NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Sarcoma

Date of Quality Standards Advisory Committee post-consultation meeting:
15 October 2014.

2 Introduction

The draft quality standard for sarcoma was made available on the NICE website for a 4-week public consultation period between 21 August and 18 September 2014. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 21 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendix 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

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

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

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

Stakeholders were also invited to respond to the following statement specific questions:

4. For draft quality statement 3: How would you define ‘specific area of expertise’ to make this statement workable in practice?

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

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

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’?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Some stakeholders disagreed with directing patients to sarcoma MDTs when age-appropriate or other cancer MDTs would have more expertise.
- A concern was raised that there is a need for greater provision in the QS for soft tissue sarcomas in children, particularly as their management requires special consideration. Clear statements/descriptions for practices for children with soft tissue sarcoma are needed.
- Inclusion of palliative care in quality statement 6 was welcomed but could greater consideration for palliative care be included elsewhere in the quality standard?
- NICE Quality Standard 55 (‘Children and young people with cancer’) should be more prominent in the QS, rather than just as a related source.
- Several stakeholders were concerned about the use of ‘Amputation rates’ as an overarching outcome measure, as:
    - Amputation can be an inevitable outcome and an appropriate option, and therefore should not be penalised. Functional outcomes can be better following amputation than after limb salvage.
    - A stakeholder suggested that physical function would be a preferable measure.
    - A suggested measure was to set a minimum percentage of cases in a sarcoma unit which resulted in amputation – if a unit performed fewer than this percentage then it may indicate that the unit was taking too many risks.
    - A stakeholder noted that there are there are situations where the patient’s own choice will be to take reconstructive surgery, at the

expense of increased risk of local relapse. Such situations reflect good shared decision making and needs to be understood in this outcome.

Consultation comments on data collection

- A stakeholder commented that it should be reasonably straight-forward to collect data for these quality statements with the possible exception of statement 3 regarding liaison between sarcoma MDTs and other cancer services.
- Stakeholders commented that if systems and structures (such as a secure internet based common database) were supported locally and nationally then data collection would be possible. A stakeholder also noted that much of the burden for data collection would fall on MDT meetings – potentially overburdening their resources and reducing time available in meetings for patient management planning.

5 Summary of consultation feedback by draft statement

5.1 Draft 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).

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Several stakeholders commented on the need for clearer and/or stronger language than ‘supervised by’ or ‘in conjunction with’.
- A stakeholder suggested that this statement should apply to all people with suspected sarcoma, rather than just people with a confirmed sarcoma diagnosis – with diagnostic pathways supervised by, or provided by, a sarcoma MDT. A further stakeholder also suggested that this quality statement should cover diagnostic services.
- A stakeholder commented that this quality statement doesn’t identify who is responsible for patient management. While a sarcoma MDT won’t always be treating a sarcoma patient, they should be discussing and confirming treatment. An altered statement was suggested by the stakeholder: “*People with a confirmed diagnosis of bone or soft tissue sarcoma will have their care plan discussed and confirmed by the sarcoma multi-disciplinary team (MDT)*.”
- A stakeholder commented that gynaecological sarcomas should be predominantly managed by gynaecological cancer MDTs. Sarcoma MDTs should be notified about the majority of cases (endometrial stromal sarcoma/lieomyosarcomas) and consulted for opinion in selected cases. The stakeholder suggested improving liaisons between sarcoma and gynaecancer MDTs.
- A stakeholder commented that children and young people with soft tissue sarcoma should be first discussed at a paediatric oncology diagnostic and treatment MDT. If appropriate they should be referred onto the Sarcoma MDT. In addition, a stakeholder commented that Rhabdomyosarcoma (RMS) in children

are generally reviewed and treated within the ‘site-specific’ MDT of children’s cancer, rather than a separate - usually adult-oriented - sarcoma MDT. If this quality standard is to relate to all RMS then the sarcoma MDTs will require paediatric expertise added to their list of professionals.

