National Standards for Sarcoma Services

2009
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1. INTRODUCTION TO THE NATIONAL CANCER STANDARDS

1.1 The Healthcare Standards for Wales\(^1\) set out the Welsh Assembly Government’s common framework of healthcare standards to support the NHS and partner organisations in providing effective, timely and quality services across all healthcare settings. The Healthcare Standards are used by Healthcare Inspectorate Wales as part of their processes for assessing the quality, safety and effectiveness of healthcare organisations across Wales.

1.2 To complement the Healthcare Standards the National Cancer Standards define the core aspects of the service that should be provided for cancer patients resident in Wales. Planning departments should use these Standards to form the basis of care for Welsh residents whether provided by Welsh or English providers. The Standards should be used in conjunction with other requirements for example from the Health and Safety Executive, NHS, Royal Colleges and the National Institute for Health and Clinical Excellence [NICE] recommendations and guidelines that cover patient care, facilities and staff. Trusts may provide or aim to provide additional services and work to more rigorous and/or wide-ranging standards. This should be encouraged.

1.3 A series of National Cancer Standards were published in 2005. This latest set of standards for the management of patients with sarcoma follow the format of the 2005 standards and incorporates the key principles recommended by Improving Outcomes Guidance from NICE in 2006\(^2\).

1.4 These new standards are developmental and will involve a new model of service delivery. It is recognised that such changes take time and resource to implement and it will therefore be important that the process of implementation is planned to start as soon as possible. In developing the service model, planning departments will need to take account of the NICE service guidance for Children and Young People with Cancer\(^3,4\). Commissioners and providers, as Cancer Network stakeholders, will need to work with each Cancer Network core team of Lead Clinician and Director to plan and deliver the service changes required.

1.5 Ongoing implementation of the Cancer Information Framework\(^5\) will support the implementation of these new Standards as it focuses on the clinical information required for cancer teams and discussed at the team meeting.

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3 Improving Outcomes in Children and Young People with Cancer. National Institute of Health and Clinical Excellence. 2005
4 National Cancer Standards, Children and Young People with Cancer, Welsh Assembly Government. In preparation
1.6 It is recognised that these standards will be published at a time of significant change in NHS Wales and DHSS and, as a result, all the National Cancer Standards will be re-issued later in 2009 to clarify the responsible organisations for specific standards. These will be posted on the Welsh Assembly Government’s web site.
2. METHODOLOGY

2.1 The Welsh Assembly Government has tasked the Cancer Services Coordinating Group [CSCG] to oversee the development of National Cancer Standards. For this latest set of standards for the management of sarcoma patients the CSCG Standards Group set up an Advisory sub group involving clinical and patient experts from each of the Welsh Cancer Networks and a neighbouring English Bone Cancer Treatment Centre and representation from Health Commission Wales. Membership is at Appendix 1. Work commenced in September 2006 with a review of the generic National Cancer Standards issued in 2005. Additional standards have been added that take account of the recommendations of ‘Improving Outcomes in People with Sarcoma’ published by NICE in 2006.

3. FORMAT

3.1 The standards are presented as a series of key Topics with one or more objectives and specific standards. These address the organisational and service requirements that are key to effective delivery of care and the main stages in the patient journey.

3.2 Within each Topic, a Rationale is presented that provides the context to the specific objectives and standards that follow. Where a standard applies to both bone and soft tissue sarcomas the clinical team is referred to as the sarcoma supra network specialist multidisciplinary team (MDT). Where there are specific requirements for bone or soft tissue sarcomas these are indicated in the text.

3.3 Mapping to the Healthcare Standard/s has been undertaken at the level of the objective. The associated Healthcare Standards are listed after the rationale for each objective.

3.4 Attached to each standard are monitoring criteria. The monitoring criteria are included in this document as indicative of the monitoring required. A separate and more detailed self assessment monitoring tool will be developed and piloted in 2010 for the 2009/10 financial year. 


4. INTRODUCTION TO SARCOMA

4.1 Sarcomas are rare cancers and cover two broad categories namely bone and soft tissue. These rare cancers are estimated to account for 0.2% (bone) and 1% (soft tissue) of all malignant tumours. Data on registrations of sarcoma excluding rhabdomyosarcoma and osteosarcoma, provided by the Welsh Cancer Intelligence and Surveillance Unit, are summarised in Table 1 with data definitions and morphology codes provided in Appendix 2. The annual registrations of bone sarcomas and rhabdomyosarcomas are much lower than for the other soft tissue sarcomas. Considering all age groups, on average 5 rhabdomyosarcomas and 9 osteosarcomas respectively were registered for each year (2000 – 2005).

Table 1 Incidence of Sarcoma, excluding rhabdomyosarcoma and osteosarcoma in Wales in 2000 to 2005

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<tr>
<th>Persons</th>
<th>2000</th>
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<th>2002</th>
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<td>166</td>
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The data presented include carcinosarcoma which is a malignant tumour that is a mixture of carcinoma (cancer of epithelial tissue, which is skin and tissue that lines or covers the internal organs) and sarcoma (cancer of connective tissue, such as bone, cartilage, and fat).
The data on sarcoma registrations, presented in Table 1, have also been analysed by Cancer Network and are presented in Tables 2, 3 and 4.

Table 2 – Sarcoma cases, excluding rhabdomyosarcoma and osteosarcoma registered in the North Wales Cancer Network in 2000 to 2005

<table>
<thead>
<tr>
<th>Persons</th>
<th>2000</th>
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Table 3 Sarcoma cases, excluding rhabdomyosarcoma and osteosarcoma registered in the South West Wales Cancer Network in 2000 to 2005

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Table 4 – Sarcoma cases, excluding rhabdomyosarcoma and osteosarcoma registered in the South East Wales Cancer Network in 2000 to 2005

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4.2 NICE guidance recommends that a soft tissue sarcoma multidisciplinary team (MDT) should serve a population of 2 to 3 million people and a bone sarcoma MDT 7 to 8 million. This is based on the minimum numbers of patients necessary to justify establishment of an MDT and on-going maintenance of specialist skills. The service model required is one of a limited number of supra network MDTs across England and Wales with the sarcoma MDT based either in a single hospital or several geographically close or affiliated hospitals constituting the sarcoma treatment centre. For Wales, the population in South Wales would be adequate to support a soft tissue sarcoma MDT whilst in North Wales it is expected that patients will continue to be referred to a neighbouring sarcoma MDT in England. Services for bone cancers are already commissioned on this basis via the National Specialist Commissioning Advisory Group (NSCAG). For supra network sarcoma MDTs situated outside Wales but serving Welsh patients the MDT lead clinician must satisfy those planning the service for Welsh patients that the MDT complies with the National Cancer Standards for Sarcoma.

4.3 As with all other NICE service guidance, the central role of the MDT in managing the care of all cancer patients is a basic requirement and this is reflected in this new set of National Cancer Standards. However, for sarcoma the role of the MDT is extended to specifically lead on and support a managed clinical network. The diverse nature of sarcoma means that there will be a need for collaboration between cancer site MDTs and the sarcoma MDT and agreed, well defined referral criteria for those patients requiring surgery at the sarcoma treatment centre. The sarcoma MDT will be responsible for the overall patient pathway and agree the arrangements for the delivery of specific aspects of care involving other cancer site MDTs and including radiotherapy and chemotherapy as necessary. Collaboration between clinical teams is summarised in Appendix 3.

