination • annual CT chest/abdo/pelvis[2] to 10 years
	Or MRI abdo/pelvis and CXR *or* abdo and transvaginal USS and CXR
Discharge at 10 years after surgery	
Intermediate and high grade*	
Year 1	• post-operative visit in first 6 weeks • 3 monthly clinical examination, CXR • baseline CT chest/abdo/pelvis[2] post-surgery, then at 6 and 12 months
Year 2	• 3 monthly clinical examination, CXR • CT scan chest/abdo/pelvis[2] at 18 and 24months
Years 3 – 4	• 6 monthly clinical examination and CXR • annual CT chest/abdo/pelvis[2]
Years 5 – 10	• annual clinical examination and CXR • annual CT chest/abdo/pelvis[2] year 5, thenstop
Discharge at 10 years after surgery	
Clinically directed follow-up	
Follow up intervals as above, with evaluation for new abdominal symptoms and clinical examination. Scanning (CT chest/abdo/pelvis[2]) is instituted for clinical suspicion ofrecurrence. Chest surveillance is performed at each visit by CXR.	
3. Head and neck sarcomas	
Year 1	• post-operative visit in first 6 weeks • 3 monthly clinical examination and CXR • post-treatment MRI of primary site at 3 months after completing treatment • surveillance MRI of primary site at 9 months
Year 2	• 3 monthly clinical examination and CXR • surveillance MRI of primary site at 15 and21 months
Years 3 – 4	• 6 monthly clinical examination and CXR • surveillance MRI of primary site at 27 months • thereafter annual MRI of primary site
Years 5 – 10	• annual clinical examination and CXR
Discharge at 10 years after surgery	
4. Post pulmonary metastasectomy	
Year 1	• post-operative visit in first 6 weeks • 3 monthly clinical examination, CXR • baseline CT scan and CXR post-surgery (within 3 months) • thereafter 6 monthly CT scans

Year 2	• 3 monthly clinical examination, CXR • CT scans at 18 and 24 months
Years 3 – 4	• 6 monthly clinical examination and CXR
	• continue CT scans at clinician's discretion if felt to be at high risk or recurrence
	• continue CT scans at clinician's discretion if felt to be at high risk or recurrence
Years 5 – 10	• Annual clinical examination and CXR
Discharge at 10 years after surgery	
5. Locally advanced or metastatic disease	
Year 1+	• 3-monthly clinical examination and CXR (ormore frequently as clinically indicated) • imaging of disease sites as clinically appropriate at clinician's discretion (usually 3-monthly CT scan)

† **Patients treated within clinical trials should be followed up according to the trial protocol**

[1] Routine imaging of primary site at clinician's discretion, if clinical detection of recurrence is anticipated to be difficult, e.g. deep tumours; large tumours; post-radiotherapy.

[2] Alternatives to CT chest abdomen and pelvis include:
- MRI abdomen and pelvis, CXR
- Abdominal ultrasound scan, transvaginal ultrasound scan, CXR(for gynae sarcomas).

Follow-up guidelines for benign bone tumours (aneursymal bone cyst, giantcell tumour), 'low' grade bone sarcomas (grade 1 - 3 chondrosarcoma, periosteoal and parosteal osteosarcoma, chordoma.	
Stage of disease	**Disease/late toxicity monitoring**
1. Aneurysmal bone cyst, giant cell tumour	
Year 1	• post-operative visit in first 6 weeks • 3 - 6 monthly clinical examination, plain films of primary site
Years 2 - 3	• 6 monthly clinical examination, plain films of primary site
Discharge 3 years after surgery	
2. Grade 1 chondrosarcoma	
Localised post primary treatment – curettage +/- cementation	
Year 1	• post-operative visit in first 6 weeks • 3 - 6 monthly clinical examination, plain films of primarysite[1]
Years 2 - 5	• 6 monthly clinical examination, plain films of primary site[1]
Discharge at 5 years fromsurgery	
Localised post primary treatment – on observation only	
Years 1 - 2	• interval MRI scans at 6 months and 18 months. If no change, and patient does not want curettage,