- A stakeholder was in agreement with the statement but cautioning that further rationalisation of services would need to be carefully considered as there is a risk that valuable regional expertise would be lost and patients would need to travel larger distances for specialist care for no additional benefit.
- A stakeholder commented that it would be potentially beneficial to put in place an arrangement for case-review or second opinion between sarcoma MDTs for unusually complex or rare STSs (beyond current informal arrangements).
- Quality measure: Structure measure b) should set out that sarcoma MDTs are responsible for all sarcoma patients and that they determine protocols and pathways for the involvement of non-sarcoma MDTs. Without this lead, non-sarcoma MDTs will continue to manage and treat sarcoma patients without referring on to sarcoma MDTs.
- A stakeholder suggested that the section ‘*What the quality statement means for patients, service users and carers*’ for this quality statement is too vague and not consistent with the rest of the statement.

5.2 Draft statement 2

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

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- It was suggested by several stakeholders that the statement should exactly reflect current National Cancer Peer Review measures.
- A stakeholder commented that the statement did not reflect scenarios where treatment is delivered locally by a ‘designated’ member of an MDT who is recognised as an extended member of the MDT. A further stakeholder also suggested the need for the National Cancer Peer Review team to reconsider criteria used to define ‘extended’ MDT members to more tightly define this role.
- A stakeholder suggested that the ‘specialist sarcoma radiologists’ members of the core MDT should be defined by more precise criteria.
- A further stakeholder suggested that the sarcoma MDT core roles should include a physiotherapist and an occupational therapist.

5.3 Draft statement 3

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

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Stakeholders commented that this quality statement was too vague, potentially of limited value and is also unmeasurable.
- A stakeholder commented that defining 'areas of specific expertise' would not be possible and the absence of a definition could lead to this statement being misused as a tool for self-promotion.
- A stakeholder commented that it would be better to focus on pathways for site-specific sarcomas, i.e. "*Sarcoma MDTs share information about shared pathways for site specific sarcomas*".
- A stakeholder suggested that this quality statement should be focused on sharing information about pathways between site-specific or non-sarcoma MDTs and sarcoma MDTs. Achievement measures could be based on evidence that such pathways are in place and that they are being used.
- A stakeholder also commented that this quality statement appears to put the onus on sarcoma MDTs to share information – rather than emphasising that non-sarcoma MDTs should take responsibility to refer sarcoma cases to a sarcoma MDT.
- A stakeholder noted that the provision of information on sarcoma MDTs/treatment centres should be easily accessible (including contact and referral guidelines) and that this is measured by peer review.

Consultation question 4

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

Stakeholders made the following comments in relation to consultation question 4:

- A stakeholder suggested that ‘specific area of expertise’ would need to be agreed nationally for each speciality (e.g. surgeon, pathologist, nurse).
- A stakeholder suggested that specific areas of expertise would become apparent if a national internet based common database was set up.
- Stakeholders noted that sarcoma MDTs should already write guidelines detailing at what point suspected sarcomas are highlighted to the sarcoma MDT, along with a specification of the roles of the sarcoma MDT and site specific teams. Specific area of expertise should be apparent from these guidelines.

Consultation question 5

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

Stakeholders made the following comments in relation to consultation question 5:

- A stakeholder suggested that services could measure achievement of this statement using website information, patient surveys, national website availability and through GP knowledge of local sarcoma services.
- A further stakeholder suggested the use of national databases and audits.
- Stakeholders suggested that practice could be measured using guidelines written by sarcoma MDTs detailing their interactions with other site-specific MDTs.
- Stakeholder suggested that this statement could be assessed in terms of outcome, e.g. by looking at patient experience (was care ‘joined up’ or ‘coordinated’?). Alternatively, assessment could be via examining MDT documentation.

