# Sarcoma

# NICE quality standard

## Draft for consultation

August 2014

## Introduction

This quality standard covers the diagnosis, treatment, support and follow-up of sarcoma in children, young people and adults. For more information see the topic overview.

### *Why this quality standard is needed*

Sarcomas are a rare and diverse group of cancers that arise from cells that make up the connective tissue structure, including bone, cartilage, muscle, blood vessels, nerves and fat. Sarcomas can be broadly divided into bone and soft tissue sarcomas. Collectively, bone and soft tissue sarcomas account for around 1% of all malignancies diagnosed in the UK. Incidence figures from the National Cancer Intelligence Network (NCIN) show that there were 3298 new diagnoses of soft tissue sarcoma and 531 new diagnoses of bone sarcoma during 2010 in the UK.

Most healthcare professionals will see only a few cases of sarcoma in their working lives. A key part of this quality standard is therefore focused on ensuring that people with sarcoma are treated by healthcare professionals with experience and expertise in treating sarcoma. Sarcomas are a diverse set of tumours, and particular sarcoma types can pose different challenges for treatment. Because rarer sarcoma subtypes are uncommon, experience in treating them may not be present at every sarcoma treatment centre. A further focus of this quality standard is to ensure that people with sarcoma have their treatment carried out by, or in conjunction with, healthcare professionals with experience in their particular sarcoma type.

This quality standard also aims to ensure that people with sarcoma are informed about their condition, receive appropriate and timely advice and are able to access relevant services.

The quality standard is expected to contribute to improvements in the following outcomes:

- Amputation rates
- Survival rates
- Local disease recurrence rates
- Patient experience of services

### *How this quality standard supports delivery of outcome frameworks*

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 2 outcomes frameworks published by the Department of Health:

- NHS Outcomes Framework 2014/15
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, Parts 1A, 1B and 2.

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

**Table 1** NHS Outcomes Framework 2014/15

| Domain | Overarching indicators and improvement areas |
|---|---|
| 1 Preventing people from dying prematurely | ***Overarching indicator***<br>1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare<br>i Adults ii Children and young people<br>1b Life expectancy at 75<br>i Males ii Females<br>***Improvement areas***<br>**Reducing premature mortality from the major causes of death**<br>1.4 Under 75 mortality rate from cancer* (PHOF 4.5)<br>i One- and ii Five-year survival from all cancers<br>**Reducing deaths in babies and young children**<br>1.6 iii Five-year survival from all cancers in children |
| 4 Ensuring that people have a positive experience of care | ***Overarching indicator***<br>4a Patient experience of primary care<br>i GP services<br>4b Patient experience of hospital care<br>***Improvement areas***<br>**Improving people's experience of outpatient care**<br>4.1 Patient experience of outpatient services<br>**Improving the experience of care for people at the end of their lives**<br>4.6 Bereaved carers' views on the quality of care in the last 3 months of life<br>**Improving children and young people's experience of healthcare**<br>4.8 Children and young people's experience of outpatient services |
| **Alignment across the health and social care system**<br>***** Indicator shared with Public Health Outcomes Framework (PHOF) | |

**Table 2 Public health outcomes framework for England, 2013–2016**

| Domain | Objectives and indicators |
|---|---|
| 2 Health improvement | ***Objective***<br>People are helped to live healthy lifestyles, make healthy choices and reduce health inequities<br>***Indicators***<br>2.19 Cancer diagnosed at stage 1 and 2 |
| 4 Healthcare public health and preventing premature mortality | ***Objective***<br>Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities<br>***Indicators***<br>4.1 Infant mortality* (NHSOF 1.6i)<br>4.3 Mortality rate from causes considered preventable** (NHSOF 1a)<br>4.5 Under-75 mortality rate from cancer* (NHSOF 1.4i) |
| **Aligning across the health and care system**<br>* Indicator shared with the NHS Outcomes Framework (NHSOF)<br>** Complementary to indicators in the NHS Outcomes Framework (NHSOF) | |

## *Coordinated services*

The quality standard for sarcoma specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole sarcoma care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with sarcoma.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality sarcoma service are listed in ‘Related quality standards’.

### Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in assessing, caring for and treating people with sarcoma should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

### Role of families and carers

Quality standards recognise the important role families and carers have in supporting people with sarcoma. If appropriate, healthcare professionals should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

## List of quality statements

Statement 1. People with a confirmed diagnosis of bone or soft tissue sarcoma have their care supervised by, or provided in conjunction with, a sarcoma multidisciplinary team (MDT).

Statement 2. Sarcoma multidisciplinary teams (MDTs) have designated staff assigned to all core roles in the team.

Statement 3. Sarcoma multidisciplinary teams (MDTs) share information about their specific areas of expertise with other cancer services.

Statement 4. People with retroperitoneal sarcoma are referred to a sarcoma treatment centre in which there is a designated surgeon with special expertise in managing this type of tumour.

Statement 5. People who have resection of their sarcoma have it performed by a surgeon who is a member of a sarcoma multidisciplinary team (MDT), or by a surgeon with tumour site-specific or age-appropriate skills in consultation with the sarcoma MDT.

Statement 6. People who are referred to a sarcoma diagnostic clinic or treatment centre are given information that is specific to the clinic or centre, that describes the tests and treatments it provides and that describes the person's diagnosis or disease stage.

Statement 7. People with sarcoma whose care is being managed by a sarcoma multidisciplinary team (MDT) are allocated a key worker with specialist knowledge of sarcomas and their treatment, and are provided with their key worker's name and contact details.

## Questions for consultation

### *Questions about the quality standard*

**Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?

**Question 2** If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

**Question 3** For each quality statement what do you think could be done to support improvement and help overcome barriers?

### *Questions about the individual quality statements*

**Question 4** For draft quality statement 3: How would you define 'specific area of expertise' to make this statement workable in practice?

**Question 5** For draft quality statement 3: How could services measure practice and show levels of achievement in sharing information?

**Question 6** For draft quality statement 4: The proposed quality statement 5 also focusses on surgical skills, so is statement 4 creating duplication and overlap?

**Question 7** For draft quality statement 4: Is it possible to define a surgeon with 'special expertise' in managing retroperitoneal sarcoma to make this statement workable in practice? And if so, how could we define this 'special expertise'?

# Quality statement 1: Multidisciplinary teams for sarcoma

## *Quality statement*

People with a confirmed diagnosis of bone or soft tissue sarcoma have their care supervised by, or provided in conjunction with, a sarcoma multidisciplinary team (MDT).

## *Rationale*

The involvement of sarcoma MDTs in the assessment and treatment of all people with sarcoma will ensure that appropriate expertise is available. It is particularly important that sarcoma MDTs are involved in the treatment of people with sarcoma who are initially referred to non-sarcoma MDTs.

## *Quality measures*

### Structure

a) Evidence of written protocols and local arrangements for people with a confirmed diagnosis of bone or soft tissue sarcoma to have their care provided by, or provided in conjunction with, a sarcoma MDT.

***Data source:*** Local data collection. National Cancer Peer Review Report: Manual for cancer services: sarcoma measures [measures 14-1C-113l to 14-1C-117l, 14-1D-106l to 14-1D-108l and 14-2L-110 to 14-2L-112].

b) Evidence of written protocols and local pathways between sarcoma MDTs and site-specific cancer MDTs clarifying the circumstances in which patient care should be transferred from one team to the other.

***Data source:*** Local data collection. National Cancer Peer Review report: Manual for cancer services: sarcoma measures [measure 14-2L-112].

### Process

Proportion of people with a confirmed diagnosis of bone or soft tissue sarcoma who have their care supervised by, or provided in conjunction with, a sarcoma MDT.

Numerator – the number of people in the denominator who have their care supervised by, or provided in conjunction with, a sarcoma MDT.

Denominator – the number of people with a confirmed diagnosis of bone or soft tissue sarcoma.

***Data source:*** Local data collection. National Cancer Intelligence Network: Cancer outcomes and services dataset (COSD).

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (such as hospitals and sarcoma treatment centres) ensure that a sarcoma multidisciplinary team is in place to agree and provide treatment and support for people with sarcoma, either alone or in conjunction with another team.