	discharge.
3. Grade 2 – 3 chondrosarcoma, periosteal and parosteal osteosarcoma	
Localised post-resection	
Years 1 - 2	• post-operative visit in first 6 weeks • 3 monthly clinical examination, plain films of primarysite[1], CXR
Years 3 – 5	• 6 monthly clinical examination, plain films of primarysite[1], CXR
Years 6 - 10	• annual clinical examination, plain films of primary site[1], CXR
Discharge at 10 years fromsurgery	
4. Chordoma	
Localised post-resection +/- radiotherapy	
Years 1 - 2	• post-operative visit in first 6 weeks • 3 – 6 monthly clinical examination, CXR • MRI of primary site at 6 months, 1 year, 2 years
Years 3 - 5	• 6 monthly clinical examination, CXR • MRI of primary site annually
Years 6-10	• annual clinical examination, CXR, MRI of primary site
Discharge at 10 years from surgery	

[1] Plain films not required after amputation

Follow-up Guidelines for high grade osteosarcoma/spindle cellsarcoma of bone/de-differentiated chondrosarcoma[†]	
Stage of disease	**Disease/late toxicity monitoring**
1. Localised post primary treatment	
Year 1	• post-operative visit in first 6 weeks (if primary surgery) • 2 monthly clinical examination, CXR, plain films ofprimary site[1] • annual blood biochemistry (U&E, LFT, Ca, PO_4, Mg,HCO_3)[2] • end of year 1 - gonadal function (males: testosterone,LH, FSH; females: oestradiol, LH, FSH)[2]
Year 2 - 3	• 3 monthly clinical examination and CXR, plain films ofprimary site[1] • annual blood biochemistry (U&E, LFT, Ca, PO_4, Mg,HCO_3)[2] • end of year 2 - MUGA or ECHO[2]

Year 4	• 6 monthly clinical examination and CXR, plain films ofprimary site[1] • annual blood biochemistry (U&E, LFT, Ca, PO_4, Mg,HCO_3) [2] • end of year 4 - MUGA or ECHO[2]
Year 5	• 6 monthly clinical examination and CXR, plain films ofprimary site[1] • annual blood biochemistry (U&E, LFT, Ca, PO_4, Mg, • HCO_3) [2]
Years 6 - 10	• annual clinical examination and CXR, plain films ofprimary site[1] • annual blood biochemistry (U&E, LFT, Ca, PO_4, Mg,HCO_3) [2] • end of year 6 - MUGA or ECHO[2]
Discharge at 10 years after surgery, unless: • Patient has had radiotherapy with toxicity that requires long term follow-up • Patient has a prosthesis *in situ* (follow-up evaluation by orthopaedic team) • Teenage and young adult patients (<25 years at diagnosis) - will require long term follow-upin a late effect service • Clinical trial patients on active follow-up	
2. Post pulmonary metastasectomy	
Year 1	• post-operative visit in first 6 weeks • 3-monthly clinical exam, CXR, plain films of primary site • baseline CT scan post-surgery, thereafter 6-monthly
Year 2	• 3-monthly clinical examination, CXR, plain films of primary site • 6-monthly CT scan
Years 3 – 4	• 6-monthly clinical examination, CXR, plain films of • primary site
Years 5 – 10	• annual clinical examination, CXR, plain films of primary site
Discharge at 10 years after surgery	

3. Relapsed metastatic disease	
Year 1+	• 2 - 3 monthly clinical examination and CXR • imaging of disease sites as clinically appropriate

† **Patients treated within clinical trials should be followed up according to thetrial protocol.**

[1] Plain films not required after amputation

[2] Investigations to be carried out post-chemotherapy only.

