



# Sarcoma

Quality standard

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This standard is based on CSG9.

This standard should be read in conjunction with QS13, QS15, QS55 and QS124.

## 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 [sarcoma 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 subtypes can pose different challenges for treatment. In addition, there may not be healthcare professionals with experience in treating rarer sarcoma subtypes at every sarcoma treatment centre.

This quality standard also aims to ensure that people with sarcoma are informed about their condition, receive appropriate and timely advice and can access relevant services. It is important that people with sarcoma understand their condition and treatment options. Therefore this quality standard should be considered alongside the NICE quality standard for [patient experience in adult NHS services](#) (statement 5 in particular).

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

- patient experience of care
- recurrence rates

- survival rates
- treatment morbidity and physical function.

### *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	<p><b>Overarching indicator</b></p> <p>1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare</p> <p>i Adults ii Children and young people</p> <p>1b Life expectancy at 75</p> <p>i Males ii Females</p> <p><b>Improvement areas</b></p> <p>Reducing premature mortality from the major causes of death</p> <p>1.4 Under 75 mortality rate from cancer* (PHOF 4.5)</p> <p>i One- and ii Five-year survival from all cancers</p> <p>Reducing deaths in babies and young children</p> <p>1.6 iii Five-year survival from all cancers in children</p>

<p>4 Ensuring that people have a positive experience of care</p>	<p><b>Overarching indicator</b></p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p>4b Patient experience of hospital care</p> <p><b>Improvement areas</b></p> <p><b>Improving people's experience of outpatient care</b></p> <p>4.1 Patient experience of outpatient services</p> <p><b>Improving hospitals' responsiveness to personal needs</b></p> <p>4.2 Responsiveness to in-patients' personal needs</p> <p><b>Improving the experience of care for people at the end of their lives</b></p> <p>4.6 Bereaved carers' views on the quality of care in the last 3 months of life</p> <p><b>Improving children and young people's experience of healthcare</b></p> <p>4.8 Children and young people's experience of outpatient services</p>
<p><b>Alignment across the health and social care system</b></p> <p>* Indicator shared with Public Health Outcomes Framework (PHOF)</p>	

**Table 2 Public health outcomes framework for England, 2013–16**

Domain	Objectives and indicators
<p>2 Health improvement</p>	<p><b>Objective</b></p> <p>People are helped to live healthy lifestyles, make healthy choices and reduce health inequities</p> <p><b>Indicators</b></p> <p>2.19 Cancer diagnosed at stage 1 and 2</p>

<p>4 Healthcare public health and preventing premature mortality</p>	<p><b>Objective</b></p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities</p> <p><b>Indicators</b></p> <p>4.3 Mortality rate from causes considered preventable** (NHSOF 1a)</p> <p>4.5 Under-75 mortality rate from cancer* (NHSOF 1.4i)</p>
<p><b>Aligning across the health and care system</b></p> <p>* Indicator shared with the NHS Outcomes Framework (NHSOF)</p> <p>** Complementary to indicators in the NHS Outcomes Framework (NHSOF)</p>	

## *Patient experience and safety issues*

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to sarcoma.

NICE has developed guidance and an associated quality standard on patient experience in adult NHS services (see the NICE pathway on [patient experience in adult NHS services](#)), which should be considered alongside this quality standard. They specify that people receiving care should be treated with dignity, have opportunities to discuss their preferences, and be supported to understand their options and make fully informed decisions. They also cover the provision of information to patients and service users. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development sources for quality standards that impact on patient experience and are specific to the topic are considered during quality statement development.

## *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. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development sources on specific types of training for the topic that exceed standard professional training are considered during quality statement development.

## **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 Sarcoma advisory groups and sarcoma multidisciplinary teams (MDTs) have pathways for referral and diagnosis in place for people with suspected sarcoma.

Statement 2 Adults, children and young people with bone sarcoma and adults with soft tissue sarcoma have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the sarcoma advisory group.

Statement 3 Sarcoma MDTs publish information about their shared pathways, activity and patient outcomes, including information on site-specific sarcomas.

Statement 4 People with a retroperitoneal sarcoma are referred before having any treatment to a sarcoma treatment centre with special expertise in managing this type of tumour.

Statement 5 Surgeons performing planned resections of sarcomas are core or extended members of a sarcoma MDT.