**Healthcare professionals** work collaboratively across sarcoma multidisciplinary teams and non-sarcoma multidisciplinary teams to agree and deliver treatment and support for people with sarcoma.

**Commissioners** (such as NHS England) ensure that they commission services for people with sarcoma that includes the provision of a sarcoma multidisciplinary team.

## *What the quality statement means for patients, service users and carers*

**People diagnosed with sarcoma (a rare type of cancer that develops in a bone or in soft tissue such as muscle or fat)** are looked after with the help of a sarcoma multidisciplinary team (a specialist team of healthcare professionals who have training and experience in bone or soft tissue sarcoma).

## *Source guidance*

- Sarcoma (NICE cancer service guidance), Key recommendations (page 8).

## *Equality and diversity considerations*

When referring people to a sarcoma MDT, potential difficulties in access such as travelling distance, disability or financial barriers should be taken into account.

# Quality statement 2: Sarcoma multidisciplinary team composition

## *Quality statement*

Sarcoma multidisciplinary teams (MDTs) have designated staff assigned to all core roles in the team.

## *Rationale*

To operate effectively, a sarcoma MDT needs to have staff to fulfil each core role on the team. This will ensure that healthcare professionals with the necessary experience in sarcoma are available to coordinate and plan care. Often these roles will be carried out by the core members of the sarcoma MDT, but sometimes they are performed by staff based in affiliated hospitals who are extended members of the sarcoma MDT. This allows local services to be provided to people with sarcoma who live a long distance away from hospitals or treatment centres where core sarcoma MDT members are based.

## *Quality measures*

### Structure

Evidence that sarcoma MDTs have designated staff assigned to all core roles in the team.

***Data source:*** Local data collection. National Cancer Peer Review Report: Manual for cancer services: sarcoma measures [measure 14-2L-101].

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (such as sarcoma MDTs based either in a hospital or in several closely affiliated hospitals) ensure that they have designated staff assigned to all core roles in a sarcoma MDT.

**Healthcare professionals** ensure that sarcoma MDTs fill all core roles in the team.

**Commissioners** (such as NHS England) ensure that they commission services from providers that have designated staff assigned to all core roles in the sarcoma MDT.

### *What the quality statement means for patients, service users and carers*

**People with sarcoma (a rare type of cancer that develops in a bone or in soft tissue such as muscle or fat)** who are treated by a multidisciplinary sarcoma team (a specialist team of healthcare professionals who have training and experience in bone or soft tissue sarcoma) have their treatment agreed and provided by a team that has a special healthcare professional for each part of their treatment.

### *Source guidance*

- Sarcoma (NICE cancer service guidance), Improving treatment – sarcoma multidisciplinary teams:
  - Sarcoma MDT membership (page 55).
  - Role of the sarcoma MDT (page 56).

### *Definitions of terms used in this quality statement*

#### Core roles in a sarcoma MDT

- Two sarcoma surgeons with a relevant surgical practice for the sarcoma type (bone or soft tissue) that the MDT deals with.
- Two specialist sarcoma radiologists with a special interest in musculoskeletal or oncological imaging.
- Two oncologists (at least 1 responsible for radiotherapy and at least 1 responsible for chemotherapy).
- Two histopathologists.
- Two clinical nurse specialists.
- An MDT coordinator or secretary.

[Adapted from National Cancer Peer Review Report: Manual for cancer services: sarcoma measures (measure 14-2L-101)]

# Quality statement 3: Sharing information about specific areas of expertise

## *Quality statement*

Sarcoma multidisciplinary teams (MDTs) share information about their specific areas of expertise with other cancer services.

## *Rationale*

Managing less common bone and soft tissue sarcomas is complicated and particularly complex cases may need referral to a specific MDT for specialist advice. A greater awareness of the expertise of sarcoma MDTs in treating particular types of sarcoma will allow cases to be referred to the most appropriate sarcoma MDTs. Specific areas of expertise include gynaecological sarcomas, head and neck sarcomas, retroperitoneal and pelvic sarcomas, chest wall and intrathoracic sarcomas, skin sarcomas, central nervous system sarcomas, gastrointestinal stromal tumours, adult-type soft tissue sarcomas arising in children and the use of isolated limb perfusion.