Follow-up Guidelines for Ewing's sarcoma/Rhabdomyosarcoma†	
Stage of disease	**Disease/late toxicity monitoring**
1. Localised post primary treatment	

Year 1	• 2 monthly clinical examination, CXR, plain films of primary bony site[1] • soft tissue tumours – baseline end of treatment MRI/CT primary site, thereafter at clinician's discretion[2] • radiotherapy as definitive local treatment - baseline end of treatment MRI/CT of primary site, then at 6 and 12 months • end of year 1 - gonadal function (males: testosterone, • LH, FSH; females: oestradiol, LH, FSH); renal function (Cr, Na, K, Ca, PO_4, HCO_3, tubular phosphate resorption).
Year 2 - 3	• 3 monthly clinical examination, CXR, plain films of bony primary site[1] • MRI of soft tissue primary site at clinician's discretion[2] • radiotherapy as definitive local treatment - MRI/CT of primary site at 18 and 24 months • MUGA/ECHO 2 years post diagnosis[3] • Annual renal function (Cr, Na, K, Ca, PO_4, HCO_3, tubular phosphate resorption)
Year 4	• 6 monthly clinical examination, CXR, plain films of primary site[1] • MRI of soft tissue primary site at clinician's discretion[2] • MUGA/ECHO 4 years post diagnosis[3] • Annual renal function (Cr, Na, K, Ca, PO_4, HCO_3, tubular phosphate resorption.
Year 5	• 6 monthly clinical examination, CXR, plain films of primary site[1] • Annual renal function (Cr, Na, K, Ca, PO_4, HCO_3, tubular • phosphate resorption.
Years 6 - 10	• annual clinical examination, CXR, plain films of primary site[1] • MUGA/ECHO 6 years post diagnosis[2] • Annual renal function (Cr, Na, K, Ca, PO_4, HCO_3, tubular phosphate resorption.
Discharge at 10 years after surgery, unless: • Patient has had radiotherapy with toxicity that requires long term follow-up • Patient has a prosthesis *in situ* (follow-up evaluation by orthopaedic team) • Teenage and young adult patients (<25 years at diagnosis) - will require long term follow-up in a late effect service • Clinical trial patients on active follow-up	
2. Relapsed metastatic disease	
Year 1+	• Follow up as clinically indicated on a case-by-case basis depending on ongoing treatments or potential treatments.

† **Patients treated within clinical trials should be followed up according to thetrial protocol.**

[1] Plain films of primary site not required after amputation in adults unless clinically indicated but should happen in children.
[2] If clinical detection of recurrence is anticipated to be difficult.
[3] Perform only for patients who have received doxorubicin.

Follow-up Guidelines for Gastrointestinal Stromal Tumours	
Stage of disease	**Disease monitoring**
1. Post-resection of localised disease	
Very low risk[1]	
No follow-up required – discharge to primary care.	
Low risk[1]	
Year 1	• CT abdo/pelvis[2] +/- CXR[3] at 12 months post-surgery. Then discharge.
Intermediate risk[1]	
Year 1	• baseline CT abdo/pelvis[2] +/- CXR[3] post-surgery and 6 months later
Years 2 - 5	• annual CT abdo/pelvis[2] +/- CXR[3]
Discharge after 5 years after surgery	
High risk[1]	
Years 1 - 2	• 3 monthly clinical examination and CT abdo/pelvis[2] +/- CXR[3]
Years 3 - 4	• 6 monthly clinical examination and CT abdo/pelvis[2] +/- CXR[3]
Years 5 -10	• annual clinical examination • annual CT abdo/pelvis[2] +/- CXR[3] year 5, then stop
Discharge at 10 years after surgery	
Adjuvant imatinib	
Years 1 - 5	• 6 monthly clinical examination and CT abdo/pelvis[2] +/- CXR[3]
Years 6 - 10	• annual clinical examination and CT abdo/pelvis[2] +/- CXR[3]
Discharge at 10 years after surgery	
2. Post-resection of localised disease following neo-adjuvant imatinib	As for high risk resected patients (above)
Discharge at 10 years	
3. Metastatic disease	
Years 1 - 3	• 3 monthly clinic review and CT chest/abdo/pelvis[2,3]
Year 4 onwards	• 3 monthly clinic review • 6 monthly CT chest/abdo/pelvis[2,3]

† **Patients treated within clinical trials should be followed up according to thetrial protocol.**

[1] Risk grouping as defined in: Miettinen M, Lasota J. Semin Diagn Pathol. 2006May;23(2):70-83.
[2] CT may be replaced by MRI at clinician's discretion.
[3] CXR may be replaced by CT chest for syndromic and paediatric GIST.