Statement 6 People with sarcoma are supported by an allocated key worker with specialist knowledge of sarcomas and their treatment.

## Quality statement 1: Diagnostic pathways

### *Quality statement*

Sarcoma advisory groups and sarcoma multidisciplinary teams (MDTs) have pathways for referral and diagnosis in place for people with suspected sarcoma.

### *Rationale*

Because malignant sarcomas are rare, they are often diagnosed late, resulting in poorer patient outcomes. To improve diagnosis, people with suspected sarcoma need to be recognised early and quickly referred to services that can confirm the diagnosis. However, because sarcomas often can't be reliably distinguished from benign conditions using clinical judgement, a large number of benign cases will also be referred to diagnostic services, creating a large diagnostic workload. To prevent specialist sarcoma services from becoming overwhelmed by referrals to confirm diagnosis, diagnostic pathways will need to be developed by sarcoma advisory groups in conjunction with sarcoma MDTs. These pathways will need to be agreed with the services providing the referrals, including GPs, general diagnostic imaging services and other secondary care providers.

### *Quality measures*

#### **Structure**

a) Evidence that sarcoma advisory groups and sarcoma MDTs have pathways for referral and diagnosis in place for people with suspected sarcoma.

*Data source:* Local data collection.

b) Evidence of local arrangements to agree and communicate diagnostic pathways with primary and secondary care providers.

*Data source:* Local data collection.

#### **Outcome**

Stage of sarcoma at diagnosis.

*Data source:* Local data collection.

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

Sarcoma advisory groups and sarcoma MDTs establish and implement pathways for referral and diagnosis for people with suspected sarcoma, ensuring that primary and secondary care providers are involved in their design.

Primary and secondary service providers (hospitals, sarcoma specialist centres, diagnostic clinics, GPs) follow pathways for referral and diagnosis for people with suspected sarcoma that have been agreed by sarcoma advisory groups and sarcoma MDTs. They should also ensure information about these pathways is easily accessible to staff.

Healthcare professionals ensure that they follow pathways for referral and diagnosis for people with suspected sarcoma that have been agreed by sarcoma advisory groups and sarcoma MDTs.

Commissioners (clinical commissioning groups and NHS England) ensure that all sarcoma advisory groups and sarcoma MDTs work with primary and secondary care providers to establish and implement pathways for referral and diagnosis for people with suspected sarcoma.

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

People with symptoms that suggest sarcoma (a rare type of cancer that develops in a bone or in soft tissue such as muscle or fat) are referred and have investigations carried out by healthcare professionals who follow advice on diagnosing sarcoma from specialists in sarcoma.

## *Source guidance*

- [Sarcoma](#) (2006) NICE cancer service guidance, Section 3: Improving diagnosis of bone and extremity soft tissue sarcoma (page 37)

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

### **Suspected sarcoma**

The NICE guideline [suspected cancer: recognition and referral](#) includes recommendations for referral for suspected sarcoma.

## Quality statement 2: Multidisciplinary teams for sarcoma

### *Quality statement*

Adults, children and young people with bone sarcoma and adults with soft tissue sarcoma have their care plan confirmed by a sarcoma multidisciplinary team (MDT) and treatment delivered by services designated by the sarcoma advisory group.

### *Rationale*

A sarcoma MDT should confirm care plans for adults, children and young people with bone sarcoma and adults with soft tissue sarcoma, although they might not deliver all of their care. Treatment may be provided by other services if agreed by the sarcoma MDT and sarcoma advisory group. Children with soft tissue sarcoma, for example children with rhabdomyosarcoma, would usually be managed by paediatric oncology MDTs.

### *Quality measures*

#### **Structure**

a) Evidence of written protocols and local arrangements for adults, children and young people with bone sarcoma and adults with soft tissue sarcoma to have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the sarcoma advisory group.

**Data source:** Local data collection.

b) Evidence of written protocols and pathways agreed 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 [Manual for cancer services: sarcoma measures](#), measure 14-2L-112.

#### **Process**

a) Proportion of adults, children and young people with bone sarcomas who have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the sarcoma advisory group.

Numerator – the number in the denominator who have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the sarcoma advisory group.

Denominator – the number of adults, children and young people with bone sarcomas.

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

b) Proportion of adults with soft tissue sarcomas who have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the sarcoma advisory group.

Numerator – the number in the denominator who have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the sarcoma advisory group.