## *Quality measures*

### Structure

Evidence of arrangements made by sarcoma MDTs to share information about their specific areas of expertise with other cancer services.

***Data source:*** Local data collection.

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (such as hospitals and sarcoma treatment centres) ensure that they share information about their specific expertise with other cancer services.

**Healthcare professionals** ensure that they are aware of any sarcoma MDTs with expertise in treating a particular sarcoma type.

**Commissioners** (such as NHS England) ensure that they commission services that share information about their specific expertise with other cancer services.

### *What the quality statement means for patients, service users and carers*

**People with sarcoma (a rare type of cancer that develops in a bone or in soft tissue such as muscle or fat)** have their treatment provided by healthcare professionals who can refer them to specialists with training and experience in the type of sarcoma they have.

### *Source guidance*

- Sarcoma (NICE cancer service guidance). Improving treatment: sarcoma multidisciplinary teams (page 54).

### *Question for consultation*

How would you define ‘specific area of expertise’ to make this statement workable in practice?

How could services measure practice and show levels of achievement in sharing information?

# Quality statement 4: Retroperitoneal sarcoma treatment

## *Quality statement*

People with retroperitoneal sarcoma are referred to a sarcoma treatment centre in which there is a designated surgeon with special expertise in managing this type of tumour.

## *Rationale*

Retroperitoneal sarcomas pose particular challenges in treatment. If cases of retroperitoneal sarcoma are evenly distributed to sarcoma treatment centres, each centre will see only a small number per year. Concentrating retroperitoneal sarcoma cases in a small number of specialist centres will ensure that healthcare professionals at these units maintain expertise in treating this type of tumour. This will improve outcomes, for example, by reducing postoperative mortality and recurrence rates.

## *Quality measures*

### Structure

Evidence of local arrangements and protocols to ensure that people with retroperitoneal sarcoma are referred to a sarcoma treatment centre in which there is a designated surgeon with special expertise in managing this type of tumour.

***Data source:*** Local data collection.

### Process

Proportion of people with retroperitoneal sarcoma who are referred to a sarcoma treatment centre in which there is a designated surgeon with special expertise in managing this type of tumour.

Numerator – the number of people in the denominator who are referred to a sarcoma treatment centre in which there is a designated surgeon with special expertise in managing this type of tumour.

Denominator – the number of people with retroperitoneal sarcoma.

***Data source:*** Local data collection. National Cancer Intelligence Network: Cancer outcomes and services dataset (COSD).

**Outcome**

Retroperitoneal sarcoma survival rate.

***Data source:*** Local data collection.

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (such as sarcoma advisory groups) ensure that sarcoma treatment centres have a designated surgeon with special expertise in managing this type of tumour in place, or ensure that systems and protocols to refer people with retroperitoneal sarcoma to such a treatment centre are in place.

**Healthcare professionals** ensure that they are aware of local referral pathways for people with retroperitoneal sarcoma and refer them to a sarcoma treatment centre in which there is a designated surgeon with special expertise in managing retroperitoneal sarcoma.

**Commissioners** (such as NHS England) ensure that they either commission services that include the provision of a sarcoma treatment centre in which there is a designated surgeon with special expertise in managing this type of tumour, or commission services that have in place systems and protocols to refer people with retroperitoneal sarcoma to such a treatment centre.

## *What the quality statement means for patients, service users and carers*

**People with retroperitoneal sarcoma (a rare type of cancer that develops in the soft tissues of the abdomen or pelvis)** receive treatment from healthcare professionals who have special expertise in treating this type of sarcoma.

## *Source guidance*

- Sarcoma (NICE cancer service guidance), Improving treatment – soft tissue sarcomas:

  - Retroperitoneal and pelvic soft tissue sarcomas (page 73).

### *Equality and diversity considerations*

When referring people to a sarcoma treatment centre, potential difficulties in access such as travelling distance, disability or financial barriers should be taken into account.

### *Question for consultation*

The proposed quality statement 5 also focusses on surgical skills, so is statement 4 creating duplication and overlap?