5.4 Draft 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.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- A stakeholder commented that a specific measure for retroperitoneal sarcoma was unnecessary.
- A stakeholder commented that retroperitoneal sarcoma is a rare group of sarcomas occurring in a challenging anatomical area of the body, and that optimum time for resection with curative intent is at primary resection.
- A stakeholder asked what the national definition of a retroperitoneal surgeon is, and who would designate these surgeons nationally. The stakeholder also asked if retroperitoneal surgery should be recognised as a sub-speciality nationally, and how this would be achieved.
- Stakeholders commented that concentrating retroperitoneal sarcomas in specialist/high-volume centres would improve patient outcomes.
- Stakeholders commented that this statement should not focus on an individual surgeon, but rather that this tumour type should be treated by a specialist service/centre.
- Stakeholders were clear that ‘special expertise’ (as in the statement) needs to be carefully defined – as discussed in responses to consultation question 7 below.

Consultation 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?

Stakeholders made the following comments in relation to consultation question 6:

- Two stakeholders commented that retroperitoneal sarcoma pathways are quite different to other sarcoma pathways and warrant a separate quality statement.

- A stakeholder commented that statement 4 does duplicate and overlap with statement 5.
- A further stakeholder commented that statement 4 is a subset of statement 5.

Consultation 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’?

Stakeholders made the following comments in relation to consultation question 7:

- Several stakeholders commented that defining ‘specific expertise’ should be based on centre or sarcoma MDT activity rather than based on an individual surgeon, with the centre having more than one surgeon with suitable experience in retroperitoneal sarcoma surgery and requisite support infrastructure. Stakeholders suggested that the definition should be based on the number of cases a centre/sarcoma MDT deals with. A stakeholder suggested that the minimum number of new patients with retroperitoneal sarcoma managed by a sarcoma MDT to qualify for ‘special expertise’ should be 25 (excluding gastrointestinal stromal tumour [GIST]). A further stakeholder suggested that a specialist retroperitoneal sarcoma service should deal with 25 retroperitoneal sarcomas per year (not including GIST and intra-abdominal sarcomas not arising in the retroperitoneum).
- Several stakeholders suggested that surgeons with ‘special expertise’ in managing retroperitoneal sarcoma should be members of a sarcoma MDT. Alternatively, a stakeholder suggested that surgical teams should show close working with a sarcoma MDT by demonstrating written guidelines on shared pathway involving relevant members of the sarcoma MDT (e.g. oncologists and pathologists).
- A stakeholder commented that ideally surgeons with special expertise should have a certain number of cases per year, but that this would be hard to set as there are so few new patients.
- A stakeholder commented that this is a very contentious subject and that the use of bare numbers to assess expertise is a blunt tool. The number of retroperitoneal

sarcoma surgeries carried out per year does not necessarily indicate the quality of surgery; particularly if, in addition to retroperitoneal sarcoma, a surgeon has a large non-sarcoma retroperitoneal practice.

- A stakeholder commented that if competency must be set by arbitrarily selecting an indicative number of cases per year, then a whole year of experience in retroperitoneal surgery, not just primary resection of retroperitoneal sarcoma, should be considered. Alternatively a further stakeholder commented that a surgeon would need a full understanding of the biological behaviour and disease process of retroperitoneal sarcoma, and not only anatomical expertise and practical skills of performing surgery in the retroperitoneum. Further stakeholders suggested that named surgeons should demonstrate expertise in total numbers of retroperitoneal operations performed per year and also expertise in sarcoma by stating the number of sarcomas operated on in a year.
- A stakeholder commented that a surgeon with ‘special expertise’ in managing retroperitoneal sarcoma is a consultant with CCT in general surgery who has spent time either as a senior trainee or as a consultant in theatre with a surgeon already recognised as an expert in this field (experience, prospective audit) assisting with the operations, and then who maintains a link to such a person as a mentor as they develop their own practice. Such surgeons must commit to auditing their work prospectively and comparing with benchmarks and including results in annual appraisal and revalidation reviews.
- A stakeholder asked if this should be nationally agreed, or potentially measured in hours of operating time or by set surgical standards.