APPENDIX 3: MEASURING AND MONITORING

Measuring and monitoring are key components of contemporary best practice and should form the basis of a service improvement plan. For sarcoma the measures outlined below will be monitored by the two sarcoma centres, with reports made available 6-monthly.

1. Timely access to services

MR1A: Reporting on 62-day indicator, 31-day Health Target and two- week indicator quarterly.

MR1B: Reports to include data as defined by Faster Cancer Treatment Indicators and Health Target (Sept 2023).

MR1C: Reports will be reviewed annually by a yet to be determined sarcoma expert group.

2. Referral and communication

MR2A: Audit correspondence between secondary/tertiary care and GPs.

MR2B: Provide evidence of culturally appropriate person and family/whānau satisfaction surveys, and audit complaints processes.

3. Investigation, diagnosis, and staging

MR3A: Ensure that sarcoma MDMs provide details of appropriate procedures required.

4. Multidisciplinary care

MR4A: Ensure that sarcoma MDMs have annual audit of operation aspects and member experience.

MR4A.1: Annual review of the terms of reference to ensure they remain fit for purpose.

MR4A.2: Annual review of FCT quarterly indicators and Health Target.

MR4B: Ensure sarcoma MDMs provide documented evidence of surveys, and audit complaints processes.

5. Treatment

MR5A: Ensure that sarcoma MDMs perform clinical audits on clinical outcomes and associated morbidity.

MR5B: Ensure that cancer centres keep a record of oncologists as members of the extended sarcoma MDT.

MR5C: Ensure that sarcoma MDMs are audit compliant.

MR5D: Audit certification and credentialing processes.

MR5E: Ensure that sarcoma MDMs maintain a record of surgeons who are affiliated to the MDM.

MR5F: Audit the records of proposed care plans, onward referrals and follow-up responsibilities recorded at sarcoma MDT reviews and in a person's clinical notes.

6. Complex surgery

Refer 5. Treatment.

7. Follow up and surveillance

MR7A: Audit follow-up practices, including the timeliness and appropriateness of investigations.

MR7B: Audit written follow-up information provided to people following agreed surveillance protocols.

8. Supportive care

MR8A: Provide evidence of culturally appropriate person and family/whānau satisfaction surveys, and audit complaints processes.

MR8B: Provide evidence of a persons' access to adequately trained specialist orthotists and prosthetists.

MR8C: Provide evidence of people receiving specialist therapist services.

MR8D: Provide evidence of adequate arrangements for long-term care provision.

9. Care-coordination

MR9A: Ensure that sarcoma MDMs provide records of identified care coordinators.

MR9B: Audit database records and clinical notes on contact points between care coordinators and people with sarcoma.

MR9C: Provide evidence of culturally appropriate persons' and family/whānau satisfaction surveys, and audit complaints processes.

10. Clinical performance monitoring and research

MR10A: Provide evidence of reporting of required patient data sets to national data repositories (as available) at the agreed frequency.

MR10B: Ensure that sarcoma MDMs regularly audit their processes.

MR10C: Ensure that MDMs provide documentation of all open trials/research projects, and the number of patients entered per trial per year.

