



**Report of the
Midland DHB review against
Standards of Service Provision for Sarcoma
Patients in New Zealand**

December 2015

Acknowledgement

The Midland Cancer Network would like to thank all the people from Bay of Plenty, Lakes, Tairāwhiti, Waikato and Counties Manukau DHBs who provided information to complete this regional review against the *Standards of Service Provision for Sarcoma Patients in New Zealand*. Your time, effort and contribution are greatly appreciated.

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Table of Contents

ACKNOWLEDGEMENT	2
TABLE OF CONTENTS	3
1. EXECUTIVE SUMMARY	4
1.1. Summary of the sarcoma patients in the Midland cohort	5
1.2. Conclusion	8
2. INTRODUCTION	9
3. BACKGROUND	9
3.1. National work programme	10
3.2. Regional work programme	10
4. AIMS AND OBJECTIVES	10
5. METHODOLOGY	10
6. DATA COLLECTION	11
7. MIDLAND DASHBOARD SUMMARY OF SARCOMA TUMOUR STANDARDS REVIEW	12
8. EQUITY FOR MĀORI	15
9. ADOLESCENT AND YOUNG ADULTS (AYA)	15
10. ISSUES IDENTIFIED FROM THE DHB SELF-ASSESSMENT AND RECOMMENDATIONS ...	16
APPENDIX 1 – DATA POINTS AND DEFINITIONS	17
APPENDIX 2 - MIDLAND SARCOMA CANCER DATA TABLES	17
APPENDIX 3 – DHB SELF-ASSESSMENT TOOLS	18

1. Executive summary

The Midland DHB review of the *Standards of Service Provision for Sarcoma Patients in New Zealand - provisional* (Ministry of Health. 2013) is retrospective and covers the time period 1 July 2014 to 30 June 2015.

This review summarised the waiting time and pathway for 16 Midland sarcoma patients. There were significant limitations with this review therefore the report should only be noted. It is recommended that Midland approach Northern Cancer Network to undertake a supra-regional review against the National Sarcoma Service Standards to ensure that there is a larger cohort of patients and adequate data to undertake analysis.

National tumour standards have been developed as part of the faster cancer treatment (FCT) work programme, to ensure all people have access to quality services, in a timely way to improve overall cancer outcomes. In addition to the national standards the Ministry of Health announced a new cancer health target (62 day indicator with 85% achievement by July 2016 and 90% by June 2017), phase 2 national tumour stream work programme 2014-2016 and the strategic regional approach to improve timely access to cancer services.

The Midland Regional Services Plan 2015-16 prioritised a review against the national sarcoma service standards.

The review methodology included District Health Boards (DHBs) undertaking a self-assessment against the standards and analysis of the relevant data. This is the first Midland review against the provisional national standards for sarcoma cancer.

The review team noted the following limitations with the regional review:

- very small number of patients from each Midland DHB in the cohort i.e. 16 patients in total for the region (01/07/14 - 30/06/15)
- only two of 16 patients were referred as a high suspicion of cancer (HSCAN) and triaged as needing to be seen within two weeks
- no specialty service is specifically dedicated to sarcoma patients unlike other tumour streams
- multiple pathways that sarcoma patients enter secondary services i.e. the pathway depends on the site of the tumour
- some sarcoma patients are referred to other multidisciplinary teams for discussion and treatment planning, for example general surgery, orthopaedics, gynaecology, plastics
- the national standards pathway is largely focussed on bone sarcoma and excludes many other sarcomas, for example head and neck and viscera
- no clear guidance around multidisciplinary meetings such as which patients should be referred and responsibilities around communicating MDM outcome to all relevant clinicians
- establishing a regional sarcoma working group was a difficult due to multiple players
- some patients are diagnosed with sarcoma after they have had initial surgery at DHB of domicile
- Midland DHBs refer suspected sarcoma patients to the supra-regional multidisciplinary meeting (MDM) held by Counties Manukau DHB (CMDHB). Pathologists may also send specimens to the sarcoma MDM pathologists for expert opinion rather than a full patient discussion
- referring lead clinicians are not always available to attend the MDM (via videoconferencing)
- local treating clinicians such as oncologists are not always aware that patients have been referred to the supra-regional sarcoma MDM for discussion
- The time of the sarcoma MDM clashes with the Waikato Head & Neck MDM therefore it is difficult for clinicians to attend both MDMs. The Waikato Clinical Nurse Specialist (CNS) and/or Cancer Nurse Coordinator (CNC) videoconference into the weekly sarcoma MDM and at times, a referring Pathologist. Hauora Tairāwhiti CNC videoconference to MDM if there are any Hauora Tairāwhiti patients on the agenda