Draft 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.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- A stakeholder commented that surgeons with age-appropriate skills alone may not be suitable to deliver sarcoma surgery - as they may not have experience in oncological surgery. A further stakeholder also commented that there is little value in the term ‘age appropriate’ which, in itself, does not denote skills relating to sarcoma which are important in all age groups, including adolescent and paediatric patients and the elderly.
- A stakeholder noted that, for children and young people, who performs the surgery is adequately covered by the statement (a surgeon with age-appropriate skills) however the statement should also state that such cases should be discussed at a paediatric oncology diagnostic and treatment MDT and then referred as appropriate to the sarcoma MDT.
- A stakeholder commented that paediatric oncology surgeons are used to dealing with soft tissue sarcomas in children – but that there is no description of how a paediatric oncology surgeon would be designated as a soft-tissue surgeon and what limitations would be considered with regard to operating on special sites (e.g. the bladder/prostate, orbit or cranium).
- A stakeholder commented that surgery for sarcoma should be planned operations undertaken by surgeons who are members of sarcoma MDTs. The inclusion of ‘*or by a surgeon with tumour site-specific or age-appropriate skills in consultation with the sarcoma MDT*’ removes clarity, adds ambiguity and could be used to support sub-optimal practice.
- Two stakeholders commented that the statement should be amend to specify that all sarcoma patients that have resection have it carried out by a surgeon who is a core member of a sarcoma MDT or, if appropriate, by a tumour-specific surgeon who is an extended member of the sarcoma MDT.

- A stakeholder commented that a majority of gynaecological sarcomas are mistaken pre-operatively for benign fibroids – therefore the majority of major resections for these sarcomas are not performed at an institution with a specialist sarcoma MDT or a specialist gynaecological oncology centre. Only after surgery will cases be referred to gynaecological cancer centres/regional sarcoma MDTs. The stakeholder also stated that ovarian sarcomas present in the same manner as epithelial ovarian tumours and primary surgery for these cases should be performed by subspecialist gynaecological oncologists working within specialist gynaecological cancer centres. Again, referral should be made post-operatively to the regional sarcoma MDT.
- A stakeholder asked if there should be a requirement for plastic surgeons to be a core member of a sarcoma MDT, given that STS patients often need their expertise.

5.5 Draft 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.

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- Stakeholders commented that patients need information at every stage throughout their sarcoma diagnosis and treatment – however the current wording of the quality statement appears to relate only to early stages of diagnosis.
- A stakeholder suggested that, rather than providing information that describes a person's diagnosis or disease stage, information should describe both.
- A stakeholder noted that producing information that matches the heterogeneity of a sarcoma patient's experiences was a formidable challenge.
- A stakeholder commented that information on palliative care and pain control should not just be provided when 'no other treatment than palliative is available' (as per Table 3). The stakeholder emphasised that palliative care may be of benefit at various points in the pathway. Furthermore, the stakeholder commented that it made no sense that such information be provided by a palliative care centre – as a patient would need to know why they were going to a palliative care centre before they arrived.
- A stakeholder suggested that further information on pre-habilitation/rehabilitation and on how to get referral to specialist allied health professionals should be included in the Information Pathway (Table 3) on referral to sarcoma treatment centres and at diagnosis.
- A stakeholder suggested that the statement should include the provision of details of national patient organisations that can provide further information and support.

5.6 Draft 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.

Consultation comments

Stakeholders made the following comments in relation to draft statement 7:

- Stakeholder suggested that 'key worker' should be replaced with 'clinical nurse specialist' in line with current trends and practice. A stakeholder commented that patient experience is maximised through contact with a clinical nurse specialist.
- Stakeholders commented that just providing the contact details of a key worker was not sufficient – and that key workers should make personal contact with sarcoma patients.
- Stakeholders suggested that key workers should be present with patients at key stages of the pathway (diagnosis, treatment and follow-up). A further stakeholder suggested that this would require investment in the sarcoma service so that clinical nurse specialists have dedicated time for all parts of pathway.
- A stakeholder suggested that some expectation of what key workers provide should be specified. In particular, the stakeholder commented that it would be important to specify a key worker's level of knowledge and expertise.
- A stakeholder commented that cover for key workers should be provided by someone with similar sarcoma knowledge/expertise, rather than by another key worker from a different cancer site or a clerical worker.
- A stakeholder commented that key workers should be emphasised as members of a sarcoma MDT.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Stakeholders suggested that the QS should also address accurate and prompt diagnosis of sarcoma. A stakeholder commented that diagnostic clinics (under the auspices of a Sarcoma Advisory Group and linked to a sarcoma MDT) should be expanded to facilitate investigation of patients who fulfil criteria for referral – improving the timely and appropriate diagnosis of sarcoma.
- A stakeholder suggested that improving the general public's and GP's awareness of sarcoma and best practice goals would also drive up standards.
- A stakeholder recommended that an additional statement relating to discharge and care pathways should be included, covering access to rehabilitation services.
- A stakeholder noted that it would be interesting to review histology diagnoses across sarcoma MDTs to determine the level of consistency of reporting by pathologists at different sarcoma MDTs.

Appendix 1: Quality standard consultation comments table

ID	Stakeholder	Statement No	Comments[1]
1	Sarcoma UK	Why this quality standard is needed	We agree that people with sarcoma should be treated by healthcare professionals with experience and expertise in treating sarcoma. We agree with the further focus that people with sarcoma should have their treatment carried out by, or in conjunction with healthcare professionals with experience in their particular sarcoma type. However, we believe that this Quality Standard in its current format is not currently clear enough to ensure that this focus will be achieved fully and consistently. Most significantly, this Quality Standard fails to address the vital issue of accurate and prompt diagnosis of sarcoma, and in our view this is a major omission and failing. There are two key issues for sarcoma patients that have a significant impact on outcomes and the quality of their experience: earlier diagnosis and prompt access to sarcoma specialist services. Neglecting to address the first issue minimises the impact and benefit this quality standard could have. A Sarcoma UK telephone survey of GPs in 2013 indicated that GPs were unaware of the red flag signs of sarcoma, but importantly they also didn't understand the pathways for referral to sarcoma diagnostic services. One GP said "I don't think there is a pathway for sarcoma"; another said, "We do refer but before sending we have a lot of hurdles to pass". A NICE Quality Standard that provides guidance for the diagnosis of sarcoma has the potential to make a significant impact for sarcoma patients across the country. Access to sarcoma specialist services is still a problem despite the NICE IOG, and in our view unacceptably low. Only one in every four referrals for sarcoma is to a sarcoma specialist centre. Data from NCIN/West Midlands KIT indicates that 40% of sarcoma patients (with soft tissue sarcomas of the extremities) are not treated in a sarcoma specialist centre. We broadly support the four areas where improvement in outcomes will be seen through this Quality Standard although we question the order of the list and in particular the focus on amputation rates rather than physical function as a measure.
2	Alder Hey Children's NHS Foundation Trust	General	Professor Barry Pizer, Consultant Paediatric Oncologist:

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement No	Comments[1]
			I have reviewed the quality standards relating to sarcomas which I note applies to children, young people and adults. Whilst I am in favour of specialist MDTs in the management of rare tumours, I am concerned to how the process by which the standards were developed, the representation on the standards committee particularly with respect to paediatric oncology and the lack of consultation with regard to the children's cancer and leukaemia group. In my opinion the paediatric oncology community fully recognise the benefit of centralisation of surgery for bone tumours. This long established practice is clearly of benefit to patients. However, the quality standards seem to have been constructed as an expansion of the rationale for bone sarcomas rather than fully considering all the many different types and circumstances with respect to soft tissue sarcomas in childhood. Whilst many of the considerations regarding the management of bony sarcomas are similar to those for children with, for example, limb sarcomas, we recognise that soft tissue sarcomas can occur in many sites of the body including well recognised sites such as the orbit and the bladder/prostate. The quality standards do not recognise this. The description of the representation on the soft tissue sarcoma MDT should be relevant to the paediatric population if children are to be included in these quality standards. The management of children with soft tissue sarcomas does require special consideration but the document has not been drawn up with clear statements and description of practices with respect to children. We do have an informal (non-MDT) soft tissue sarcoma advisory service under the auspices of the children's cancer and leukaemia group (CCLG). It could be argued that this scheme could be formalised into a paediatric soft tissue sarcoma MDT but this and other ramifications of the quality standards for children does not seem to be described in the document. With regard to paediatric practice, the management of paediatric oncology surgeons are used to dealing with soft tissue sarcomas in children. There is no description about how a paediatric oncology surgeon would be designated as a soft tissue surgeon and what limitations would be considered with regard to operating on special sites such as the bladder/prostate, orbit, cranium etc. There are other example where the ramification of the quality standards for the paediatric population are not described. With regard to consultation I discussed the standards with the chair of the CCLG, Dr James Nicholson, and to his knowledge the CCLG have not been consulted with respect to writing these standards.

ID	Stakeholder	Statement No	Comments[1]
			I know Professor Jeremy Whelan is on the standards writing committee. I fully respect Professor Whelan's knowledge and expertise with regard to bone sarcomas but Professor Whelan's principle practice is with the TYA population and not within the paediatric population which, as above, have a wide range of different types of soft tissue sarcomas occurring in several different sites throughout the body all of which require specific treatment, particularly surgical considerations. May I urge NICE to discuss this fully with the CCLG and particularly involve the recognised soft tissue sarcoma expert -both rhabdomyosarcoma and non-rhabdomyosarcoma- members of the CCLG. I would be happy to discuss further.
3	Association for Palliative Medicine of Great Britain and Ireland	General	We welcome the inclusion of palliative care within table 3, but wonder whether consideration for palliative care for patients should be made elsewhere in the document? Patients may have difficult to control symptoms that would benefit from palliative care assessment / input at various stages in their illness.
4	British Gynaecological Cancer Society	General	The British gynaecological cancer society comprises gynaecological cancer surgeons, medical and clinical oncologists, pathologists, radiologists with an interest in treating gynaecological malignancies, gynaecological clinical nurse specialists and trainees. We invited our membership to respond to this draft document. Responses are collated below BGCS members feel that as gynaecological sarcomas are a different clinical entity that they should be managed predominantly by gynaecological cancer MDTs with notification to sarcoma MDT for the majority (endometrial stromal sarcoma/lieomyosarcomas) and opinion sought from sarcoma MDT's in selected cases. This liaison could be helped either by extended MDTs or a designated gynaecological MDT team member/s attending the sarcoma MDT for select cases. If gynaecological sarcomas could be clearly delineated as a different entity in the document and some suggestions made for entrenching liaison between gynaecancer MDTs and sacrcoma MDTs in this document, that would help for national guidance and audit. Optimal methods of follow-up vary in these cases and we feel that gynaecological cancer MDTs with their experience of managing gynaecological sarcoma, particularly low risk cases maybe best placed to devise appropriate follow-up strategies.
5	Children's Cancer and Leukaemia Group	General	NICE quality standard 55 (2014) Children and young people with cancer should be part of the definitions and data sources for the quality measures, and not a related source
6	Department of Health	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
7	GlaxoSmithKline	General	No comments to add
8	NHS England	General	The Sarcoma CRG would like QS to focus on timely and appropriate diagnosis. Not having a QS linked to this will perpetuate the problem of patients not accessing specialised sarcoma services:-