Is it possible to define a surgeon with ‘special expertise’ in managing retroperitoneal sarcoma to make this statement workable in practice? And if so, how could we define this ‘special expertise’?

# Quality statement 5: Surgical skills

## *Quality statement*

People who have resection of their sarcoma have it performed by a surgeon who is a member of a sarcoma multidisciplinary team (MDT), or by a surgeon with tumour site-specific or age-appropriate skills in consultation with the sarcoma MDT.

## *Rationale*

Surgery carried out by a surgeon who has experience in dealing with sarcoma is more likely to result in improved outcomes and is more likely to be limb-sparing. In some cases, the most appropriate surgeon to carry out a sarcoma resection may not be a sarcoma specialist but a surgeon with skills relevant to the age of the patient or the site of the tumour. In these cases, such surgeons should work closely with a sarcoma MDT to utilise their expertise.

## *Quality measures*

### Structure

Evidence of local arrangements and protocols to ensure that people who have resection of their sarcoma have it performed by a surgeon who is a member of a sarcoma MDT or by a surgeon with tumour site-specific or age-appropriate skills, in consultation with the sarcoma MDT.

***Data source:*** Local data collection. National Cancer Peer Review Report: Manual for cancer services: sarcoma measures [measure 14-1D-104l].

### Process

Proportion of people who have resection of their sarcoma who have it performed by a surgeon who is a member of a sarcoma MDT or by a surgeon with tumour site-specific or age-appropriate skills, in consultation with the sarcoma MDT.

Numerator – the number of people in the denominator who had their surgery performed by a surgeon who is a member of a sarcoma MDT or by a surgeon with tumour site-specific or age-appropriate skills, in consultation with the sarcoma MDT.

Denominator – the number of people who had resection of their sarcoma.

***Data source:*** Local data collection. National Cancer Intelligence Network: Cancer outcomes and services dataset (COSD).

**Outcome**

a) Incidence of amputation as the definitive local treatment for sarcoma.

***Data source:*** Local data collection.

b) 30-day mortality rate post-sarcoma resection.

***Data source:*** Local data collection.

c) Incidence of sarcoma recurrence after surgery.

***Data source:*** Local data collection.

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (such as sarcoma treatment centres) ensure that policies and procedures are in place for people who need resection of their sarcoma to either have their surgery carried out by a surgeon who is a member of a sarcoma MDT or by a surgeon with tumour site-specific or age-appropriate skills working in conjunction with a sarcoma MDT.

**Healthcare professionals** ensure that they refer people who need resection of their sarcoma to either a surgeon who is a member of a sarcoma MDT or a surgeon with tumour site-specific or age-appropriate skills working in conjunction with a sarcoma MDT.

**Commissioners** (such as NHS England) ensure that they commission services from service providers that have policies and procedures are in place for people who need resection of their sarcoma to either have their surgery carried out by a surgeon who is a member of a sarcoma MDT or by a surgeon with tumour site-specific or age-appropriate skills working in conjunction with a sarcoma MDT.

### *What the quality statement means for patients, service users and carers*

**People with sarcoma (a rare type of cancer that develops in a bone or in soft tissue such as muscle or fat) that needs to be removed** have their operation done by an experienced surgeon who specialises in sarcomas or by a surgeon who has suitable skills and works with a sarcoma multidisciplinary team (a specialist team of healthcare professionals who have training and experience in bone or soft tissue sarcoma).

### *Source guidance*

- Sarcoma (NICE cancer service guidance). Key recommendations (page 8).

### *Equality and diversity considerations*

When considering appropriate surgeons for referral, any potential difficulties in accessing services, which may include distance, disability and financial barriers, should be taken into account.

# Quality statement 6: Tailored information for people with sarcoma

## *Quality statement*

People who are referred to a sarcoma diagnostic clinic or treatment centre are given information that is specific to the clinic or centre, that describes the tests and treatments it provides and that describes the person's diagnosis or disease stage.

## *Rationale*

Providing specific, clear, well-communicated and timely information will improve people's understanding of their condition and treatment. It has been found that people with sarcoma often don't receive information that is specific to their condition.