4.4 These National Cancer Standards, in-line with the NICE guidance, reflect the division of the most common soft tissue sarcomas into the following three categories.

- Limb, limb girdle and truncal soft tissue sarcomas
- Retroperitoneal and pelvic soft tissue sarcomas
- Soft tissue sarcomas requiring shared management with other site specialist MDTs.

4.5 Patients with suspected sarcoma need to access a rapid process to diagnosis and treatment. For patients with localised disease at diagnosis, there is a clear relationship between survival and size of tumour. Early referral and improvements in the diagnostic pathway are therefore expected to have most significant impact on outcomes. Expertise in both radiology and histopathology are central to accurate diagnosis and subsequent treatment. Most patients with suspected sarcoma will in fact have benign disease. For the minority found to have malignant disease rapid referral to a specialist team is

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7 NICE Guidance on Cancer Services. Improving Outcomes for People with Sarcoma, 2006
essential to achieve the best outcome. A pathway for patients referred as urgent with suspected cancer is provided in Appendix 4.

4.6 Patient access to clinical trials is a generic requirement of the National Cancer Standards. For rare cancers such as sarcoma, commissioners will need to ensure that the service model agreed supports participation in European clinical trials. These multinational trials require a clearly identified clinical team that is able to enter a minimum number of patients per year.

4.7 The standards detailed in this document refer to the management of sarcoma in adults. The National Cancer Standards for Children and Young People will detail the requirements for the management of this group of patients, including those with sarcoma, and are expected to be published later in 2009. Reflecting this further work will be required by clinicians and planning departments to establish an appropriate interface between those MDTs that share a responsibility and function for the same patient.

Key References

- The Joint Collegiate Council for Oncology. Principles to underpin the delivery of radiotherapy and chemotherapy services to NHS cancer patients. Royal College of Physicians and the Royal College of Radiologists. 2007.
- National Cancer Standards for Children with Cancer (in preparation)
- Improving Outcomes in Children and young people with cancer, Nice Institute of Health and Clinical Excellence [2005]
- NICE Guidance for Supportive and Palliative Care [2004]
- The Use of Computed Tomography in the Initial Investigation of Common Malignancies. Royal College of Radiologists [1994].
TOPIC: ORGANISATION

**OBJECTIVE 1: TO STRUCTURE CANCER NETWORKS SUCH THAT THEY BRING TOGETHER KEY STAKEHOLDERS IN BOTH COMMISSIONING AND PROVIDING CANCER CARE, WITH AN OPEN AND TRANSPARENT MANAGEMENT STRUCTURE.**

**Rationale:** A Cancer Network is an organisational association between primary, secondary, tertiary and voluntary sector providers, social services and service planners with care delivered by multidisciplinary clinical teams within a geographic area. As sarcoma patients will need to be managed by a limited number of supra network specialist multidisciplinary teams (MDT) across England and Wales it will be important that effective communication is established at all levels to ensure continuity of care and appropriate service developments. Regular meetings between service planners, Cancer Network and Trust/s that host the supra network sarcoma team will facilitate review of service provision and ensure uniform standards of care are applied. Cancer Networks and service planners will need mechanisms in place to action reorganisation of services where appropriate.

The host Network of the supra network sarcoma specialist MDT should produce a Services Development Plan [SDP] that needs to involve all stakeholders.

The Chief Executive of the organisation on whose premises care is being delivered remains the accountable officer for the quality of care. Where the supra network sarcoma MDT provides care to more than one organisation, clear agreements will be required between organisations about how clinical governance responsibilities are to be carried out. In relation to team working, the recommendations made at the team meeting are advisory, and the responsibility for clinical decisions and actions always rests with the senior clinician under whose care the patient is at that point of their journey.

Associated Healthcare Standards that map to Objective 1 are: 2,11,12,25,27-29 and 31

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1.1 STANDARD
The management arrangements and accountability for the host Cancer Network should be documented.

MONITORING CRITERIA

1.1 The establishment agreement detailing host Cancer Network management accountability is held by the Regional Office or equivalent.

1.2 STANDARD

Agreements on clinical governance lines of accountability for the supra network specialist sarcoma MDT and its designated, associate clinical teams should be clearly documented if provided by more than organisation.

MONITORING CRITERIA

1.2 Documentation is available detailing agreements on lines of accountability for clinical governance.

1.3 STANDARD

The host Cancer Network in collaboration with its stakeholders should produce a Service Development Plan for the supra network sarcoma MDT, which takes account of the requirements of the National Cancer Standards for Wales and is updated annually.

MONITORING CRITERIA

1.3
a. The host Cancer Network SDP for the supra network sarcoma MDT, is approved by the Network Board and all stakeholders of the service and is available for external peer review
b. The host Cancer Network reports to the Regional Office or equivalent on implementation of the service plan
OBJECTIVE 2: CARE PROVIDED BY TEAMS SHOULD BE WELL CO-ORDINATED TO PROVIDE AN EFFICIENT, EFFECTIVE SERVICE TO PATIENTS.

Rationale: Cancer care involves a number of different specialists working together as a team. To effectively work as a team, particularly across Departments within a Trust, coordination and clinical leadership is required.

The Trust Cancer Lead Clinician [TCLC] is accountable to the Trust Board via the Medical Director or Executive Lead for cancer and is responsible for identifying requirements to ensure cancer teams comply with the cancer standards. The TCLC needs to be supported by a senior management team.

The supra network sarcoma MDT Lead Clinician must report to the TCLC of the Trust/s where services are provided and is responsible for identifying requirements to ensure the team complies with the National Cancer Standards for Sarcoma. For supra network sarcoma MDTs situated outside Wales but serving Welsh patients the MDT lead clinician must satisfy those planning the service for Welsh patients that the MDT complies with the National Cancer Standards for Sarcoma.
Associated Healthcare Standards that map to Objective 2 are: 11,12,24,27, and 28
2.1 STANDARD

Each Trust should have an identified Cancer Management Team that reflects the manner in which cancer is treated across the management structures. Each team should include at a minimum
a. A Trust Cancer Lead Clinician
b. A designated Lead Manager
c. The lead Cancer Co-ordinator
d. A nominated Executive Lead
e. A designated Lead Cancer Nurse/Allied Health Professional

MONITORING CRITERIA

2.1 Documentation is available detailing names and designation and a description of how the management team relate to internal management structures.

2.2 STANDARD

The TCLC should be appointed by the Trust Chief Executive and have recognised dedicated sessional time with administrative and senior management support.

MONITORING CRITERIA

2.2 Job plan details role, sessional time and management support for TCLC.

2.3 STANDARD

The TCLC should attend both Trust and Network cancer meetings as appropriate.

MONITORING CRITERIA

2.3 Detail available in Job Plan.

2.4 STANDARD

The supra network sarcoma MDT lead clinician should be confirmed by and have clinical responsibility to the host Cancer Network Board in consultation with their respective TCLC and Medical Director or Executive Lead.

MONITORING CRITERIA

2.4 Host Network documentation is available.
2.5 STANDARD

The supra network sarcoma MDT lead clinician should
a. Have overall responsibility for team working, the team meeting, clinical audit and communication with referring units
b. Provide clinical advice and co-ordinate any modernisation projects that are associated with working of the MDT
c. Have dedicated administrative and secretarial assistance to support the functioning of the MDT
d. Attend both Trust and Network cancer meetings as appropriate

MONITORING CRITERIA

2.5
Responsibility detailed in job plan with evidence provided of
a. Regular team meetings with attendance register
b. Clinical audit undertaken
c. Service modernisation e.g. process mapping and capacity/demand studies
d. Dedicated administrative and secretarial staff
e. Attendance at Trust and Network meetings

2.6 STANDARD – soft tissue sarcoma

The lead clinician of the supra network sarcoma MDT managing soft tissue sarcomas should work with service planners and local cancer diagnostic services to formally designate diagnostic clinics and agree referral pathways to the MDT.