- at least 12 standards refer specifically to the supra-regional sarcoma treatment unit and MDM located at CMDHB. Therefore the review was reliant on information available from CMDHB for these standards to be reviewed
- data from the New Zealand Bone and Soft Tissue Cancer Registry (NZBSTCR) held by CMDHB was unavailable to the Midland review team. The network was informed that NZBSTCR information is available for research and teaching purposes only
- data to inform the standards such as treatment and first specialist assessment (FSA) dates were not available from the NZBSTCR
- the NZBSTCR uses a different coding system to ICD codes therefore the possibility of sourcing data from the registry was not explored
- an electronic proforma is available for referrals to the supra-regional sarcoma MDM although consultants also refer patients via phone, email, text messages and letter, sometimes with insufficient information
- Lack of information when verbal referrals are made to CMDHB for example a referral date may not be captured for Midland data purposes
- incomplete data for example source of referral and date of FSA data was not available for all patients
- staging information was not available as data
- patient electronic records were reviewed to extract some information
- there has been little time for DHBs to implement the standards monitoring requirements
- some process improvements have occurred during the review period. For example at Waikato DHB, a centralised email address has been established to improve communications around the supra-regional sarcoma MDM, and Bay of Plenty (BOP) has developed a documented sarcoma pathway which has been forwarded to CMDHB.

1.1. Summary of the sarcoma patients in the Midland cohort

Sarcoma is a rare cancer and this is reflected in the small cohort of 16 patients for the Midland region – eight patients domiciled to Waikato DHB, three patients from Lakes DHB, three patients from BOP DHB and two patients from Hauora Tairāwhiti.

1.1.1 Fibromatosis

Standard 4.2 of the national sarcoma service standards requires that *'patients with fibromatosis are managed by a sarcoma multidisciplinary team (MDT)'*. Although fibromatosis is a benign tumour it often appears similar to soft tissue sarcomas. Treatment of this disease is challenging and involves multiple modalities, and often differs on a case-by-case basis.

The regional FCT database excludes non cancer patients such as fibromatosis. However one patient domiciled to Waikato DHB in the time period reviewed, was identified with fibromatosis. In addition to the 16 sarcoma patients, the pathway of this one patient was reviewed to confirm compliance against the standard.

The fibromatosis patient was referred to the supra-regional sarcoma MDM and had a biopsy done at CMDHB. The sarcoma treatment unit at Middlemore Hospital referred the patient to Waikato Hospital for surgical treatment.

Hauora Tairāwhiti advised that patients with fibromatosis are currently not managed by the sarcoma multidisciplinary team (MDT). The reason why fibromatosis patients were not referred was not specified.

1.1.2 Demographics

Nine (56%) patients identified as European and seven (44%) as Māori. Six patients were female and 10 male.

- Seven patients were aged 60 years and above
- Five patients were aged between 40-60 years of age
- Two patients were aged between 24 and 40 years
- Two patients were under 24 years of age.

1.1.3 62 day indicator

The 62 day indicator applies to all patients referred and triaged with a HSCAN and needing to be seen within two weeks. Two of 16 patients in the region were referred and triaged as HSCAN.

Patient 1 from Waikato DHB did not meet the 62 day indicator.

The patient had multiple imaging investigations including an ultrasound, a CT scan and an MRI. A 49 day timeframe from referral to the MRI, contributed to the delay to treatment. It was noted that an MRI was attempted at day 38 however that was still a lengthy timeframe for a HSCAN patient.

The patient was promptly referred to Middlemore Hospital where a biopsy was done and radiation therapy commenced prior to surgery.

Patient 2 from Bay of Plenty DHB met the 62 day indicator.

The patient, who was non curative, had chest CT and MRI imaging then chemotherapy as first treatment. This patient was referred directly to palliative care and was not referred to the supra-regional sarcoma MDM.

1.1.4 31 day indicator

The 31 day indicator is the length of time from decision to treat (DTT) to first treatment. The DTT is the date on which the treatment plan is agreed between the patient and the clinician responsible for first treatment.

Two of 16 patients did not meet the 31 day indicator.

Patient 1 from Lakes DHB waited 89 days from DTT to first treatment. The patient had a biopsy followed by an excision of lesion at Lakes DHB. The patient was then referred to Auckland Orthopaedic service and waited 49 days for a clinic appointment. Surgery at Auckland occurred 89 days following the clinic appointment and DTT.

Patient 2 from Waikato DHB was referred from the urology service to the general surgical service following an incidental finding of a retroperitoneal mass when a MRI scan was done. The patient was consented for surgery and was placed on the wait list at Waikato Hospital. Surgery was 51 days following DTT. The patient was referred post-surgery to the supra-regional sarcoma MDM for opinion on further treatment. Radiation therapy and additional surgery was carried out at Waikato Hospital.

1.1.5 MDM

Nine (56%) of 16 patients were referred to the supra-regional sarcoma MDM, one patient was referred to the Waikato Neuro-oncology MDM and one to the Waikato gastrointestinal MDM.

Of the five who were not referred to the supra-regional sarcoma MDM:

- one patient was under the care of the Waikato plastics team
- one patient declined treatment and was referred to palliative care
- one patient was non curative and for palliative care
- one patient was referred directly to the sarcoma treatment unit at Middlemore Hospital
- one patient was referred to the orthopaedic unit at Auckland Hospital.