Denominator – the number of adults with soft tissue sarcomas.

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

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

**Service providers** (such as hospitals, sarcoma MDTs and cancer MDTs) ensure that adults, children and young people with bone sarcomas and adults with soft tissue sarcomas have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the sarcoma advisory group. Site-specific cancer MDTs that are not specifically for sarcoma should liaise with sarcoma MDTs when people with sarcoma are referred to them.

**Healthcare professionals** ensure that adults, children and young people with bone sarcomas and adults with soft tissue sarcomas have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the sarcoma advisory group.

**Commissioners** (such as NHS England and clinical commissioning groups) ensure that adults, children and young people with bone sarcomas and adults with soft tissue sarcomas receive a care plan that is confirmed by a sarcoma MDT and treatment that is delivered by services designated by the sarcoma advisory group.

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

Adults with soft tissue or bone sarcoma (a rare type of cancer that develops in a bone or in soft tissue such as muscle or fat) and children and young people with bone sarcoma are cared for with the help of a sarcoma multidisciplinary team (a specialist team of healthcare professionals who have training and experience in caring for people with sarcoma) who will advise on their care plan. Children with soft tissue sarcoma are usually cared for by a team that specialises in children's cancers (a paediatric oncology multidisciplinary team).

### *Source guidance*

- [Sarcoma](#) (2006) NICE cancer service guidance, Section 5: Improving treatment: sarcoma multidisciplinary teams (pages 54 and 56)

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

#### **Sarcoma multidisciplinary team (MDT)**

The core membership of a sarcoma MDT is defined in the National Cancer Peer Review [Manual for cancer services: sarcoma measures](#).

Sarcoma MDTs can also have extended team members, some of whom may work as part of the core team. Extended team members can work at sites distant from the sarcoma MDT. Extended team members should participate in sarcoma MDT meetings when appropriate. Extended team roles include:

- specialist sarcoma physiotherapist
- specialised allied health professionals (such as therapy radiographers, occupational therapists, prosthetists, orthotists, dietitians, social workers, counsellors or psychologists)
- paediatric oncologist (specifically for MDTs that treat children and young people with bone and/or soft tissue sarcoma)
- specialist nurse(s) (including palliative care nurses and appropriately trained ward staff)
- designated medical or clinical oncologist from a linked cancer centre
- affiliated diagnostic service clinicians
- other professionals including orthopaedic, thoracic, plastic, head and neck, gynaecological,

- gastrointestinal and vascular surgeons.

[Adapted from [Sarcoma](#) (NICE cancer service guidance), Section 5: Improving treatment: sarcoma multidisciplinary teams and National Cancer Peer Review [Manual for cancer services: sarcoma measures](#)]

### *Equality and diversity considerations*

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



## Quality statement 3: Publishing information about areas of expertise

### *Quality statement*

Sarcoma multidisciplinary teams (MDTs) publish information about their shared pathways, activity and patient outcomes, including information on site-specific sarcomas.

### *Rationale*

Sarcoma MDTs should increase awareness of their pathways and arrangements to treat sarcomas, and their patient outcomes and activity. This will demonstrate their expertise and help commissioners to identify which sarcoma MDTs are best suited to treat particular sarcoma types and help in making decisions about referrals.

### *Quality measures*

#### **Structure**

Evidence of local arrangements for sarcoma MDTs to publish information about shared pathways, activity and patient outcomes, including information on site-specific sarcomas.

*Data source:* Local data collection.

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

**Service providers** (sarcoma MDTs) ensure arrangements are in place for the publication of information about their shared pathways, activity and patient outcomes, including information for site-specific sarcomas. This may involve working in collaboration with NHS England specialised services, specialist centres and the NHS England Sarcoma Clinical Reference Group.

**Healthcare professionals** ensure that they collect data and publish activity and patient outcome data, including information for site-specific sarcomas.

**Commissioners** (NHS England and clinical commissioning groups) ensure that they commission services that publish details of their arrangements with site-specific cancer MDTs to manage site-specific sarcomas, and that also collect and publish activity and patient outcome data, including information for site-specific sarcomas.

## *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) can see how different sarcoma multidisciplinary teams (specialist teams of healthcare professionals who have training and experience in caring for people with sarcoma) treat their particular type of sarcoma, which may help them decide on the best sarcoma multidisciplinary team to treat them.