ID	Stakeholder	Statement No	Comments[1]
			Diagnostic clinics, under the auspices of a Sarcoma Advisory Group and linked to a specified sarcoma multidisciplinary team, should be expanded to allow rapid access to GPs in England for further investigations of patients presenting with a soft tissue or bony lump fulfilling the criteria for referral. This will provide earlier diagnosis for patients with sarcoma. The Sarcoma CRG do not believe that Improvements in amputation rates is an appropriate outcome measure for the QS. Amputation is an appropriate operation for some patients with sarcoma. It is occasionally an essential operation as a consequence of initial mismanagement from an absence of timely and appropriate diagnosis. Amputation rates should be monitored between sarcoma centres.
9	North Bristol NHS Trust	General	Patients from NBT would also like to feedback to the committee the importance of their clinical nurse specialist being present in clinic at diagnosis and key points along their sarcoma pathway and the huge benefit they have from being able to contact their specialist nurse with any questions or concern they may have. Just having a contact name was not felt by them to be sufficient.
10	Plymouth Hospital NHS Trust	General	We are concerned that the incidence of amputation has been chosen as an outcome measure. We feel that the outcome measure should perhaps be percentage of amputations where amputation was the appropriate outcome!. It is obviously ideal to reduce the incidence of amputation; however, there are certain cases where amputation is an inevitable outcome, (delayed presentation through lack of knowledge for example). Fear of having a high amputation rate could possibly lead a unit advising against this procedure inappropriately.
11	Royal College of Nursing	General	This is to inform you that there are no comments to submit on behalf of the Royal College of Nursing
12	Royal College of Paediatrics and Child Health	General	Currently, rhabdomyosarcoma in children are generally reviewed and treated within the ‘site-specific’ MDT of children’s cancer, rather than a separate - usually adult-oriented - sarcoma MDT. If this guidance is to relate to all RMS then the sarcoma MDTs will require paediatric expertise added to their list of professionals.
13	Royal College of Paediatrics and Child Health	General	Information sharing. This could be assessed in terms of process by examining MDT documentation noting correspondence, or in its outcomes by looking at patient experience -- do they feel their care is ‘joined up’ and ‘coordinated’
14	The Royal College of Surgeons of Edinburgh	General	In response to your quality standard consultation on Sarcoma, I have been asked to pass on the support of The Royal College of Surgeons of Edinburgh. Having circulated amongst our relevant specialists there were no suggested amendments, and not comments beyond those of support for the draft documents
15	Association of Chartered Physiotherapists in Oncology and Palliative Care	Table 1 4a [NHS Outcomes Framework]	“Ensuring that people have a positive experience of care” – patient experience of hospital/primary care/outpatient services – Should include Specialist Allied Health Professionals services as well.

ID	Stakeholder	Statement No	Comments[1]
16	London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)	Outcomes	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 We do not support this as a valuable outcome measure 1. Amputation can be a really good option for some patients. For example those with sarcomas around the foot. Functional outcome following amputation is better than after limb salvage. Sarcoma surgeons shouldn't be discouraged from performing amputation for the sake of targets. 2. One of the reasons for amputation is referral/delayed presentation. There is nothing in the document which addresses this. If the aim is to reduce amputation rates for this reason then education of GPs, hospital doctors and patients needs to be included. 3. It is already extremely rare for a patient to require amputation because of mismanagement (e.g. intralesional surgery) within a sarcoma unit. Amputation as a measurable outcome does not necessarily reflect quality of a unit's ability to achieve local control of the primary tumour. 4. If a sarcoma unit is not doing a minimum amount of amputations in percentage terms it may indicate they are taking too many risks. So the guidance could say the expected amputation rate should be X%. If a unit is performing significantly fewer amputations it would be a cause for concern.
17	Royal College of Paediatrics and Child Health	Outcomes	All outcomes are measurable, given appropriate data collection systems. Amputation rates & local control rates are interesting: there are situations where the patient’s own choice will be to take reconstructive surgery, at the expense of increased risk of local relapse. Such situations reflect good shared decision making and need to be understood in reporting the metrics.
18	Bristol Sarcoma Service	1	We are in agreement with this statement. However we would like to express the opinion that we do not think that all soft tissue sarcoma MDTs need to be co-located at units with a bone sarcoma service, which may be suggested by some. It is perfectly possible to have competent sarcoma surgeons for soft-tissue, and retroperitoneal disease, who can deal with the majority of cases without the need for an orthopaedic sarcoma surgeon. In recent years the management of sarcoma patients has been coordinated by regional sarcoma MDTs, either soft-tissue of soft-tissue and bone combined. We support this arrangement which has certainly improved patient care. However any further rationalisation of services would need to be carefully considered as there is a risk that valuable regional expertise would be lost and patients would need to travel larger distances for specialist care for no additional