## *Quality measures*

### Structure

Evidence of local arrangements that sarcoma diagnostic clinics or treatment centres are making available information that is specific to that clinic or centre, including the tests and treatments it provides, and that describes an individual person's diagnosis or disease stage.

***Data source:*** Local data collection. National Cancer Peer Review Report: Manual for cancer services: sarcoma measures [measures 14-2L-116].

### Process

Proportion of people referred to sarcoma diagnostic clinics or treatment centres who receive information that is specific to that clinic or centre, including the tests and treatments it provides, and that describes their diagnosis or disease stage.

Numerator – the number of people in the denominator who receive information that is specific to that clinic or centre, including the tests and treatments it provides, and that describes their diagnosis or disease stage.

Denominator – the number of people referred to a sarcoma diagnosis clinic or treatment centre.

***Data source:*** Local data collection. National cancer patient experience survey [Questions 14 and 68].

**Outcome**

People with sarcoma feel informed about their diagnosis, condition and treatment.

***Data source:*** Local data collection. National cancer patient experience survey [Question 67].

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (such as sarcoma diagnosis clinics and treatment centres) ensure that they make available information that is specific to their service and that describes the tests and treatments provided and the person's diagnosis and disease stage, and that healthcare professionals are trained to understand and explain the information and to give it to people with sarcoma.

**Healthcare professionals** ensure that they provide people with sarcoma with information that is specific to a sarcoma diagnosis clinic or treatment centre and the person's diagnosis and disease stage, and that they understand and can explain this information.

**Commissioners** (such as NHS England) ensure that they commission sarcoma diagnosis clinics or treatment centres that make available information that is specific to the clinic or treatment centre and describes the tests and treatments provided and the person's diagnosis and disease stage, and that the centres and clinics train healthcare professionals to understand and explain the information and to give it to people with sarcoma.

## *What the quality statement means for patients, service users and carers*

**People referred to a specialist clinic that diagnoses or treats sarcoma (a rare type of cancer that develops in a bone or in soft tissue such as muscle or fat)** are given information about their cancer and what stage it is at, as well as information about the tests and treatments that the clinic provides.

## Source guidance

- Sarcoma (NICE cancer service guidance), Patient perspectives:
  - Information (page 28).

## Definitions of terms used in this quality statement

### Information

Information should be provided in a variety of formats (for example, written or oral) and be supported by information about access to online resources. People with sarcoma should be involved in developing and reviewing all information [Adapted from Sarcoma, NICE cancer service guidance]. If possible, information should be certified by The Information Standard.

Table 3 maps the scope of the information that should be made available to patients at each stage in the disease and treatment pathway, and indicates which organisation(s) should be responsible for ensuring the patient has access to that information [Adapted from Sarcoma, NICE cancer service guidance – Patient perspectives: table 4].

**Table 3 The Information pathway**

| Time | Nature of information | Responsibility |
|---|---|---|
| On referral to diagnostic clinic | Information on diagnostic clinic, tests it undertakes and who will be involved with the patient. | Diagnostic clinic by post |
| If sarcoma is suspected and the term is specifically used with the patient | Generic information on sarcoma. | Diagnostic clinic |
| On diagnosis | Generic information on sarcoma.<br>Specific information on the diagnosis (such as histological type or grade) and the proposed treatment (if known). | Diagnostic clinic face-to-face or by telephone or post if requested by patient |
| Confirming referral to sarcoma treatment centre | Information on sarcoma treatment centre, names of consultants and nurses who will be involved in treatment and the named key worker for the patient. | Sarcoma treatment centre by post |