MONITORING CRITERIA

2.6 Documentation to support this arrangement is provided by service planners and local cancer diagnostic services.

2.7 STANDARD - soft tissue sarcoma

The supra network sarcoma MDT managing soft tissue sarcomas should ensure staff working in designated diagnostic clinics are trained appropriately and that work undertaken is audited.

MONITORING CRITERIA

2.7 Evidence is provided by service planners that the supra network sarcoma MDT details training requirements and results of audit of the diagnostic work undertaken.
2.8 STANDARD

The supra network sarcoma MDT Lead Clinician should ensure the team,
 a. Provides rapid diagnostic and assessment services for patients referred with either suspected bone or soft tissue sarcoma
 b. Has formal working arrangements with referring designated diagnostic clinics where the supra Network sarcoma MDT manages patients with suspected soft tissue sarcoma
 c. Provides information, advice and support to patients
 d. Liaises with the primary care team and ensures clinic letters reach the patient’s GP within a week of the clinic.

MONITORING CRITERIA

2.8 The supra network sarcoma MDT Lead Clinician to provide evidence that there is an active, written, working policy detailing the requirements of the standard.

2.9 STANDARD

All patients with sarcoma should be allocated a key worker and this should be confirmed by the MDT managing care at each point in the care pathway. This should be done at the MDT meeting where the management plan is agreed. The key worker should contact the patient within 7 days of being first allocated to a new patient.

MONITORING CRITERIA

2.9
 a. Each MDT to detail arrangements for ensuring that a key worker is assigned to each patient with a clearly defined role that includes liaising with the primary care team.
 b. The key worker to provide evidence from audit that initial contact with each new patient was within 7 days.

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9 The key worker is the person who, with the patient’s consent, takes the role of coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice. The key worker may come from any of the disciplines involved in the MDT (standard 4.2).
2.10 STANDARD

The Trust hosting the supra network sarcoma MDT should adopt a process, involving representatives from the host Cancer Network and associated stakeholder organisations, by which the Trust Cancer Management Team report to the Trust at least annually on compliance with the National Cancer Standards cancer standards.

MONITORING CRITERIA

2.10
a. Outline of process for annual assessment.
b. Minutes of Trust Board meeting covering report on compliance to standards.
TOPIC: PATIENT-CENTRED CARE

OBJECTIVE 3: TO ENSURE THAT PATIENTS AND OR THEIR CARERS HAVE SUPPORT AND ALL THE INFORMATION THEY REQUIRE REGARDING THE DIAGNOSIS, TREATMENT OPTIONS AND TREATMENT CARE PLAN.

Rationale: Appropriate information, whether provided via face-to-face communication or in written form is required to support patients and their carers throughout the cancer journey. All healthcare professionals need to be sensitive to potential communication problems with information being tailored to the needs of individual patients. Patients need appropriate information to make informed choices about their treatment. Special training can improve communication skills in general and will provide for effective communication of the diagnosis, treatment options and treatment care plan.

The psychological needs of patients are often not addressed. People cope with distressing circumstances in a number of ways however for those facing the diagnosis of initial or recurrent cancer a number will experience significant levels of anxiety and depression and may benefit from specific psychological or psychiatric therapy.

Associated Healthcare Standards that map to Objective 3 are: 4, 6, 7, 8, and 10

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10 National Service Framework No 1. NHS Cancer Care in England and Wales, Commission for Health Improvement, 2001
3.1 STANDARD

The supra network sarcoma MDT should agree an operational policy regarding
a. Communication between the MDT and hospital referring teams
b. Communication between members of the team
c. Communication between the team members and the patient and their carers
d. Communication skills training for team members with direct patient contact
   especially those involved in breaking bad news
e. Adequate time for patients to consider treatment options

MONITORING CRITERIA

3.1 Detail of communication policy to include
a. Evidence of communication skills assessment
b. Evidence that the MDT has considered the views of its patients or carers regarding
   the appropriateness of communication

3.2 STANDARD

Written information in a language and format appropriate to the patient should be
offered to each new cancer patient. This should cover
a. General background information about the specific cancer.
b. Detail of treatment options, specific local arrangements including information about
   the supra network sarcoma MDT and support services and whom the patient should
   contact if necessary.
c. Details of self-help/support groups and other appropriate organisations.

MONITORING CRITERIA

3.2 The MDT to provide evidence that information covers
a. General background information about the specific cancer
b. Detail of treatment options, specific local arrangements including information about
   the MDT and support services and whom the patient should contact if necessary
c. Details of self-help/support groups and other appropriate organisations
d. Identify the source of information e.g. Sarcoma UK
e. When was it last reviewed/ updated
f. What languages are provided
3.3 STANDARD

The supra network sarcoma MDT should nominate a person to be responsible for ensuring written information is offered to all new patients.

MONITORING CRITERIA

3.3 Name of responsible person and detail of provision of written information within the communication policy.

3.4 STANDARD

A designated person/s should be responsible for ensuring that written information is generally available in appropriate wards/outpatient areas and is checked and replenished when necessary.

MONITORING CRITERIA

3.4 Name of responsible person.

3.5 STANDARD

Trust/s hosting the supra network sarcoma MDT should ensure all communication with patients with special needs in relation to language, culture and physical or learning disabilities is addressed.

MONITORING CRITERIA

3.5 Detail audit of Trust/s communication policy.

3.6 STANDARD

There should be access to a private room or area where patients and or their carers can discuss the diagnosis in conditions of adequate privacy with the appropriate member of the supra network sarcoma MDT or soft tissue sarcoma designated diagnostic clinic.

MONITORING CRITERIA

3.6 Details are provided of facilities available.
3.7 STANDARD

The supra network sarcoma MDT should ensure that children and young people with sarcoma have access to care and facilities that address their age–related needs.

MONITORING CRITERIA

3.7 Detail access arrangements for children and young people to care and facilities that address their age-related needs.

3.8 STANDARD

The supra network sarcoma MDT should ensure that patients are assessed for ongoing support following treatment for sarcoma. Specifically this should address,

a. Psycho-social support
b. Spiritual support
c. Rehabilitation
d. Prosthetics

MONITORING CRITERIA

3.8 The supra network sarcoma MDT to detail the arrangements for assessment of ongoing support following treatment.

3.9 STANDARD

Patients found to have significant levels of anxiety and or depression should be offered prompt access to specialist psychological or psychiatric care capable of providing level 3 and level 4 psychological interventions as defined in the NICE Supportive and Palliative Care Guidance.

MONITORING CRITERIA

3.9 Detail access arrangements
3.10 STANDARD

Cancer Networks and service planners should facilitate a Network wide approach to psychological support services as recommended in the NICE Supportive and Palliative Care Guidance.

MONITORING CRITERIA

3.10 Cancer Networks/service planners to detail access arrangements.
TOPIC: MULTIDISCIPLINARY TEAM

OBJECTIVE 4: TO ENSURE THAT CARE FOR PATIENTS WITH SARCOMA IS PROVIDED BY A SPECIALIST MULTIDISCIPLINARY TEAM.