Midland DHBs also send pathology or imaging to the sarcoma MDM for expert opinion. This does not necessarily include treatment planning. Referring clinicians are not always available to attend the sarcoma MDM and treating clinicians such as medical and radiation oncologists are not always aware that patients they will be treating, have been referred for discussion. Improvement in communication and clear guidance related to patient referrals and involvement by relevant clinicians in the sarcoma MDM is required.

1.1.6 Treatment

First treatment data identified seven of 16 patients in Midland had surgery as first treatment; three had radiation treatment, one patient had chemotherapy and five patients received palliative care treatment.

Four patients had surgery at Waikato Hospital, two had surgery at Lakes, and one had surgery in Auckland. Two patients had surgery following radiation as first treatment. Five patients who had initial surgery at DHB of domicile were referred to CMDHB for further surgery.

There was a variance in some data when compared to the regional FCT database i.e. two patients had a biopsy date, an excision of lesion date, and a surgical date. For one patient the excision of lesion date was identified as the first treatment date whereas for a second patient, surgery at Auckland was identified as the first treatment date, rather than the excision of lesion date. This information is often

manually added to the database by the cancer nurse coordinators (CNCs). The variance was relayed to the regional FCT database analyst and feedback to the CNCs.

At Waikato, the same clinicians provide care in accordance with standard protocols in order to consolidate expertise around treatment. For example, radiation treatment is routinely provided by the same two radiation oncologists and chemotherapy by the same two medical oncologists.

1.1.7 Investigations

Thirteen (81%) of 16 patients had a CT scan and eleven (69%) of 16 patients had an MRI scan. One patient had only a chest x-ray in the clinical records viewed. This patient was under the care of the plastics team at Waikato and was not referred to the sarcoma MDM for discussion.

At Waikato DHB, all six patients met the two week referral to imaging timeframe. One patient had a PET-CT which took (26) days from referral to PET-CT.

Both patients at Hauora Tairāwhiti met the two week timeframe for CT and MRI.

All three Lakes DHB patients had their MRI within two weeks of referral. Two of three patients had a CT scan. One patient met the two week timeframe and one patient was 16 days from referral.

All two BOP DHB patients had their MRI within two weeks of referral. For CT scan, one patient met the two week timeframe and one patient was 19 days from referral.

Three CMDHB musculoskeletal radiologists regularly attend the weekly sarcoma MDM meeting to review imaging referred to them. In addition a radiologist from Auckland often joins via videoconferencing.

Three CMDHB pathologists who are considered specialists in sarcoma regularly attend the sarcoma MDM to provide opinion on histology presented. At times, pathology is sent to the USA for expert opinion. CMDHB pathologist advised that biopsy specimens are not in a synoptic report and although they have a synoptic report for the excisional specimens, this is not always used.

Staging information was not available as data.

1.1.8 Supportive care

There was evidence of contacts and referrals to supportive services available as well as contact with CNS and CNCs. The range of support services utilised included:

- Social Worker
- Physiotherapy
- Occupational Therapist
- Therapy Assistants
- Kaitiaki services (Waikato)
- Limb service
- District Nurses
- Cancer Society
- National Travel and Accommodation
- Canteen
- Hospice services
- Child Cancer Foundation.

1.1.9 Clinical performance monitoring and research

The NZBSTCR is maintained at Counties Manukau DHB. The NZBSTCR information is largely used for research and teaching as approved by the ethics committee and was not available to the Midland review team. The reviewer was advised that data to inform the standards is not all captured on the NZBSTCR. For example the patient's first consultation and treatment at the DHB of domicile is not held by the registry.

Standard 9.2 states '*data on clinical outcomes and patient satisfaction are regularly monitored and reported as part of a national audit*'. Ad hoc audits rather than regular monitoring of clinical outcomes are undertaken using information from the registry. A nationally agreed dataset related to sarcoma beyond the fields required by the New Zealand Cancer Registry has not been developed. DHB staff aren't always aware of research projects and/or clinical trials for sarcoma patients, or if patients are participants.

1.1.10 Monitoring requirements for standards

As this is the first regional review of the national sarcoma service standards, the monitoring requirements for the standards were not assessed for every standard i.e. evidence was not sought. It is expected that it make take time for each DHB to develop and implement all the standard monitoring requirements as there are a number of regular audits that need to be undertaken.

The FCT Health Target monitors the timely access to services cluster of standards and each DHB has a system for monitoring patient satisfaction and policies and procedures/protocols.

1.2. Conclusion

Several challenges were faced in undertaking the sarcoma standards review for Midland DHBs.

Sarcoma presents in heterogeneous groups of patients with different diseases therefore, there is no specialty service dedicated to sarcoma patients unlike other tumour streams such as breast, bowel, lung and gynaecology. Sarcoma patients are referred to various multidisciplinary teams for discussion and treatment planning. This highlighted the different pathways for sarcoma patients when they enter secondary services i.e. the pathway depends on the site of the tumour. It was noted that the sarcoma standards appear to be focussed on bone sarcoma, rather than all sarcomas.