### *Source guidance*

- [Sarcoma](#) (2006) NICE cancer service guidance, Section 5: Improving treatment: sarcoma multidisciplinary teams (page 54) and Section 10: Improving knowledge (page 96)

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

#### **Activity and patient outcomes**

Activity and patient outcomes for sarcoma MDTs include:

- number of new cases per annum
- local recurrence rates
- patient experience of care
- treatment morbidity and physical function
- survival rates.

[Definition developed from expert consensus; adapted from [Sarcoma](#), NICE cancer service guidance]

#### **Site-specific sarcomas**

Site-specific sarcomas include gynaecological sarcomas, head and neck sarcomas, retroperitoneal and pelvic sarcomas, chest wall or intrathoracic sarcomas, skin sarcomas, central nervous system sarcomas, gastrointestinal stromal tumours, urological sarcomas and breast sarcomas.

[Definition developed from expert consensus; adapted from [Sarcoma](#), NICE cancer service guidance]

## Quality statement 4: Retroperitoneal sarcoma

### *Quality statement*

People with a retroperitoneal sarcoma are referred before having any treatment to a sarcoma treatment centre with special expertise in managing this type of tumour.

### *Rationale*

Treating retroperitoneal sarcomas poses particular challenges, and experience of treating this tumour type will vary between sarcoma treatment centres. Outcomes for people with retroperitoneal sarcoma will be improved by concentrating their treatment at centres with staff who are experienced in managing this type of tumour.

### *Quality measures*

#### **Structure**

Evidence of local arrangements and protocols to ensure that people with a retroperitoneal sarcoma are referred before having any treatment to a sarcoma treatment centre with special expertise in managing this type of tumour.

*Data source:* Local data collection.

#### **Process**

Proportion of people with a retroperitoneal sarcoma who are referred before having any treatment to a sarcoma treatment centre with special expertise in managing this type of tumour.

Numerator – the number in the denominator who are referred before having any treatment to a sarcoma treatment centre with special expertise in managing this type of tumour.

Denominator – the number of people with a retroperitoneal sarcoma.

*Data source:* Local data collection.

#### **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 such as hospitals, sarcoma multidisciplinary teams (MDTs) and cancer MDTs) ensure that protocols are in place to refer people with a retroperitoneal sarcoma before they have any treatment to an identified treatment centre with special expertise in treating this type of sarcoma.

**Healthcare professionals** ensure that they refer people with retroperitoneal sarcoma before they have any treatment to a treatment centre with special expertise in treating this type of sarcoma.

**Commissioners** (NHS England Sarcoma Clinical Reference Group) may wish to consider including a definition for retroperitoneal sarcoma centres with special expertise in national service specifications. Clinical commissioning groups ensure that they commission services that have protocols in place to refer people with a retroperitoneal sarcoma before they have any treatment to an identified treatment centre with special expertise in treating this type of sarcoma.

### *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) are referred to a centre that has special expertise in treating this type of sarcoma before being offered any treatment.

### *Source guidance*

- [Sarcoma](#) (2006) NICE cancer service guidance, Section 7: Improving treatment: soft tissue sarcomas (page 73)

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

#### **Sarcoma treatment centre with special expertise in managing this type of tumour**

Treatment centres with special expertise in treating retroperitoneal sarcoma should be identified locally by taking into account case volumes and patient outcomes for retroperitoneal sarcoma.

[Definition developed from expert consensus]

## *Equality and diversity considerations*

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

## Quality statement 5: Surgical skills

### *Quality statement*

Surgeons performing planned resections of sarcomas are core or extended members of a sarcoma multidisciplinary team (MDT).

### *Rationale*

Sarcoma resection carried out by a specialist sarcoma surgeon, who is a core member of the sarcoma MDT, is generally more likely to result in improved patient outcomes. However, 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 the surgeon should be an extended member of a sarcoma MDT.

### *Quality measures*

#### Structure

Evidence of local arrangements and protocols to ensure that people who have planned resection of their sarcoma have it performed by a surgeon who is a core or extended member of a sarcoma MDT.

**Data source:** Local data collection.

#### Process

Proportion of planned sarcoma resections that are performed by a surgeon who is a core or extended member of a sarcoma MDT.

Numerator – the number in the denominator that are performed by a surgeon who is a core or extended member of a sarcoma MDT.

Denominator – the number of planned sarcoma resections.