Rationale: Patient care needs to be provided by a team of specialists with a range of expertise within different specialties to ensure provision of high quality care. For soft tissue sarcomas, Improving Outcomes Guidance recommends a designated network of diagnostic clinics with referral on to a supra network sarcoma MDT as the configuration to effectively utilise resources to achieve best clinical outcomes for patients living at a distance from the MDT. Patients with suspected bone sarcoma follow a different pathway and should be referred directly, according to protocols, to the sarcoma supra network team with expertise in bone sarcomas. Certain supra network sarcoma MDTs may manage both bone and soft tissue sarcomas.

A programme of national clinical audit, defining performance against the National Cancer Standards, will provide service planners, the public, and the Welsh Assembly Government with the information needed to maintain and improve cancer services. Identifying and rewarding areas of strength are important for morale and motivation. By developing an effective audit programme, Cancer Networks hosting supra network sarcoma MDTs can define whether any weaknesses are due to organisational factors or to resource issues which is a distinction that is of the utmost importance in seeking the appropriate remedy.

Associated Healthcare Standards that map to Objective 4 are: 2,3,11,12,21,22,24,27,28
4.1 STANDARD

All clinicians treating soft tissue sarcoma should be designated members of a supra network multidisciplinary team managing at least 100 new soft tissue sarcomas a year. If the supra network sarcoma MDT also manages the care of patients with bone sarcoma it should see at least 50 new patients with bone sarcoma per year and at least 100 new patients with soft tissue sarcoma per year.

MONITORING CRITERIA

4.1 Data on new patients per year to be provided by the supra network sarcoma MDT

4.2 STANDARD

The supra Network sarcoma MDT should include the following specialists with a particular and declared interest in sarcoma, all of whom have time allocated in their job plan to attend the MDT meeting. There should be two members from each specialty to ensure specialist cover at all times.

a. Specialist Surgeons involved in the resection of soft tissue sarcoma spending at least 5 clinical sessions involved in managing sarcomas\textsuperscript{11}

b. Specialist Oncologists, with at least one being a clinical oncologist, who have a specialist interest in musculoskeletal\textsuperscript{12} oncology with 3 clinical sessions involved in managing sarcomas

c. Specialist Radiologists with a special interest in musculoskeletal/oncological imaging

d. Specialist Sarcoma Pathologists with a specialist interest in musculoskeletal/oncological pathology\textsuperscript{13}

e. Clinical nurse specialists

f. Physiotherapists specialising in musculoskeletal or post reconstruction care

g. Representatives\textsuperscript{14} of the Specialist Palliative Care Team

h. MDT co-ordinator/data clerk

\textsuperscript{11} Once a specialist MDT is established it is expected that activity will increase requiring a time commitment of 5 clinical sessions as outlined in NICE guidance. The number of sessions are based on theatre lists, out patient clinics, the MDT meeting and clinical audit.

\textsuperscript{12} Expertise in musculoskeletal sarcomas applies to those MDTs managing both soft tissue and bone sarcomas. MDTs only managing soft tissue would not be expected to have expertise or manage bone sarcomas and vice versa.

\textsuperscript{13} Where there is only one sarcoma specialist pathologist (SSP) formal links with an SSP in another centre must be established for consultation, audit and cross-cover.

\textsuperscript{14} One representative to be a consultant in palliative medicine
MONITORING CRITERIA

4.2
a. Detail names of MDT clinical members and their sessional commitment to the MDT (DCC or SPA) confirmed by a copy of their current job plan. Evidence of appraisal in the specialty and the settings of outcomes related to sarcoma.
b. Surgeons to detail training and expertise in the resection and reconstruction of the defect
c. Histopathologists to detail evidence of participation in histopathological EQA for soft tissue sarcoma and/or bone sarcoma
d. Detail evidence that expert cover is provided when a core MDT member is absent.
e. Detail arrangements for coordination and secretarial support.

4.3 STANDARD

The supra network sarcoma MDT should have contact and appropriate access to the following support staff/services,

a. specialist allied health professionals
b. paediatric oncologist
c. specialist nurses
d. affiliated medical or clinical oncologist from linked cancer centre
e. affiliated diagnostic service clinicians
f. other professionals including orthopaedic, thoracic, plastic, head and neck, gynaecological, gastrointestinal, vascular surgeons and clinical psychologists
g. interventional analgesia services
h. lymphoedema specialists

MONITORING CRITERIA

4.3 Detail access arrangements to the support staff/services and provide names of specialists designated to work with/advise the MDT.
4.4 STANDARD

A weekly team meeting should form the basis of clinical management and inter-team communication

MONITORING CRITERIA

4.4
a. Detail team meetings held and attendance of individual team members.
b. Provide confirmation that the MDT documented working arrangements include discussion at the MDT meeting of all newly diagnosed patients, all patients following tumour resection and all patients with first recurrence.

4.5 STANDARD

The supra Network sarcoma MDT should agree a means of rapid communication to facilitate clinical management of appropriate cases should they present after the regular team meeting.

MONITORING CRITERIA

4.5 Detail arrangements for discussion of cases presenting between team meetings

4.6 STANDARD

The supra network sarcoma MDT and all associated MDTs should ensure that all relevant sections of the all Wales Cancer Data Set are completed for each new patient diagnosed with sarcoma so that the MDT is able to participate in national/UK clinical audits as specified by the CSCG and the Healthcare Quality Improvement Partnership.

MONITORING CRITERIA

4.6 Detail the number of new sarcomas referred to the MDT [or members of the team] per year and recorded on the all Wales Cancer Data Set.

4.7 STANDARD

Trusts should ensure that the expected registration of incidence, using the Patient Episode Database for Wales [PEDW] data, is submitted to the Welsh Cancer Intelligence and Surveillance Unit [WCISU] within 3 months of calendar year end.

MONITORING CRITERIA
4.7 WCISU to monitor registrations received against expected registrations
TOPIC: INITIAL INVESTIGATIONS AND TIMES TO TREATMENT

OBJECTIVE 5: PATIENTS WITH SARCOMA SHOULD BE REFERRED, DIAGNOSED AND TREATED PROMPTLY.

**Rationale:** There is evidence that higher survival rates are associated with detection and treatment of early stage, less advanced disease. Therefore it is important to support public awareness of symptoms that may indicate cancer and ensure GPs refer promptly to appropriate cancer teams for assessment and treatment if necessary. There is also evidence that patient anxiety contributes to worse clinical outcomes. Prompt access to see a specialist will lessen this anxiety. Patients and/or their carers may want to discuss the diagnosis and treatment with their GPs. The GP needs adequate information transferred rapidly in order to support such patients at a time of great distress.

Initially efforts have been directed to ensure that patients referred urgently with suspected cancer are offered an appointment with a member of the MDT within 10 working days. This now needs to be built upon and extended to ensure that patients are not only seen promptly but also, should they be found to have cancer, should complete diagnostic investigations and start treatment within an accepted time frame that applies generally to all cancers. Shorter waiting times are required for specific cancers and procedures where clinically indicated. The focus in setting waiting times targets is to work towards continual improvement. It is recognised that an MDT may already meet the new targets and such performance needs to be maintained and further improved. Where waiting times are longer than now specified the MDT should work to reduce them to the target.

Associated Healthcare Standards that map to Objective 5 are: 3, 6, 8, 11, 12, 25, and 28.