A number of sarcoma patients were excluded from the review e.g. head and neck and viscera in accordance with the standards as well as under 16 year olds as they are not included in the FCT target. Therefore, with the very small cohort of 16 patients, one might question whether this number is sufficient to accurately reflect delivery of services against the sarcoma service standards.

While all Midland DHBs supported the review, the review team were directed to CMDHB as Midland sarcoma patients are generally referred to the sarcoma treatment unit and supra-regional sarcoma MDM at CMDHB. A number of standards also refer to the sarcoma MDM and the regional sarcoma treatment unit at CMDHB. For example Standards 3.4 and 3.5 refer to radiologists and pathologists with expertise in bone and soft tissue sarcoma to review imaging and histology. The expectation is that processes and systems are in place at CMDHB to also support the standards. CMDHB were consulted in relation to at least 12 standards.

The Waikato CNS has been working with staff at CMDHB who organise the sarcoma MDM to improve processes including: earlier notification of patients to be discussed at MDM so clinicians can be notified and invited and to ensure relevant clinical information is available, as well as establishing a generic email address for correspondence such as MDM outcome letters.

Some focus areas for Midland to consider are:

- approach Northern Cancer Network to undertake a supra-regional review of the national sarcoma service standards, lead by CMDHB and supported by the Midland DHBs
- develop a plan so that referring and treating clinicians are involved at the supra-regional sarcoma MDM
- work with CMDHB regional sarcoma treatment unit to develop clear pathways and guidance for sarcoma patients referred to the sarcoma MDM and treatment unit
- improve communication and sharing of information with relevant clinicians involved in individual patient care and treatment
- provide review limitations feedback to the National Pan Tumour Standards Work Group at Ministry of Health.

2. Introduction

The Midland DHB review against the *Standards of Service Provision for Sarcoma Patients in New Zealand (provisional)* is retrospective and covers the time period 1 July 2014 to 30 June 2015.

National tumour standards have been developed as part of the faster cancer treatment (FCT) work programme, to ensure all people have access to quality services, in a timely way to improve overall cancer outcomes. The Ministry of Health has announced a new cancer health target (62 day indicator with 85% achievement by July 2016 and 90% by June 2017) and phase 2 national tumour stream work programme 2014-2016 is in progress.

The Midland DHBs review against the national sarcoma standards is a mandatory requirement of the Regional Service Plan 2015/2016.

The report identifies other national and/or regional initiatives that are in progress or planned that link to and will contribute to improving breast cancer services.

The review methodology included DHBs undertaking a self-assessment against the standards and analysis of the relevant data.

This is the first time Midland has reviewed its performance against the national sarcoma standards. The report identifies the level of current achievement for each standard, and where there is a need, recommendations to guide Midland DHBs to meet the standards.

The review report includes:

- a self-assessment report for each DHB (Appendix 1)
- the dashboard report (Section 6) summarising the performance of each DHB in the region against each of the standards - note: caution required when interpreting the dashboard
- analysis of the available data
- recommendations for service improvement.

3. Background

Tumour standards have been developed as part of the FCT programme, to ensure all people easily access the best services, in a timely way to improve overall cancer outcomes.

Sarcomas are a rare form of cancer that can occur in any part of the body and in any age group. Sarcoma can be either a bone (about 3-4 per 1,000,000 per year) or soft tissue (about three cases per 100,000 population per year). According to the New Zealand Cancer Registry, sarcomas account for <1% of all malignancies in New Zealand.

The sarcoma treatment unit at Middlemore Hospital, CMDHB maintains the NZBSTCR.

Because of the rarity of sarcoma, there is often a delay in diagnosis. Earlier recognition and referral to specialist treatment centres can lead to improved outcomes in terms of both survival and a reduced need for disabling surgery. Treatment generally consists of surgery, combined with radiotherapy and chemotherapy.

The standards recommend that all sarcoma patients be referred to the supra-regional sarcoma MDM held weekly at CMDHB. However, sarcoma patients may also be managed by other MDMs such as head and neck, gynaecology, or neuro-oncology which means that the pathway for patients varies depending on the site and whether it is bone or soft tissue.

Sarcomas of the head and neck and viscera are not covered in the standards document; treatment for these conditions should be managed according to the site-specific standards of care.

Although the national sarcoma standards document relates to the management of adult and child patients, children under the age of 16 were excluded from the review as they are not included in the FCT 62 day indicator.

The intention is for DHBs and the regional cancer network to work with local service providers to implement the tumour standards over the coming years. It is noted that changes will take time and possible resources to implement. It is anticipated that the review of services against standards will provide a baseline to demonstrate how the standards are currently implemented. The review will lead to

a clearer understanding of the level, quality and timeliness of services currently being provided at DHB and/or regional level as well as used nationally to further develop and improve the provisional tumour standards.

