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standard

Sarcoma

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This standard is based on CSG9.

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

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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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 different audiences

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 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.

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

Improving outcomes for people with sarcoma. NICE guideline CSG9 (2006), 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 on 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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 different audiences

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 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.

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

Improving outcomes for people with sarcoma. NICE guideline CSG9 (2006), 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 NICE's guideline on improving outcomes for people with sarcoma, 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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 different audiences

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 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.

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

Improving outcomes for people with sarcoma. NICE guideline CSG9 (2006), 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 NICE's guideline on improving outcomes for people with sarcoma]

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 NICE's guideline on improving outcomes for people with sarcoma]

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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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 different audiences

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 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.

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

Improving outcomes for people with sarcoma. NICE guideline CSG9 (2006), 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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 different audiences

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 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.

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

Improving outcomes for people with sarcoma. NICE guideline CSG9 (2006), 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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 different audiences

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 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.

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

Improving outcomes for people with sarcoma. NICE guideline CSG9 (2006), 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. [NICE's guideline on improving outcomes for people with sarcoma]

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.

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, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See our webpage on quality standards advisory committees for details about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

Equality issues were considered during development and equality assessments for this quality standard are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

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.

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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