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16 Urgent Referrals of Patients with Suspected Cancer. NICE.
5.1 STANDARD – Soft tissue sarcoma

Diagnostic clinics should be designated by the sarcoma treatment centre and run by a radiologist with a special interest in soft tissue sarcoma. The clinic should provide ultrasound imaging, biopsy and initial counselling and information for patients. Local initial histopathology should be reported to the diagnostic clinic, and to the soft tissue sarcoma treatment centre where sarcoma is diagnosed or suspected, within one week of biopsy.

MONITORING CRITERIA

5.1 Service planners to provide details of the designated sarcoma treatments centre and associated diagnostic clinics. The sarcoma treatment centre to provide details of the referral pathway and services provided.

5.2 STANDARD – Soft tissue sarcoma

Biopsy of patients with possible soft tissue sarcoma should only be carried out by a member of the supra network soft tissue sarcoma MDT or designated diagnostic clinic run under its auspices. Biopsy of patients with possible bone sarcoma should only be carried out at a bone tumour treatment centre.

MONITORING CRITERIA

5.2 Audit of histopathological reports diagnosing sarcoma to identify by whom and where biopsies were conducted.

5.3 STANDARD

Where retroperitoneal or pelvic soft tissue sarcomas is suspected, biopsy should be carried out by the supra network sarcoma MDT surgical team.

MONITORING CRITERIA

5.3 Audit of proportion of patients with retroperitoneal or pelvic soft tissue sarcomas referred to a supra Network sarcoma MDT with a specialist surgeon.
5.4 STANDARD

All patients requiring shared care should be discussed by the supra network sarcoma MDT. Where shared management involving children or young adults\textsuperscript{17} is required the appropriate site specific MDT, the MDT for children or the MDT for teenagers and young adults should be responsible for liaising with the supra Network sarcoma MDT to discuss the management plan before treatment commences.

MONITORING CRITERIA

5.4 Audit of proportion of patients requiring shared management whose management was discussed at the supra Network sarcoma and site specific MDT meetings.

5.5 STANDARD

The supra network sarcoma MDT should agree referral guidelines for use in primary and secondary care and covering both patients with suspected sarcoma and patients diagnosed following excision of a lump initially thought to be benign. The guidelines should also cover referral for tumours of borderline malignancy such as fibromatosis.

MONITORING CRITERIA

5.5 The supra network sarcoma MDT lead clinician to confirm that
a. Referral guidelines follow NICE guidance for suspected sarcoma.
b. There is an agreed referral pro forma in place

c. A copy of the referral guidelines agreed by the supra network MDT is held by the Network Directors
d. Cancer Network Directors have made these referral guidelines available within their Network.

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\textsuperscript{17} Shared management will be required for gynaecological sarcomas, head and neck sarcomas, chest wall/intrathoracic sarcomas, skin sarcomas, central nervous system sarcomas, gastro-intestinal stromal tumours and adult type soft tissue sarcomas arising in children.
5.6 STANDARD

Written referral pathways should be drawn up by the supra network MDT in collaboration with primary care which detail the patient journey from whichever point patients access the system.

MONITORING CRITERIA

5.6 Confirmation that Network Directors have a copy of the agreed referral pathways.

5.7 STANDARD

Cancer Networks should ensure that referral pathways to the supra network sarcoma MDT are adhered to particularly where pathways cross Trust or Network boundaries.

MONITORING CRITERIA

5.7 Network Directors to provide evidence of review of agreed referral pathways.

5.8 STANDARD

Patients presenting to their GP with symptoms within the criteria for suspected soft tissue sarcoma should be referred as ‘urgent suspected cancer’ to either a designated diagnostic clinic linked to the supra network sarcoma MDT or directly to the supra network sarcoma MDT. Patients with suspected bone sarcoma should be referred directly in accordance with agreed protocols to the supra network MDT managing bone sarcomas.

MONITORING CRITERIA

5.8 Detail audit of referral process
5.9 STANDARD

Patients referred as urgent suspected cancer by the GP to a designated diagnostic clinic or directly to a member of the supra network sarcoma MDT should, if diagnosed with sarcoma, start definitive treatment within 2 months of the receipt of the referral at the diagnostic clinic or hospital.

MONITORING CRITERIA

5.9 Waiting times from receipt of confirmed ‘urgent suspected cancer’ referrals to start of definitive treatment

5.10 STANDARD

The GP should be informed if the specialist downgrades an urgent suspected cancer referral to non-urgent.

MONITORING CRITERIA

5.9 Detail audit of downgraded referrals

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18 This only applies where soft tissue sarcoma is suspected by the GP
5.11 STANDARD

Confirmation of the diagnosis, treatment plan and contact details of the key worker should reach the GP within 24 hours of the patient being informed.

MONITORING CRITERIA

5.11 Detail audit of timescale for required information to reach the GP.

5.12 STANDARD

When diagnosed with a sarcoma, patients not already included as an urgent suspected cancer referral should start definitive treatment within 1 month from diagnosis regardless of referral route.

MONITORING CRITERIA

5.12 This standard is monitored centrally.

5.13 STANDARD

Patients undergoing radiotherapy should be treated within the maximum waiting times as recommended by the Joint Collegiate Council for Clinical Oncology [JCCO].

MONITORING CRITERIA

5.13 Detail audit of waiting times from receipt of the request form by the radiotherapy department, or verbal request, to the date of the first radiotherapy fraction
**TOPIC:** DIAGNOSIS, STAGING AND TREATMENT

**OBJECTIVE 6: PATIENTS WITH SARCOMA SHOULD BE DIAGNOSED, STAGED AND TREATED PROMPTLY AND IN-LINE WITH BEST PRACTICE**

**Rationale:**
Clearly defined clinical policies will improve the consistency and equity of care for these patients and the appropriate use of resources. For patients with sarcoma, NICE guidance recognises that early detection of recurrent disease and hence follow up is of benefit.

There is good evidence from clinical trials that patients treated within a trial setting fare better than those treated outside of a trial setting, and this is thought to be due in large measure to the benefits of treatment according to documented protocols, with details of action to be taken in case of adverse affects, dose escalation, etc. Standardisation of protocols across the supra Network will enable outcome assessment to be performed in a uniform manner, and staff gain expertise by concentrating on a lesser number of well-defined protocols.

In relation to rare cancers such as sarcoma it is essential that the supra Network MDT participates in European and other National or multinational clinical trials.

Associated Healthcare Standards that map to Objective 6 are: 3,11,12,28
6.1 STANDARD

Clinical management of patients including follow-up should follow written agreed clinical policies, in-line with the NICE service guidance and national clinical guidelines. These clinical policies should be developed by the supra network sarcoma MDT.

MONITORING CRITERIA

6.1 Documentation detailing the agreed clinical policies including imaging for high risk patients on follow up and access to genetic counselling is provided by the supra network sarcoma MDT lead clinician.

6.2 STANDARD

Each supra network sarcoma MDT should provide a written programme of audit to assess adherence to clinical policies.

MONITORING CRITERIA

6.2 Documentation of the MDT audit programme of clinical policies, results and resulting action plans is provided by the supra network sarcoma MDT lead clinician.

6.3 STANDARD

Patients should be given the opportunity to enter all approved clinical trials for which they fulfil the entry criteria. If a specific trial is not available the patient should be informed and given the choice of opting for treatment with a specialist sarcoma MDT participating in the required trial.