3.1. National work programme

The three year New Zealand Cancer Plan 2015-2018 brings together the work of the DHBs, regional cancer networks and the Ministry of Health to implement the Government's priorities for cancer.

Other key national cancer programme initiatives that align with this initiative are:

- facilitate implementation of the *Radiation Oncology National Linear Accelerator and Workforce Plan* (Health Partners Consulting Group. 2014)
- facilitate the Adolescent and Young Adult (AYA) network and annual plan
- support implementation of the *New Zealand Cancer Health Information Strategy* (2015)
- implementing the Faster Cancer Treatment (FCT) work programme:
 - phase 2 of the national tumour standards work programme that includes sarcoma:
 - implementation of high suspicion of cancer definitions
 - tumour specific national core datasets and business rules (TBC)
 - MDM prioritisation criteria (TBC)
 - follow-up guidance (TBC)
 - cancer nurse coordinator initiative
 - psychological and social support for cancer patients workforce initiative that includes:
 - establish 1 FTE psychologist in each of the six tertiary cancer centres in 2015/16
 - establish psychological and social support positions throughout New Zealand in 2015/16.

3.2. Regional work programme

The following summarises regional initiatives that align with Midland DHB sarcoma review.

- Faster Cancer Treatment 62 day Health Target and 31 day wait time indicators
- Improving Midland Cancer Midland Multidisciplinary Meetings Action Plan 2015
- Implementation of Midland Psychological and Social Support Plan 2015
- Midland Cancer Care Strategy 2015 Launch September 2015
- FCT Round 2 Service Improvement Project initiatives from October 2015
- Midland Specialist Palliative Care Service Development Plan 2015-18
- Kia ora e te Iwi programme in partnership with Māori health providers, Cancer Society, clinicians and network.
- Cancer nurse coordinator initiative.

4. Aims and objectives

Provisional national tumour standards of service provision developed as a part of the Ministry of Health's 'Faster Cancer Treatment' (FCT) work programme aim to review existing services and make service improvements along the cancer management continuum. When used as a quality tool, the standards will promote nationally coordinated and consistent standards of service provision across New Zealand.

The review objectives are to:

- compare existing service provision with that outlined in the tumour standards
- highlight where there are gaps in the provision of cancer services for sarcoma cancer
- determine areas for improvement
- inform DHBs' decision making about key priorities and implications for implementation.

5. Methodology

The review included the following components:

- a self-assessment against standards by each Midland DHB i.e. Bay of Plenty, Lakes, Tairāwhiti and Waikato to validate service provision against the sarcoma standards.
- collation and analysis of quantitative data for Midland DHBs patients with sarcoma having treatment between 1 July 2014 to 30 June 2015

- consideration of equity and Māori health outcomes

The *Report of the Midland DHBs review against Standards of Service Provision for Sarcoma Patients in New Zealand* was submitted to the Midland Cancer Network Executive Group in November 2015.

6. Data collection

The cohort of 16 patients was identified from the Midland regional FCT database having treatment for sarcoma for the period 1 July 2014 to 30 June 2015. The New Zealand Cancer Registry was not used as the main data source as it has a two year lag and this information was considered dated. The CMDHB supra-regional sarcoma MDM agendas were sourced, however matching of agenda NHIs with the FCT database resulted in a higher number of patients from the FCT database. Therefore, the cohort for the review were patients diagnosed with sarcoma entered onto the Midland regional FCT database

All patients had confirmed sarcoma according to the ICD codes below.

ICD C40, C41, C48 C49 and M72.9

Exclusions were:

- patients not coded as ICD C40, C41, C48 C49 and M72.9
- patients with head and neck and viscera
- patients with benign bone and soft tissue tumours
- private patients
- patients under the age of 16 years
- metastases to bone and soft tissue from tumour of other primary sites

A review of individual patient records for missing data was also undertaken.

Data points for the review are attached in Appendix 1.