APPENDIX 4: GLOSSARY

Adjuvant therapy	Additional treatment to increase the effectiveness of the main treatment (often surgery), such as chemotherapy, systemic therapy, or radiation therapy.
Advance care planning	A process of discussion and shared planning for future health care.
Allied health professional	One of the following groups of health care workers: physiotherapists, occupational therapists, dietitians, orthoptists, paramedics, prosthetists/orthotists, psychologists, social workers and speech and language therapists.
Asymptomatic	Without obvious signs or symptoms of disease. In early stages, cancer may develop and grow without producing symptoms.
AYA	Adolescent and young adult.
Best practice	A method or approach that is accepted by consensus to be the most effective way of doing something, in the circumstances; may or may not be based on evidence.
Biopsy	Removal of a sample of tissue or cells from the body to assist in the diagnosis of a disease.
Bone sarcoma	Sarcoma that affects the bone.
Cancer journey	The individual and personal experience of a person with cancer throughout the course of their illness.
Cancer networks	Cancer Networks were formed in response to national policy to drive change and improve cancer services for the population in specific areas. There are four regional networks: Northern, Midland, Central and Southern.
Cancer service pathway	The cumulative cancer-specific services that a person with cancer uses during their experience with cancer.
Care coordination	Entails the organising and planning of cancer care, who people and family/whānau see, when they see them and how this can be made as easy as possible. It may also include identifying people and family/whānau who need to help them on the cancer pathway.
Chemotherapy	The use of drugs that kill cancer cells or prevent or slow their growth (also see systemic therapy).
Clinical trial	An experiment for a new treatment.
Computed tomography (CT)	A medical imaging technique using X-rays to create cross-sectional slices through the body part being examined.

Confirmed diagnosis (used in FCT indicators)	The preferred basis of a confirmed cancer diagnosis is pathological, noting that for a small number of people with a cancer diagnosis will be based on diagnostic imaging findings.
Cytogenetics	The study of chromosomes and chromosomal abnormalities.
Decision to treat (used in FCT indicators)	A decision to begin a persons' treatment plan or other management plan, following discussion between the person and treating clinician.
End of life care	The provision of supportive and palliative care in response to the assessed needs of the person and family/whānau during the end-of-life phase.
Ewing's sarcoma	A type of bone cancer that usually forms in the middle of large bones and occurs most frequently in children and young adults.
Family/whānau	Can include extended family/whānau, partners, friends, advocates, guardians, and other representatives.
Faster Cancer Treatment (FCT)	A Ministry of Health programme that will improve services by standardising cancer care pathways and timeliness to services for people with cancer.
Faster Cancer Treatment indicators	Measures of cancer care collected through District reporting of timeframes within which people with a high suspicion of cancer access services. The indicators are internationally established and provide goals for Districts to achieve over time.
Fibromatosis	A group of tumours sometimes known as desmoid tumours. They are classified as benign – not cancerous – and do not tend to spread to other parts of the body, but can spread into nearby tissues, and so are usually treated in a similar way to cancerous sarcomas.
Fine needle aspiration cytology	The use of a fine needle to biopsy a tumour or lymph node to obtain cells for cytological confirmation of diagnosis.
First specialist assessment (FSA)	Face-to-face contact (including telemedicine) between a person and a registered medical practitioner or nurse practitioner for the purposes of first assessment for that client for that condition for that specialty.
First treatment (used in FCT indicators)	The treatment or other management that attempts to begin the persons' treatment, including palliative care.
Gastrointestinal stromal tumour (GIST)	An unusual and specific type of tumour that usually begins in cells in the wall of the gastrointestinal tract (stomach, small bowel).
Health equality/equity	Absence of unnecessary, avoidable, and unjust differences in health (Ministry of Health 2002).
Health inequality/inequity	Differences in health that are unnecessary, avoidable, or unjust (Ministry of Health 2002).