MONITORING CRITERIA

6.3 The supra network sarcoma MDT lead clinician to provide documentation of all open trials and numbers of patients entered per trial per year.
**OBJECTIVE 7: THE MDT SHOULD HAVE ACCESS TO HIGH QUALITY IMAGING SERVICES.**

**Rationale:** Imaging is important in the diagnosis and staging of patients with suspected sarcoma. Waits for imaging investigations may introduce significant delays before clinical diagnosis is confirmed and appropriate treatment can be instituted. This is particularly true for complex investigations. A major problem in diagnosing soft tissue sarcoma is the difficulty in distinguishing the large number of benign tumours from the much smaller number of malignant tumours by clinical judgement. As a result the key objective is for any patient with suspected or possible sarcoma to access a rapid pathway to diagnosis and, where sarcoma is confirmed, prompt referral for management to a sarcoma treatment centre. Where primary bone cancers are suspected patients need to be directly referred to a bone cancer treatment centre.

Imaging departments need to work to high standards of service delivery that encompass management systems, waiting list management, procedural work, examination reporting, provision of clinical advice and quality assurance. In order to achieve this initial work is required to unify imaging protocols and staging reports between different hospitals. This will avoid additional unnecessary studies and make clinically meaningful comparison and review of services and outcomes possible.

Associated Healthcare Standards that map to Objective 7 are: 3,11,12,22,25,and 28
7.1 STANDARD

Any patient with a soft tissue mass fitting the guidelines for urgent referral\textsuperscript{19} or with any other cause for clinical concern should have rapid access to a sarcoma treatment centre or a designated diagnostic clinic affiliated to a sarcoma treatment centre. Patients with suspected bone cancer should be referred to a bone treatment centre.

**MONITORING CRITERIA**

7.1 Copy of documentation to be provided by the appropriate clinical head of imaging services.

7.2 STANDARD

All Departments of Clinical Radiology should have written policies on the referral and imaging investigation of patients with cancer or suspected cancer by cancer site. These should reflect the latest advice from the Royal College of Radiologists [RCR]\textsuperscript{20}.

**MONITORING CRITERIA**

7.2 Detail of written policies to be provided by the appropriate clinical head of imaging services.

7.3 STANDARD

Where sarcoma is suspected there should be a protocol in place for rapid communication with the supra network sarcoma and/or bone treatment centre. Standardised imaging protocols for staging and tumour imaging for soft tissue sarcoma should be agreed between the supra network sarcoma MDT and the designated diagnostic clinics. All images should be available for electronic transfer and review by specialist sarcoma radiologists and discussion at the sarcoma MDT meeting.

**MONITORING CRITERIA**

7.3 Cancer Network Directors to have copies of standardised protocols. Local copies of documentation including details of electronic image storage, retrieval and transfer protocols to be provided by the appropriate clinical lead of imaging services.

\textsuperscript{19} NICE Referral Guidance for Suspected Cancer, 2005

\textsuperscript{20} RCR Guidelines for Doctors, ‘Making the Best Use of a Department of Clinical Radiology, 2003
7.4 STANDARD

Staging should be reported in a standardised format.

MONITORING CRITERIA

7.4 The supra network sarcoma MDT lead clinician to provide documentation of audit of adherence to the standardised format.

7.5 STANDARD

All reports should, as a minimum, allow assessment of that component of TNM status which relies on diagnostic radiology.

MONITORING CRITERIA

7.5 Clinical audit of assessment and recording of stage.

7.6 STANDARD

The supra network MDT specialist radiologists should have regular sessions in their area of expertise identified in their job plan.

MONITORING CRITERIA

7.6 Detail of sessional commitment in job plan.
OBJECTIVE 8: THE MDT SHOULD HAVE ACCESS TO HIGH QUALITY PATHOLOGY SERVICES.

Rationale: Pathology laboratories should work to high standards of service delivery that encompass management systems, diagnosis, specimen reporting, provision of clinical advice and quality assurance.

Adequate and appropriate information in pathology reports is essential to inform prognosis, plan individual patient treatment, support epidemiology and research and to evaluate clinical services and support clinical governance. Specialist histopathologists should be members of a relevant specialist UK society and participate in the relevant specialised national External Quality Assessment [EQA] scheme.

Associated Healthcare Standards that map to Objective 8 are: 3,14, and 25
8.1 STANDARD

All pathology laboratories should participate in Technical EQA and Clinical Pathology Accreditation [CPA].

MONITORING CRITERIA

8.1 Certificate of participation in EQA/CPA

8.2 STANDARD

Reports on resection specimens should comply with all items of the pathology component of the all Wales Cancer Data Set.

MONITORING CRITERIA

8.2 Audit of completeness of pathological reporting

8.3 STANDARD

The supra network MDT pathologists have ready access to molecular pathology/cytogenetics via an integrated laboratory approach.

MONITORING CRITERIA

8.3 Detail integrated laboratory arrangements

8.4 STANDARD

All patients with a provisional histological diagnosis of bone or soft tissue sarcoma should have their diagnosis reviewed and confirmed by a specialist sarcoma pathologist who is a core member of the supra network sarcoma MDT prior to the MDT’s agreement of the patient management options.

MONITORING CRITERIA

8.4 Audit of results of supra network sarcoma pathologists’ work
OBJECTIVE 9: SURGICAL MANAGEMENT FOR SARCOMA PATIENTS REQUIRES APPROPRIATELY DESIGNATED, STAFFED AND RESOURCED FACILITIES.

Rationale: Evidence has been published by NICE that a concentration of activity to a small number of professionals usually leads to an increase in the effectiveness of that intervention. This improvement in outcomes may be owing to concentration of services to higher volume providers; alternatively it may be caused by the development of an increased skill base amongst medical, nursing, allied profession, managerial and support staff. The relative importance of these two mechanisms is unclear from the literature. Whilst there is little evidence that specifically assesses the effect of MDT working by professionals, there is evidence that supports the belief that specialist care offers improved patient outcomes.

It is recommended that bone sarcomas continue to be referred for diagnosis and treatment to a limited number of specialist bone treatment centres. For soft tissue sarcomas, NICE recommendations depend upon whether the tumour is a limb, limb girdle or truncal soft tissue sarcoma; a retroperitoneal or pelvic soft tissue sarcoma; or a soft tissue sarcoma requiring shared management with other site specialist MDTs.

It is recommended that treatment for patients with limb, limb girdle and truncal soft tissue sarcomas is planned by the supra Network sarcoma MDT with definitive surgical resection being undertaken at the soft tissue treatment centre. This approach will ensure that surgeons achieve and maintain experience in this complex area.

In relation to retroperitoneal and pelvic soft tissue sarcomas, late diagnosis is common and total excision with clear histological margins rarely possible. To address these issues, it is recommended that treatment be carried out at a sarcoma treatment centre where there is an MDT member with special expertise in these tumours.

Shared management by site specific cancer MDTs in conjunction with the supra network sarcoma MDT will be required for gynaecological sarcomas, head and neck sarcomas, chest wall/intrathoracic sarcomas, skin sarcomas, central nervous system sarcomas, gastro-intestinal stromal tumours and adult type soft tissue sarcomas arising in children.

Associated Healthcare Standard that maps to Objective 9 is 4
9.1 STANDARD - Soft tissue sarcoma

All patients with limb, limb girdle and truncal soft tissue sarcomas should undergo definitive surgical resection at a soft tissue sarcoma treatment centre.

MONITORING CRITERIA

9.1 Surgical resection as detailed in the standard to be monitored by the referring networks and reported by the soft tissue sarcoma treatment centre.