7. Midland dashboard summary of sarcoma tumour standards review

	Waikato	Bay of Plenty	Lakes	Tairāwhiti
Standards				
Cluster 1: Timely access to services				
1.1. Patients referred urgently with a high suspicion of a sarcoma receive their first cancer treatment within 62 days.	1 patient	1 patient	0 patients	0 patients
1.2. Patients referred urgently with a high suspicion of a sarcoma have their first specialist assessment (FSA) within 14 days.	1 patient	1 patient	0 patients	0 patients
1.3. Patients referred urgently with a high suspicion of sarcoma after a local FSA are reviewed by a sarcoma treatment unit within 14 days.	1 patient	1 patient	0 patients	0 patients
1.4. Patients with a confirmed diagnosis of a sarcoma receive their first treatment within 31 days of the decision to treat.	7 (88%) of 8 patients	3 (100%) of 3 patients	*2 (67%) of 3 patients.	2 (100%) of 2 patients
1.5. Patients needing radiotherapy or systemic therapy receive their first treatment within four weeks of the decision to treat.	3 (75%) of four patients	1 patient	1 patient	1 patient
Cluster 2: Referral and communication				
2.1 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.				
2.2 Patients and their general practitioners (GPs) are provided with verbal and written information about sarcoma, diagnostic procedures, treatment options (including effectiveness and risks), final treatment plan and support services.				
2.3 Communications between health care providers include the patient's name, date of birth, national health index (NHI) number and contact details, and are ideally electronic.				
Cluster 3 Investigations, diagnosis and staging				
3.1 Imaging investigations for bone and soft tissue sarcoma follow standardised imaging pathways agreed to by regional sarcoma units based on current NCCN guidelines for bone and soft tissue sarcoma and Royal College of Radiologists cancer imaging guidelines.				
3.2 Imaging for staging is performed and reported within two weeks of referral to radiology services.				
3.3 Imaging from patients with a high probability of a bone or soft tissue sarcoma is reviewed at a regional sarcoma multidisciplinary				

	Waikato	Bay of Plenty	Lakes	Tairāwhiti
meeting (MDM) by radiologists with expertise in bone and soft tissue sarcoma.				
3.4 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.				
3.5 All patients 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.				
3.6 The histology of excised sarcoma specimens is recorded in a synoptic format.				
Cluster 4: Multidisciplinary care				
4.1 All patients with the following confirmed sarcomas are presented at a sarcoma MDM: •bone sarcoma •soft tissue sarcoma of extremities, trunk and retroperitoneum	5 of 8 patients	2 of 3 patients	1 of 3 patients	1 of 2 patients
4.2 Patients with fibromatosis are managed by a sarcoma multidisciplinary team (MDT).	1 patient			
Cluster 5: Supportive Care				
5.1 Patients with a sarcoma and their family/whānau have equitable and coordinated access to appropriate medical, allied health and supportive care services, in accordance with <i>Guidance for Improving Supportive Care for Adults with Cancer in New Zealand</i> (Ministry of Health 2010a).				
5.2 Patients 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.				
5.3 Patients have access to appropriate rehabilitation services, including physiotherapy, occupational therapy, and chronic pain and lymphoedema specialist services.				
Cluster 6: Care Co-ordination				
6.1 Patients with a sarcoma have access to a clinical nurse specialist or other health professional who is a member of the MDM to help coordinate all aspects of their care.				
Cluster 7: Treatment				
7.1 Patients with a sarcoma have access to sarcoma treatment units with appropriate resources and facilities to deliver the best standard of care.				
7.2 There is a formal working relationship between the regional sarcoma treatment units and associated providers of systemic therapy and radiotherapy detailing pathways for specialist surgery, specialist pathology, adjuvant therapies, allied health and nursing care coordination.				

	Waikato	Bay of Plenty	Lakes	Tairāwhiti
7.3 Treatment for sarcoma is based on histological subtypes, and patients are offered a combination of surgery, systemic therapy and radiotherapy where indicated				
7.4 Patients who have a primary bone sarcoma have access to surgery performed by an oncology fellowship-trained orthopaedic surgeon affiliated to a sarcoma MDT				
7.5 Patients 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 to a sarcoma MDT.				
7.6 Patients with a suspected retroperitoneal sarcoma are treated by a soft tissue sarcoma specialist affiliated to a sarcoma MDT.				
7.7 Patients 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.				
Cluster 8: Follow-up and Surveillance				
8.1 Patients are offered follow-up under the direction of the specialist sarcoma treatment unit responsible for their treatment.				
8.2 Follow-up plans include clinical review by appropriate members of the MDT, working in conjunction with the patient, their family/whānau and their GP.				
Cluster 9: Clinical Performance Monitoring and Research				
9.1 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.				
9.2 Data on clinical outcomes and patient satisfaction are regularly monitored and reported as part of a national audit.				
9.3 All patients with a sarcoma are offered the opportunity to participate in research projects and clinical trials where these are available.				

* One patient delayed starting treatment

Legend	
	Meets standard or expected performance level (at least 75%)
	Partially achieved, needs improvement or performance level is between 50% and 74%
	Does not meet standard or performance level is below 50%
	Inadequate information available / not assessed

8. Equity for Māori

Health inequity is an avoidable, unnecessary and unjust difference in the health of groups of people (Signal et al 2008). In New Zealand, inequalities exist between Māori and non-Māori in exposure to risk and protective factors for cancer, in incidence and outcomes, and in access to cancer services (Robson and Harris 2007). For sarcoma patients, local data suggest that there is a trend towards poorer outcomes for Māori.

Seven (44%) of 16 patients identified as Māori. Three patients were from Waikato DHB, two from Lakes DHB and two from BOP DHB. Considering the small number of patients in the cohort, a large proportion identified as Māori. The New Zealand cancer registration data also shows that Māori are overly represented in the sarcoma statistics in the four Midland DHBs particularly, Hauora Tairāwhiti and Lakes DHB. NB: Hauora Tairāwhiti had no patients in the cohort who identified as Māori.