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

## Outcome

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

*Data source:* Local data collection.

b) Recurrence within 2 years of initial surgery.

*Data source:* Local data collection.

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

**Service providers** (such as hospitals, sarcoma specialist centres) ensure that operational policies and procedures are in place for people having planned resection of their sarcoma to either have it carried out by a surgeon who is a core member of a sarcoma MDT or, when appropriate, by a surgeon who is an extended member of a sarcoma MDT with tumour site-specific or age-appropriate skills.

**Healthcare professionals** ensure that people having planned resection of their sarcoma have it carried out by a surgeon who is a core member of a sarcoma MDT or, when appropriate, by a surgeon with tumour site-specific or age-appropriate skills who is an extended member of a sarcoma MDT.

**Commissioners** (NHS England and clinical commissioning groups) should ensure that policies and procedures are in place for people who are having planned resection of their sarcoma to either have it carried out by a surgeon who is a core member of a sarcoma MDT or, when appropriate, by a surgeon who is an extended member of a sarcoma MDT with tumour site-specific or age-appropriate skills.

### *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 having surgery to remove their tumour have their operation done either by an experienced surgeon who specialises in sarcomas and is part of the sarcoma multidisciplinary team (a specialist team of healthcare professionals who have training and experience in bone or soft tissue sarcoma) or by a surgeon who has other suitable specialist skills and works with a sarcoma multidisciplinary team.

## *Source guidance*

- [Sarcoma](#) (2006) NICE cancer service guidance, Key recommendations (page 8) and Section 5: Improving treatment: sarcoma multidisciplinary teams (page 56)

## *Equality and diversity considerations*

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



## Quality statement 6: Key workers

### *Quality statement*

People with sarcoma are supported by an allocated key worker with specialist knowledge of sarcomas and their treatment.

### *Rationale*

Because sarcoma is such a rare cancer, specialist knowledge of the condition and its treatment is not widespread. It is important that people with sarcoma are able to contact a key worker who can provide specialist guidance and support at all stages of their care and treatment, including during follow-up. Key workers can also act as a link to local support groups. In addition, 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, and in providing necessary clinical information to these services.

### *Quality measures*

#### **Structure**

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

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

#### **Process**

Proportion of people with sarcoma who have an allocated key worker with specialist knowledge of sarcomas and their treatment.

Numerator – the number in the denominator who are allocated a key worker with specialist knowledge of sarcomas and their treatment.

Denominator – the number of people with sarcoma.

**Data source:** Local data collection.

## 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 Intelligence Network [National cancer patient experience survey](#).

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

Service providers (such as sarcoma specialist centres and hospitals) ensure that sufficient key workers with specialist knowledge of sarcomas and their treatment are available to support people with sarcoma, and that cover is available for illness or annual leave.

Healthcare professionals ensure that people with sarcoma are allocated a key worker with specialist knowledge of sarcomas and their treatment.

Commissioners (NHS England Sarcoma Clinical Reference Group) may wish to consider including in national service specifications that people with sarcoma are allocated a key worker with specialist knowledge of sarcomas and their treatment.

### *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) are supported by a 'key worker', who is a healthcare professional with specialist knowledge of sarcoma. People with sarcoma should be able to contact their key worker for information and support throughout their care.

### *Source guidance*

- [Sarcoma](#) (2006) NICE cancer service guidance, Section 8: Supportive and palliative care (page 82)

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

### **Key workers with specialist knowledge of sarcomas**

Key workers are usually specialist nurses or allied health professionals who have an in-depth or specialist knowledge of sarcomas and their treatment. They can act as advocates for the patient, helping to coordinate the diagnostic and treatment pathway, providing continuity and ensuring the patient knows how to access information and advice.

[[Sarcoma](#) (NICE cancer service guidance)]

## 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.

### *Information for the public*

NICE has produced [information for the public](#) about this quality standard. Patients, service users and carers can use it to find out about the quality of care they should expect to receive; as a basis for asking questions about their care, and to help make choices between providers of social care services.

## 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 adults, 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. Adults, 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](#).