9.2 STANDARD - Soft tissue sarcoma

Surgery for soft tissue sarcoma should only be performed by or under the supervision of designated consultant surgeons who are members of the supra network MDT and have training and expertise in resection and reconstruction of the defect.

MONITORING CRITERIA

9.2 Detail surgical activity for soft tissue sarcoma by surgeon.

9.3 STANDARD - Soft tissue sarcoma

All patients with a diagnosis of sarcoma should have a management plan agreed by the supra-network sarcoma MDT. Where patients require shared management by other specialists this should be managed by the appropriate MDT in conjunction with the supra network sarcoma MDT.

MONITORING CRITERIA

9.3
a. Detail evidence that all new patient management plans are discussed by the supra-regional sarcoma MDT.
b. Detail arrangements for patients requiring shared managed by a properly constituted other appropriate MDT as agreed by the supra regional sarcoma MDT.

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21 The site-specific MDT, the MDT for children or the MDT for young people.
9.4 STANDARD – Bone sarcoma

All patients with bone sarcoma should undergo definitive surgical resection at a bone tumour treatment centre.

MONITORING CRITERIA

9.4 Surgical resection as detailed in the standard should be monitored by referring networks and reported by the bone tumour treatment centre.

9.5 STANDARD – Bone sarcoma

Surgery for bone sarcoma should only be performed by or under the supervision of a surgeon from an NSCAG or equivalent designated centre.

MONITORING CRITERIA

9.5 NSCAG to confirm that recognised surgeons from designated centres undertake surgery for bone sarcomas.

9.6 STANDARD – Bone sarcoma

Primary cancer surgery should attempt to be limb preserving where possible.

MONITORING CRITERIA

9.6
a. Detail number of operations performed per annum.
b. Detail number of amputations required as part of the primary surgery.

9.7 STANDARD

Post operative specialist physiotherapy should be available to all patients.

MONITORING CRITERIA

9.7 Detail access to post operative physiotherapy.
9.8 STANDARD

The supra network sarcoma MDT should ensure, for those patients referred in from diagnostic clinics or other site specific MDTs for definitive surgery, that chemotherapy and or radiotherapy should be provided as locally as possible in relation to local expertise and facilities and as agreed by the supra Network sarcoma MDT.

MONITORING

9.8 The supra network sarcoma MDT to detail agreed arrangements for local radiotherapy and chemotherapy providers.
OBJECTIVE 10: TO ENSURE PATIENTS RECEIVE RADIOTHERAPY WHICH IS PLANNED, PRESCRIBED, DELIVERED AND SUPERVISED IN A SAFE AND EFFECTIVE MANNER.

Rationale: As with all other forms of treatment, the results of radiotherapy are likely to be optimum when it is delivered according to a formal written policy specifying dose, fractionation, overall treatment time, planning technique and means of verification plus other appropriate QA measures. This is especially true of radical [curative] therapy, where a uniform approach is necessary to be able to evaluate outcomes. It is also important that policies are in line with those in use elsewhere in the UK and worldwide. Where there is substantial deviation, this should be in the context of a formal clinical trial. Palliative treatments will need to be individualised on a more frequent basis, but the overall approach should conform as closely as possible to a written policy. There are circumstances where evidence exists for the superiority of one form of technology over another. An example is of the use of conformal radiotherapy in some pelvic malignancies, as a means of reducing treatment-related side effects. Networks need to have a strategy to ensure that patients for whom such technology is optimum are able to access it, even if this means crossing Trust or Network boundaries. The general quality of procedures in the radiotherapy department will be reflected in externally modulated quality schemes as originally specified by Quality Assurance in Radiotherapy [QART].

Associated Healthcare Standards that map to Objective 10 are: 2, 11, 12, 14, and 28

10.1 STANDARD

Radiotherapy centres should have clinical oncologists approved by the supra network sarcoma MDT lead clinician who specialise in the management of sarcoma and are members of the extended sarcoma supra network MDT. Clinical oncologists should work closely with surgeons in planning adjuvant and neo-adjuvant treatment.

MONITORING CRITERIA

10.1 Radiotherapy centres to detail the clinical oncologists who are members of the extended sarcoma supra network MDT.

10.2 STANDARD

Radiotherapy centres providing curative radiotherapy for children and young people with sarcoma should meet the criteria detailed in the National Cancer Standards for the management of Children with Cancer

MONITORING CRITERIA

10.2 To be monitored as part of the National Cancer Standards for the management of Children with Cancer

10.3 STANDARD

Patients receiving radiotherapy should be treated according to a documented policy as agreed with the supra network MDT or in a formal clinical trial.

MONITORING CRITERIA

10.3
a. Radiotherapy centres to work to written clinical policies.
b. Clinical audit of compliance to policies to be undertaken with deviations from the policy documented and reviewed.
10.4 STANDARD

Radiotherapy centres should jointly agree definitions to monitor major long term morbidity following radical radiotherapy.

MONITORING CRITERIA

10.4 Documentation of definitions of radiotherapy-related morbidity agreed by radiotherapy centres and provided to Network Director.

10.5 STANDARD

Major long-term morbidity rates following radical radiotherapy should be monitored.

MONITORING CRITERIA

10.5 Audits of radiotherapy-related major morbidity by cancer. Results of audit to be sent to the Network Director.

10.6 STANDARD

All radiotherapy centres should have a recognised quality system accredited by an authorised standards institution to a recognised standard.

MONITORING CRITERIA

10.6 Documentation of accreditation certification.

10.7 STANDARD

Equipment capable of delivering conformal radiotherapy should be available to each Network.

MONITORING CRITERIA

a. Detail type and location of planning equipment.
b. Detail type and location of multi-leaf collimator-equipped linear accelerators.
c. Detail availability of treatment verification facilities.
d. Accreditation certification.
10.8 STANDARD

Equipment capable of delivering Intensity Modulated Radiotherapy [IMRT] should be available to each Network.

MONITORING CRITERIA

10.8 Documentation of implementation of/or plans to implement IMRT.
OBJECTIVE 11: TO ENSURE PATIENTS RECEIVE CHEMOTHERAPY WHICH IS PLANNED, PRESCRIBED, DELIVERED AND SUPERVISED IN A SAFE AND EFFECTIVE MANNER.

Rationale: As with all other forms of treatment, the results of chemotherapy are likely to be optimum when it is delivered according to a formal written policy. It is also important that policies are in-line with those in use elsewhere in the UK and worldwide. Where there is substantial deviation, this should be in the context of a formal clinical trial.

Chemotherapeutic agents include other complex, systemic therapies such as biological agents and cytokines. Chemotherapeutic agents are potentially dangerous and fatalities have occurred due to the inappropriate administration of some chemotherapeutic agents via the intrathecal route. It is therefore essential that chemotherapy is provided by trained specialist staff in a safe environment with appropriate facilities. Standardisation of protocols across the Cancer Network will enable outcome assessment to be performed in a uniform manner and staff gain greater expertise by concentrating on a lesser number of well-defined protocols.

Associated Healthcare Standards that map to Objective 11 are: 2,11,12,14,19,and 28
11.1 STANDARD

There should be a formal working relationship between the sarcoma supra Network MDT and its associated providers of chemotherapy detailing referral pathways and routes of communication. Oncologists, approved by the supra network sarcoma MDT lead clinician, who specialise in the management of sarcoma should be members of the extended sarcoma supra network MDT.

MONITORING CRITERIA

11.1 Cancer Network Directors to confirm that formal working arrangements are in place between the supra Network sarcoma MDT and non surgical oncology providers within their Network.