In the cohort of 16 patients, four of the five patients who received palliative care as first treatment were Māori. The death rate for sarcoma patients is disproportionately higher for Māori according to the sarcoma mortality data for Midland DHBs for calendar years 2001 to 2012 (refer Table 4). This aligns with the statement above that there is a trend towards poorer outcomes for Māori. Only three patients received surgery. All patients were referred for discussion at an MDM; five to the sarcoma MDM, one to Neuro-oncology MDM and one to Gastrointestinal MDM.

9. Adolescent and young adults (AYA)

A reportⁱ prepared for the AYA Advisory Group and published in May 2013 provides an overview of New Zealand AYA cancer incidence and survival from 2000 to 2009. The report acknowledged that survival improvements during that period had not been seen within the AYA sarcoma population. This appeared to be due to a complex mix of factors including differences in cancer diagnosis, disparity in access to coordinated cancer treatment, lower enrolment in clinical trials, and poorer treatment compliance. This prompted the initiation of a national AYA programme in 2006 to improve the coordination of care for adolescent and young adults with cancer in New Zealand. A regional CNS AYA position was subsequently established at Waikato Hospital.

Two patients under the age of 24 received services from the Waikato CNS AYA service. The service has a regional focus but there are challenges due to geographical distances. The Waikato CNS supports the young people and their family/whānau while they are in hospital and when they return to the community. The service requires liaison with different health providers inside and outside of the Midland region. The AYA CNS has worked on identifying a paediatric shared care nurse and adult oncology liaison nurse at each Midland DHB.

Patient 1 from Bay of Plenty DHB was non curative and was referred for palliative care. The patient received chemotherapy as first treatment within seven days of General Practitioner (GP) HSCAN referral. The AYA CNS was in regular contact with the patient within a week of his referral to secondary services. The AYA CNS worked collaboratively with the patient's consultants at BOP and support services including Canteen, Social Worker, Youth Worker – Member Services, National Travel & Assistance programme, Hospice, Kathryn Kilgour Centre (KKC), as well as offering referrals to Child Cancer Foundation and Cancer Society.

Patient 2 from Lakes DHB was transferred acutely to Waikato Hospital for spinal surgery followed by urgent chemotherapy. The AYA CNS visited the patient while she was in hospital. The patient was discussed at the Waikato neuro-oncology MDM and transferred to Otara Spinal Unit for rehabilitation and chemotherapy. The AYA CNS referred the patient to the Auckland AYA CNS for support whilst in Auckland. The AYA CNS has been in regular contact with the patient and her whānau for the last 10 months. Collaboration was instigated with numerous health providers including Waikato Hospital consultants, CNS' at Waikato, Lakes, Auckland DHB, and CMDHB, Canteen, CMDHB MDM Coordinator, and Cancer Lodge. Other support services provided included: National Travel & Accommodation, occupational therapy, social worker, physiotherapist, dietitian, and wig specialist. The AYA CNS has referred the patient onto a new trial at Starship Hospital.

Improving communication between health providers and working together is vital for the regional AYA service. Although there is a regional database established that records all patient interventions, the inability to access patient records at each Midland DHB can be problematic as the most up to date patient information is not always readily available to the AYA CNS. For example, the CNS had not been informed that one patient in the cohort had passed away.

10. Issues identified from the DHB self-assessment and recommendations

It should be noted that the sarcoma tumour standards are still provisional and few DHBs have had time to implement the standards' monitoring requirements.

The recommendations of the Midland DHB review against the national sarcoma service standards of service provision are:

1. A supra-regional review of the national sarcoma service standards, led by CMDHB and supported by the Midland DHBs should be considered to ensure consistency of methodology.
2. Identify reasons for delays to treatment and develop and implement a plan to address the delays.
3. Detailed pathways and guidance to be developed for sarcoma patients in accordance with the site of their tumour and multiple services responsible for their care.
4. Ensure communication processes and sharing of patient information between clinicians at both Midland DHBs and CMDHB to support continuity of care for patients, including AYA patients.
5. All patients with bone and soft tissue sarcoma of extremities, trunk and retroperitoneum should be presented at a sarcoma MDM (also refer to Multidisciplinary Care; Good Practice Point 4.9).
6. Develop a plan to enable referring and treating clinicians to attend the supra-regional sarcoma MDM.
7. Ensure all patients with fibromatosis are referred to the sarcoma multidisciplinary team (MDT) for management.
8. DHBs to ensure histology of excisional sarcoma specimens are recorded in synoptic format.
9. All referrers such as surgical consultants, pathologists and radiologists to attend the MDM meetings to be recognised as an affiliated member of the sarcoma MDM.
10. Waikato DHB to develop and implement a system to ensure that written reports accompany all imaging sent for review to the supra-regional sarcoma MDM.
11. Waikato DHB to identify the administrative support required for arranging and processing patient information for the supra-regional sarcoma MDM, and implements the necessary support systems.
12. Hauora Tairāwhiti to review the chronic pain service that is currently constrained and develop a plan so patients have access if necessary.
13. Hauora Tairāwhiti to implement Standard 4.2 which requires patients with fibromatosis patients to be managed by a sarcoma multidisciplinary team.
14. As a region, work in partnership with the sarcoma treatment unit at CMDHB to develop a system to support regular monitoring of clinical outcomes.
15. Develop a supra-regional patient information follow-up care booklet that includes the sarcoma follow up regime.
16. Review the proforma to align it with DHB electronic patient management systems to enable relevant clinical information including MDM discussion and outcomes to be captured.
17. Develop a notification process so that all DHBs are informed of available clinical trials and the patients participating in them.
18. Support the development of a nationally agreed dataset related to sarcoma beyond the fields required by the New Zealand Cancer Registry.
19. Some terminology in the standards need to be reviewed e.g. Standard 7.4 requires 'surgery performed by an oncology fellowship-trained orthopaedic surgeon'. The vocational scope on the Medical Council of New Zealand register includes orthopaedic surgery but does not specify oncology as part of the scope of practice <https://www.mcnz.org.nz/>
20. Provide review limitations feedback to the National Pan Tumour Standards Work Group at Ministry of Health.