| | | |
|---|---|---|
| | Specific information on the diagnosis and the proposed treatment (if known and if not given by diagnostic clinic). | Local arrangements can apply |
| On any treatment recommendation | Generic information on that treatment (surgery, radiotherapy, chemotherapy) and any tests or imaging procedures that may accompany it. (Local or nationally published booklets may be appropriate.) | Sarcoma treatment centre by post or face-to-face as appropriate |
| On referral to another sarcoma treatment centre | Reasons for the referral. | Referring sarcoma treatment centre face-to-face or by post |
| | Information on the new sarcoma treatment centre. Identification of key worker. | New sarcoma treatment centre by post |
| After surgery or other treatment | Specific information on individual follow-up procedure, self-monitoring information, healthcare support and sarcoma-specific support.<br>Confirmation of the named key worker for that patient together with contact details.<br>Specific information on support for prosthetic limbs or endoprosthetic implants.<br>Details about relevant rehabilitation services including provision of mobility aids, home adaptations and referral to local rehabilitation services. | Sarcoma treatment centre by post or face-to-face as appropriate |
| | Details of generic local and national support groups and other support resources. | Sarcoma treatment centre or patient support centre, face-to-face or by post |
| If targeted therapy is proposed (for example, imatinib for gastrointestinal stromal tumours) | Generic information on the therapy and the applicable condition. Specific information relevant to the patient's own condition. | Sarcoma treatment centre face-to-face, with copies by post to GP |
| In the event of advanced disease (whether at diagnosis or later) | Specific information on the nature of the advanced condition. Generic information will also be appropriate when metastatic disease is diagnosed. | Sarcoma treatment centre face-to-face |
| When a clinical trial is proposed | Generic information on clinical trials. Specific information on the proposed trial. | Sarcoma treatment centre face-to-face<br>Further information may come from trials unit by post |
| When no treatment other than palliative is available | Generic information on palliative care and pain control. | Sarcoma treatment centre or palliative care centre face-to-face and GP |

Generic information may include publications from national cancer charities and other voluntary sector providers, and this should be provided by the diagnostic clinic or sarcoma treatment centre. [Adapted from Sarcoma, (NICE cancer service guidance) – Patient perspectives]

### *Equality and diversity considerations*

All information given to people with sarcoma should be accessible to people with additional needs, such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with sarcoma should have access to an interpreter or advocate if needed.

# Quality statement 7: Key workers

## *Quality statement*

People with sarcoma whose care is being managed by a sarcoma multidisciplinary team (MDT) are allocated a key worker with specialist knowledge of sarcomas and their treatment, and are provided with their key worker's name and contact details.

## *Rationale*

Care for people with sarcoma may encompass services outside a sarcoma treatment centre, such as rehabilitation, prosthetics, psychological support and palliative care. A key worker is integral in ensuring that people with sarcoma are aware of, and able to access, such services. It is important to ensure that cover can be provided if a person's key worker is unavailable because of illness or annual leave.

## *Quality measures*

### Structure

Evidence of local arrangements to provide a designated key worker with specialist knowledge of sarcomas and their treatment for all people managed by a sarcoma MDT.

***Data source:*** Local data collection. National Cancer Peer Review Report: Manual for cancer services: sarcoma measures [measure 14-2L-115].

### Process

Proportion of people whose care is being managed by a sarcoma MDT who are allocated a key worker with specialist knowledge of sarcomas and their treatment and provided with their key worker's name and contact details.

Numerator – the number of people in the denominator who are allocated a key worker with specialist knowledge of sarcomas and their treatment and provided with their key worker's name and contact details.

Denominator – the number of people whose care is being managed by a sarcoma MDT.

***Data source:*** Local data collection. National cancer patient experience survey (Question 20).

**Outcome**

a) Coordination of care.

***Data source:*** Local data collection.

b) Patient satisfaction and availability of key worker.

***Data source:*** Local data collection. National cancer patient experience survey (Questions 21 and 70).

## *What the quality statement means for service providers, healthcare professionals and commissioners*

**Service providers** (such as sarcoma treatment centres and hospitals) ensure that sufficient key workers with specialist knowledge of sarcomas and their treatment are available to be assigned to each person whose care is managed by a sarcoma MDT, and that there are key workers available to provide cover in the event of illness or annual leave.

**Healthcare professionals** ensure that all people with sarcoma whose care is managed by a sarcoma MDT are allocated a key worker with specialist knowledge of sarcomas and their treatment.

**Commissioners** (such as NHS England) ensure that they commission services that have sufficient key workers with specialist knowledge of sarcomas and their treatment available to be assigned to each person whose care is managed by a sarcoma MDT, and that there are key workers available to provide cover in the event of illness or annual leave.