High-grade cancer	These cancers tend to grow more aggressively, be more malignant, and have the least resemblance to normal cells.
High suspicion of cancer (used in FCT indicators)	Where a person presents with clinical features typical of cancer or has less typical signs and symptoms but the clinician suspects that there is a high probability of cancer.
Histological	Relating to the study of cells and tissue on the microscopic level.
Histopathology	The microscopic study of diseased tissue.
Holistic	Looking at the whole system rather than just concentrating on individual components.
Hospice	Hospice is not only a building; it is a philosophy of care. The goal of hospice care is to help people with life-limiting and life-threatening conditions make the most of their lives by providing high-quality palliative and supportive care.
Immunohistochemistry	A technique that uses antibodies to show up specific proteins in tissues seen down a microscope.
Intensity modulated radiotherapy	An attempt to optimise dose distribution during external beam radiotherapy delivery. Each radiation field is divided into small segments with varying radiation intensity, defining target shape, location, and the geometry of overlaying tissues. Intensity modulated radiotherapy fields are typically designed using computer-driven (or -aided) optimisation. This is often referred to as 'inverse treatment planning'.
Lesion	An area of abnormal tissue.
Li-Fraumeni syndrome	An inherited family trait carrying an increased risk of cancer during childhood and early adulthood.
Local recurrence	Local persistence of a primary tumour due to incomplete excision.
Lymphoedema	A condition in which excess fluid collects in tissue and causes swelling. It may occur in the arm or leg after lymph vessels or lymph nodes in the underarm or groin are removed or treated with radiation.
Magnetic resonance imaging (MRI)	A non-invasive method of imaging, which allows the form and metabolism of tissues and organs to be visualised (also known as nuclear magnetic resonance).
Malignant	Cancerous. Malignant tumours can invade and destroy nearby tissue and spread to other parts of the body.
Medical oncologist	A doctor who treats people with cancer using chemotherapy and, for some tumours, immunotherapy.

Medical oncology	The specialist treatment of people with cancer using chemotherapy and, for some tumours, immunotherapy.
Metastases	Cancerous tumours in any part of the body that have spread from the original (primary) origin. Also known as 'secondaries'.
Metastatic disease	A disease that has spread from the organ or tissue of origin to another part of the body.
Morbidity	The state of being diseased.
Mortality	Either (a) the condition of being subject to death or (b) the death rate, which reflects the number of deaths per unit of population in any specific region, age group, disease, or other classification, usually expressed as deaths per 1000, 10,000 or 100,000.
Multidisciplinary meeting (MDM)	A deliberate, regular, face-to-face meeting (which may be through videoconference) to facilitate prospective multidisciplinary discussion of options for a persons' treatment and care by a range of health professionals who are experts in different specialties. 'Prospective' treatment and care planning makes recommendations in real time, with an initial focus on the persons' primary treatment. Multidisciplinary meetings entail a holistic approach to the treatment and care of people.
Multidisciplinary team (MDT)	A group of specialists in each disease area. The MDT meets regularly to plan aspects of a persons' treatment. Individual cases might be discussed at an MDM, to best plan approach to treatments.
National Health Index (NHI) number	A unique identifier for New Zealand health care users.
Neurofibromatosis	A genetic condition in which people develop multiple, benign tumours of nerve tissue.
Oncology	The study of the biological, physical, and chemical features of cancers, and of the causes and treatment of cancers
Osteosarcoma	A cancer of the bone that usually affects the large bones of the arm or leg. It occurs most commonly in young people and affects more males than females.
Palliative	Anything that serves to alleviate symptoms due to the underlying cancer but is not expected to cure it.
Palliative care	Active, holistic care of people with advanced, progressive illness that may no longer be curable. The aim is to achieve the best quality of life for people. Many aspects of palliative care are also applicable in earlier stages of the cancer journey in association with other treatments.