Appendix 1 – Data points and definitions



Sarcoma Data Points.
xlsx

Appendix 2 - Midland sarcoma cancer data tables

Table1: Cancer Registrations for the Midland DHBs - for ICD 10 codes C40, C41,C48,C49 for calendar year 2001 to 2012

DHB	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Grand Total
Bay of Plenty	3	6	11	9	6	8	12	10	5	16	11	12	109
Lakes	10	4	5	5	3	4	1	2	4	7	2	3	50
Tairāwhiti	1	3	3	6	2	3	2	3	0	1	1	6	31
Waikato	4	5	14	10	17	21	12	15	12	16	16	20	162
Midland	18	18	33	30	28	36	27	30	21	40	30	41	352

Data source: NZ Cancer Registry. Note: data from 2010 is preliminary.

Table 2: Number of cancer registrations for Midland DHBs by Māori and Other for calendar year 2001 to 2012 for ICD code C40,C41,C48,C49.

Diagnosis Year	Bay of Plenty		Lakes		Tairāwhiti		Waikato		Midland
	Māori	Other	Māori	Other	Māori	Other	Māori	Other	
2001	0	3	3	7	1	0	1	3	18
2002	0	6	1	3	1	2	1	4	18
2003	1	10	1	4	1	2	3	11	33
2004	2	7	1	4	3	3	2	8	30
2005	0	6	2	1	1	1	4	13	28
2006	1	7	0	4	1	2	4	17	36
2007	2	10	1	0	1	1	2	10	27
2008	2	8	1	1	2	1	4	11	30
2009	0	5	2	2	0	0	2	10	21
2010	4	12	4	3	1	0	7	9	40
2011	2	9	0	2	0	1	2	14	30
2012	3	9	1	2	1	5	4	16	41
Grand Total	17	92	17	33	13	18	36	126	352

Table 3: Mortality data for the Midland DHBs - for ICD 10 codes C40, C41,C48,C49 for Calendar year 2001 to 2012

DHB	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	Grand Total
Bay of Plenty	2	4	8	6	4	6	6	8	2	10	6	3	65
Lakes	8	3	2	3	2	1	1	1	3	3	2	2	31
Tairāwhiti	0	3	1	4	2	2	1	2	0	1	1	4	21
Waikato	3	2	11	7	13	8	10	8	6	7	8	10	93
Grand Total	13	12	22	20	21	17	18	19	11	21	17	19	210

Data source: NZ Cancer Registry. Note: data from 2012 is preliminary.

Table 4 : Sarcoma mortality data for Midland DHBs for calendar 2001 to 2012 by Māori and others by ICD Codes C40,C41,C48,C49

Diagnosis Year	Bay of Plenty		Lakes		Tairāwhiti		Waikato		Midland
	Māori	Other	Māori	Other	Māori	Other	Māori	Other	
2001	0	2	2	6	0	0	0	3	13
2002	0	4	1	2	1	2	0	2	12
2003	1	7	1	1	1	0	2	9	22
2004	1	5	0	3	2	2	2	5	20
2005	0	4	1	1	1	1	4	9	21
2006	1	5	0	1	1	1	0	8	17
2007	1	5	1	0	0	1	1	9	18
2008	2	6	0	1	1	1	3	5	19
2009	0	2	2	1	0	0	1	5	11
2010	3	7	1	2	1	0	4	3	21
2011	1	5	0	2	0	1	0	8	17
2012	1	2	0	2	1	3	3	7	19
Grand Total	11	54	9	22	9	12	20	73	210

Appendix 3 – DHB self-assessment tools



17.12.15.BOP DHB



17.12.15.Lake DHB



17.12.15 Tairāwhiti



17.12.15. Waikato

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