## 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.

- [Suspected cancer: recognition and referral](#) (2015) NICE guideline NG12
- [Sarcoma](#) (2006) NICE cancer service guidance

## Policy context

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

- National Cancer Peer Review Programme (2013) [National Peer Review Report: cancer services 2012/2013](#)
- NHS England (2013) [Service specification: Cancer soft tissue sarcoma \(adult\)](#)
- NHS England (2013) [Service specification: Primary malignant bone tumours service \(adults and adolescents\)](#)
- Department of Health (2013) The national cancer strategy: 3rd annual report
- Welsh Assembly Government (2013) [Wales cancer patient experience survey 2013](#)
- Department of Health (2012) [National cancer patient experience survey 2011/12](#)
- Welsh Assembly Government (2012) [Together for health: cancer delivery plan for the NHS to 2016](#)
- Department of Health (2011) [Improving outcomes: a strategy for cancer](#)
- Department of Health (2011) [Commissioning cancer services](#)

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

- National Cancer Intelligence Network [National cancer patient experience survey](#)
- National Cancer Intelligence Network [Cancer outcomes and services dataset](#)
- National Cancer Peer Review [Manual for cancer services: sarcoma measures](#)

## Related NICE quality standards

### *Published*

- [Transition from children's to adults' services \(2016\)](#) NICE quality standard 140
- [Suspected cancer \(2016\)](#) NICE quality standard 124
- [Cancer services for children and young people \(2014\)](#) NICE quality standard 55
- [Patient experience in adult NHS services \(2012\)](#) NICE quality standard 15
- [End of life care for adults \(2011\)](#) NICE quality standard 13

### *In development*

- [End of life care for infants, children and young people](#). Expected publication October 2017

The full list of quality standard topics referred to NICE is available from the [quality standards topic library](#) on the NICE website.



## 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**

General Medical Practitioner, Tramways Medical Centre/Academic Unit of Primary Medical Care, University of Sheffield

**Jan Dawson**

Public Health Nutrition Lead and Registered Dietician, Manchester City Council

**Dr Matthew Fay**

GP, Westcliffe Medical Practice, Shipley, West Yorkshire

**Dr Malcolm Fisk**

Co-Director, Ageing Society Grand Challenge Initiative, Coventry University

**Ms Margaret Goose**

Lay member

**Mrs Geeta Kumar**

Clinical Director, Women's Services (East) Betsi Cadwaladr University Health Board

**Mrs Rhian Last**

Clinical Lead, Education for Health

**Dr Hugh McIntyre (Chair)**

Consultant Physician, East Sussex Healthcare Trust

**Mrs Mandy Nagra**

Cancer Drug Fund and Individual Funding Request Manager, Specialised Commissioning, NHS England

**Ms Ann Nevinson**

Lay member

**Dr Jane O'Grady**

Director of Public Health, Buckinghamshire County Council

**Mrs Jane Orr-Campbell**

Director, Orr-Campbell Consultancy, Bedfordshire

**Professor Gillian Parker**

Professor of Social Policy Research and Director, Social Policy Research Unit, University of York

**Mr David Pugh**

Independent Consultant, Gloucestershire County Council

**Dr Eve Scott**

Head of Safety and Risk, The Christie NHS Foundation Trust, Manchester

**Dr Jim Stephenson**

Consultant Medical Microbiologist, Epsom and St Helier NHS Trust

**Mr Darryl Thompson**

Psychosocial Interventions Development Lead, South West Yorkshire Partnership NHS Foundation Trust

**Mrs Julia Thompson**

Strategic Commissioning Manager, Sheffield City Council

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

**Professor Robert Grimer**

Consultant Orthopaedic Oncologist, Royal Orthopaedic Hospital, Birmingham

**Ms Sam Hackett**

Clinical Nurse Specialist, Royal Marsden Hospital

**Dr Philip Robinson**

Clinical Director Radiology, Leeds Teaching Hospitals

**Professor Meirion Thomas**

Professor of Surgical Oncology, Royal Marsden Hospital

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Professor of Cancer Medicine and Consultant Medical Oncologist, The London Sarcoma Service,  
University College Hospital

**Mr Roger Wilson CBE**

Lay member

*NICE project team*

**Mark Minchin**

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**Rachel Neary-Jones**

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**Thomas Walker**

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**Esther Clifford**

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**Jenny Mills**

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## Update information

### Minor changes since publication

**July 2017:** References and links to the NICE guideline on suspected cancer have been updated.

**September 2015:** A link in the definitions section for statement 1 has been updated.

## 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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## *Endorsing organisation*

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

## *Supporting organisation*

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Sarcoma UK](#)