Pathologist	A clinician who examines cells and identifies them. The pathologist can tell where a cell comes from in the body and whether it is normal or a cancer cell. If it is a cancer cell, the pathologist can often tell what type of body cell the cancer developed from. In a hospital practically all the diagnostic tests performed with material removed from the body are evaluated or performed by a pathologist.
Pathology	A branch of medicine concerned with disease; especially its structure and its functional effects on the body.
Cancer pathway	The individual and personal experience of a person with cancer throughout the course of their illness; the person's journey.
Positron emission tomography (PET)	A highly specialised imaging technique using a radioactive tracer to produce a computerised image of body tissues to find any abnormalities. PET scans are sometimes used to help diagnose cancer and investigate a tumour's response to treatment.
Positron emission tomography and computed tomography (PET-CT)	An advanced imaging technique combining an injected material (18 Fluorine) which is taken up by cancer cells and a CT scan.
Primary care	Primary-level health services provided by a range of health workers, including GPs and nurses.
Prognosis	A prediction of the likely outcome or course of a disease; the chance of recovery or recurrence.
Psychological support	Professional support that helps people with a wide range of psychological problems, such as anxiety and depression, and provides emotional assistance during times of distress.
Quality assurance	All the planned and systematic activities implemented within the quality system and demonstrated as needed.
Radiation oncologist	A person who is registered as a medical practitioner by the relevant medical board, is a fellow of the Royal Australian and New Zealand College of Radiologists or equivalent and is licensed to prescribe radiation therapy.
Radiologist	A doctor who specialises in creating and interpreting pictures of areas inside the body using X-rays and other specialised imaging techniques. An interventional radiologist specialises in the use of imaging techniques for treatment; for example, catheter insertion for abscess drainage.
Radiology	The use of radiation (such as X-rays, ultrasound, and magnetic resonance) to create images of the body for diagnosis.
Radiotherapy (radiation treatment)	The use of ionising radiation, usually X-rays or gamma rays, to kill cancer cells and treat tumours.

Randomised controlled trial	A study in which people are allocated by chance alone to receive one of several interventions, one of which is the standard of comparison
RCPA	Royal College of Pathologists of Australasia.
Recurrence	The return, reappearance, or metastasis of cancer (of the same histology) after a disease-free period.
Referred urgently (used in FCT indicators)	Describes urgent referral of a person to a specialist because he or she presents with clinical features indicating high suspicion of cancer.
Resection	Removal of tissue from the body by surgery.
Retinoblastoma	An eye cancer that most often occurs in infants and young children.
Retroperitoneum	The space behind the peritoneum (a membrane that lines the entire abdominal wall of the body).
Specialist Sarcoma Centre	A unit providing regional services specialising in sarcoma: in the northern region Auckland City Hospital/Middlemore Hospital; and in the southern region Christchurch Hospital.
Stage	The extent of a cancer; especially whether the disease has spread from the original site to other parts of the body.
Staging	Usually refers to the Tumour, node, metastasis system for grading tumours by the American Joint Committee on Cancer.
Supportive care	Supportive care helps a person and their family/whānau to cope with their condition and treatment – from pre-diagnosis through the process of diagnosis and treatment to cure, continuing illness or death, and into bereavement. It helps the person to maximise the benefits of treatment and to live as well as possible with the effects of their disease.
Synoptic report	A standardised proforma for reporting of cancer.
Systemic therapy	Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body.
Tertiary	Third level. Relating to medical treatment provided at a specialist institution.
Ultrasound	A non-invasive technique using ultrasound waves (high-frequency vibrations beyond the range of audible sound) to form an image.
Viscera	The internal organs enclosed in a body cavity such as the abdomen, chest, or pelvis.

Whānau	Māori term for a person's immediate family or extended family group. In the modern context, sometimes used to include people without kinship ties.
Whānau Ora	An inclusive interagency approach to providing health and social services to build the capacity of New Zealand families. It empowers family/whānau, rather than focusing separately on individual family members.
X-ray	A photographic or digital image of the internal organs or bones produced using ionising radiation.

APPENDIX 5: REFERENCES

Development of the Complex Sarcoma Service was informed by key national and international documents. Those documents that most directly influenced the development of the guidelines are listed below.

Achieving the Health Targets. High Level Implementation Plans July 2024 – June 2027. Health New Zealand – Te Whatu Ora

Standards for high-quality cancer Multidisciplinary Meeting (MDMs) in Aotearoa New Zealand (March 2024)

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