11.2 STANDARD

Providers of chemotherapy for children and young people with sarcoma should meet the specific criteria detailed in National Cancer Standards for Children and Young People with Cancer.

MONITORING CRITERIA

11.2 To be monitored as part of the National Cancer Standards for the management of Children and Young People with Cancer

11.3 STANDARD

There should be an overarching Trust chemotherapy policy, compatible with the latest guidance from NICE or The Joint Council for Clinical Oncology [JCCO], covering generic issues pertinent to chemotherapy

a. Staff grading, training and competencies.
b. Prescribing.
c. Preparation and dispensing.
d. Administration.
e. Disposal of waste and spillage.
MONITORING CRITERIA

11.3 Documentation of the Trust chemotherapy policy detailing the following
a. Staff authorised to initiate chemotherapy.
b. Documentation of the on-site facilities for the preparation of chemotherapy and of compliance with NHS standards for aseptic preparation.
c. Job description of designated pharmacist responsible for overseeing pharmacy services to the ward/outpatient area where chemotherapy is administered.
d. Facilities for the administration of chemotherapy plus any dedicated areas for administration of intrathecal chemotherapy if this is undertaken. To include details of policies and equipment for the administration of chemotherapy plus the management of emergencies such as anaphylaxis, extravasation, spillage of cytotoxics and cardiac arrest.
e. Training and post-registration qualifications of chemotherapy nurses.
f. Confirmation that the Trust chemotherapy policy is available in all areas where chemotherapy is administered.

11.4 STANDARD

Detailed written chemotherapy protocols, agreed with the supra network MDT should be used for the management of sarcoma patients. These protocols should include,
a. Regimen/s and their indication.
b. Drug doses and scheduling.
c. Pre- and post-treatment investigations.
d. Dose modifications.

MONITORING CRITERIA

11.4 Detail of Trust chemotherapy protocols by cancer site.

11.5 STANDARD

Intrathecal chemotherapy should be controlled by a process which ensures that it is only prepared, handled and administered by suitably trained personnel who appear on the intrathecal chemotherapy register for that site.

MONITORING CRITERIA

11.5 Annual monitoring by All Wales Principal Pharmacist Quality Control.
11.6 STANDARD

Major morbidity following chemotherapy in patients treated with curative intent should be monitored.

MONITORING CRITERIA

11.6 Detail audit of chemotherapy-related major morbidity for patients treated with curative intent by cancer.
OBJECTIVE 12: TO ENSURE THAT ALL PATIENTS RECEIVE ADEQUATE ASSESSMENT OF, AND PROVISION FOR, THEIR PALLIATIVE CARE NEEDS AT ALL TIMES AND IN EVERY SETTING. THIS INCLUDES CARE OF DYING PATIENTS, THEIR FAMILIES AND CARERS.

Rationale: The palliative approach may be applicable at any stage of a patient's illness and incorporates the particular needs of the dying patient. This is the responsibility of all health professionals caring for those with progressive life-threatening disease, informed by knowledge of palliative care principles and practice and supported by a specialist palliative care team.

Associated Healthcare Standards that map to Objective 12 are: 2, 8, 11, 12, 22 and 28
12.1 STANDARD

All health professionals engaged in caring for patients with sarcoma should receive training to allow adequate assessment and delivery of general palliative care.

MONITORING CRITERIA

12.1 Details arrangements for staff education and training in palliative care principles and practice.

12.2 STANDARD

There should be clear arrangements to access specialist palliative care services.

MONITORING CRITERIA

12.2. Details in MDT guidelines of access arrangements to specialist palliative care as defined in the CSCG National Cancer Standards for Specialist Palliative Care

12.3 STANDARD

Palliative care needs should be rapidly addressed, and specialist palliative care advice available, in all settings 24 hours a day.

MONITORING CRITERIA

12.3 Community documentation of patient records of
   a. responsibility for out –of-hours medical care
   b. detail of access to nursing care if no 24 hour district nursing service available
   c. Trust and Cancer Network documentation on accessing out-of-hours palliative care advice

12.4 STANDARD

An integrated system should be in place in all care settings to ensure best practice in the multiprofessional care of dying patients. The All Wales Care Pathway for the Last Days of Life represents an appropriate model.

MONITORING CRITERIA

12.4 Detail in the MDT guidelines on use of the end of life care pathway
12.5 STANDARD

All profession-specific teams engaged in palliative care provision such as nursing, physiotherapy, occupational therapy, should have at least one member who has undergone post-registration education and training in palliative care.

MONITORING CRITERIA

12.5 Details of
a. Availability of post registration education and training programmes.
b. Trust identification of staff training priorities in palliative care.
APPENDIX 1 – Membership of sarcoma standards group
National Cancer Standards – CSCG Sarcoma Advisory Group

Professor Mansel (Chair), Professor of Surgery, School of Medicine, Cardiff University

Ms L Abraham, Patient Forum, Cancer Services Co-ordinating Group
Ms A. Baldwin, Physiotherapist, Cardiff and Vale NHS Trust
Dr S. Closs, Consultant Palliative Medicine, Abertawe Bro Morgannwg NHS Trust
Mr P. Cool, Consultant Orthopaedic Surgeon, The Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust
Dr S. Dojcinov, Consultant Pathologist, Cardiff and Vale NHS Trust
Ms A Green, Patient Forum, Cancer Services Co-ordinating Group
Dr J. Hanson, Director Cancer Services Co-ordinating Group
Mr D. Heron, Director North Wales Cancer Network
Miss S. Hill, Consultant Surgeon, Cardiff and Vale NHS Trust
Dr M. Jenney, Consultant Paediatric Oncologist, Cardiff and Vale NHS Trust
Mr H. Laing, Consultant Plastic Surgeon, Abertawe Bro Morgannwg NHS Trust
Dr D. Lloyd, Consultant Radiologist, Cardiff and Vale NHS Trust
Ms C. Pemberton, Clinical Specialist Nurse, The Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust
Mr A. Radcliffe, Consultant Surgeon, Cardiff and Vale NHS Trust
Dr O. Tilsley, Consultant Clinical Oncologist, Velindre NHS Trust
Professor J. Wagstaff, Consultant Medical Oncologist, Abertawe Bro Morgannwg NHS Trust
A. Soft Tissue Sarcomas

### WHO classification of soft tissue tumours

<table>
<thead>
<tr>
<th>Description</th>
<th>Morphology</th>
</tr>
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<tr>
<td>atypical lipomatous tumour/ well differentiated liposarcoma</td>
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<tr>
<td>dedifferentiated liposarcoma</td>
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<td>round cell liposarcoma</td>
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<td>Tumour Type</td>
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<tr>
<td>mesenchymal chondrosarcoma</td>
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<td>Small cell sarcoma</td>
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<td>epithelioid sarcoma</td>
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Other tumours to be included not in WHO list:

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<th>Tumour Type</th>
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Malignant neoplasm of other connective and soft tissue

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### B. Soft Tissue Sarcomas

**WHO classification of bone tumours**

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<td>telangiectatic</td>
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APPENDIX 3 – Inter-MDT pathway for all soft tissue sarcomas (STS)

Site specific MDT [eg Gynae, H&N, Neuro, Skin] develops management plan

Histopathology Suggests STS

Without delay

Specialised STS Histopathology Further immunoHC & cytogenetics

Specialised Imaging / staging

Supra-network Sarcoma MDT Reviews investigations and confirms proposed management plan