## *What the quality statement means for patients, service users and carers*

**People with sarcoma (a type of cancer that develops in a bone or in soft tissue such as muscle or fat)** whose care is provided by a multidisciplinary team (a specialist team of healthcare professionals who have training and experience in bone or soft tissue sarcoma) have a key worker who is a healthcare professional with specialist knowledge of sarcoma and who they can contact for information and support.

## *Source guidance*

- Sarcoma (NICE cancer service guidance), Supportive and palliative care:
  - The key worker (page 82).

## *Definitions of terms used in this quality statement*

### Key workers

Key workers are usually specialist nurses or allied health professionals who have an in-depth/specialist knowledge of sarcomas and their treatment and who can act as advocates of the patient, facilitating the coordination of the diagnostic and treatment pathway, providing continuity, and ensuring the patient knows how to access information and advice [Sarcoma, NICE cancer service guidance].

## Status of this quality standard

This is the draft quality standard released for consultation from 21 August to 18 September 2014. It is not NICE's final quality standard on sarcoma. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 18 September 2014. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the NICE website from January 2015.

## Using the quality standard

### *Quality measures*

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its Indicators for Quality Improvement Programme. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's What makes up a NICE quality standard? for further information, including advice on using quality measures.

### *Levels of achievement*

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of

100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

### *Using other national guidance and policy documents*

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in 'Development sources'.

## Diversity, equality and language

During the development of this quality standard, equality issues have been considered and equality assessments are available.

Good communication between health, public health and social care practitioners and people with sarcoma is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with sarcoma should have access to an interpreter or advocate if needed.

Good communication between health, public health and social care practitioners and children and young people with sarcoma, and their parents/families or carers (if appropriate), is essential. Treatment, care and support, and the information given about it, should be both age-appropriate and culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Children and young people with sarcoma and their parents/families or carers (if appropriate) should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

# Development sources

Further explanation of the methodology used can be found in the quality standards Process guide on the NICE website.

## *Evidence sources*

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- Sarcoma. NICE Cancer Service Guidance (2006).

## *Policy context*

It is important that the quality standard is considered alongside current policy documents, including:

- National Peer Review Report: Cancer Services 2012/2013. National Cancer Peer Review Programme (2013)
- Service Specification: Cancer Soft Tissue Sarcoma (Adult). NHS England (2013)
- Service Specification: Primary Malignant Bone Tumours Service (Adults and Adolescents). NHS England (2013)
- The national cancer strategy: 3rd annual report. Department of Health (2013)
- Wales cancer patient experience survey 2013. Welsh Assembly Government (2013)
- National Cancer Patient Experience Survey 2011/12. Department of Health (2012)
- Together for health: cancer delivery plan for the NHS to 2016. Welsh Assembly Government (2012)
- Improving outcomes: a strategy for cancer. Department of Health (2011)
- Commissioning Cancer Services. Department of Health (2011).

## *Definitions and data sources for the quality measures*

- National cancer patient experience survey
- National Cancer Intelligence Network: Cancer outcomes and services dataset (COSD).

- National Cancer Peer Review Report: Manual for cancer services: sarcoma measures
- Sarcoma. NICE Cancer Service Guidance (2006).

## Related NICE quality standards

### *Published*

- Children and young people with cancer. NICE quality standard 55 (2014).
- Patient experience in adult NHS services. NICE quality standard 15 (2012).
- End of life care for adults. NICE quality standard 13 (2011).

### *Future quality standards*

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Referral for suspected cancer.
- Transition from children's to adult services.
- End of life care for infants, children and young people.

## Quality Standards Advisory Committee and NICE project team

### *Quality Standards Advisory Committee*

This quality standard has been developed by Quality Standards Advisory Committee 3. Membership of this committee is as follows:

**Dr Alastair Bradley**

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**Mr Darryl Thompson**

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The following specialist members joined the committee to develop this quality standard:

**Professor Robert Grimer**

Consultant Orthopaedic Oncologist, Royal Orthopaedic Hospital, Birmingham

**Dr Philip Robinson**

Clinical Director Radiology, Leeds Teaching Hospitals

**Professor Meirion Thomas**

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**Mr Roger Wilson**

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## About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the quality standards process guide.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

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