ID	Stakeholder	Statement No	Comments[1]
			benefit. Currently any bone sarcomas and selected complex soft-tissue sarcomas involving bone are referred to bone-sarcoma centres, which seems sensible. It may be useful to put in place more formal arrangements for case review or second opinions between sarcoma MDTs for unusually complex or rare soft-tissue sarcoma cases. This already happens informally but enhancing links between the various sarcoma MDTs around the country should be encouraged.
19	Children's Cancer and Leukaemia Group	1	For children and young people with soft tissue sarcomas (STS), they should be discussed at the PTC paediatric oncology diagnostic and treatment MDT as per standard below. If appropriate they should be referred onto the Sarcoma MDT. Bone tumours are discussed for all ages in any event at the Bone MDT. • Children and young people with cancer. NICE quality standard 55 (2014).
20	London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)	1	We would support the referral to and management by a sarcoma centre for all patients with sarcoma. It is our experience that pathways are still unclear in part because of the varied interpretation of terms like 'supervised by' or 'in conjunction with'. Patients and service providers would benefit from a much clearer standard which define responsibility for patient care
21	NHS England	1	Currently the QS has ambiguous wording and fails to define responsibility for patient management. The MDT won't always be treating but should be discussing and confirming – change QS to:- People with a confirmed diagnosis of bone or soft tissue sarcoma will have their care plan discussed and confirmed by the sarcoma multi-disciplinary team (MDT)
22	North Bristol NHS Trust	1	This only covers patients with a confirmed diagnosis of sarcoma. Delays in diagnosis are sadly common for many reasons. This standard should apply to all patients with suspected sarcoma and their investigation and diagnostic pathway should be supervised or provided by a sarcoma MDT IT is essential that nationally information regarding all sarcoma MDTs and their location is readily available ensuring appropriate and speedy referral
23	Sarcoma UK	1	From the patient perspective, this statement is neither clear nor strong enough. It assumes patients already have received a confirmed diagnosis, thereby missing the opportunity to address a major problem for sarcoma patients that impacts on the quality and availability of the treatment they can have within sarcoma services. Delayed diagnosis reduces the chances of treatment with curative intent, and can limit treatment options to palliative treatments, which is devastating for patients and frustrating for the sarcoma healthcare specialists. This quality statement must cover sarcoma diagnostic services to have any impact. Without this, the overall Quality Standard does not accurately reflect the key areas for quality improvement. The description in this quality statement relating to the responsibility of the MDT is, in our opinion, too weak and

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			unclear and leaves it open to interpretation. To have any real impact, the whole statement needs to provide absolute clarity about the role of the MDT. To have care only "supervised by, or provided in conjunction with, a sarcoma multidisciplinary team" leaves loop holes for patients to be treated by non-sarcoma specialists. We would like to see a stronger emphasis on the fact that sarcoma patients must have their care discussed and confirmed by a sarcoma MDT and treatment delivered by a sarcoma specialist team linked to that MDT.
24	Sarcoma UK	1 Quality measures b) Evidence of written protocols etc	In principle, this is sensible. However, it should also set out where the responsibility lies for doing this. We know that in practice that there is little formal agreement between sarcoma and non-sarcoma MDTs about pathways and circumstances for transferring care between teams. We would like to see NICE take a strong lead on this through a quality statement that sets out that sarcoma MDTs are responsible for all sarcoma patients and that they determine protocols and pathways for the involvement of non-sarcoma MDTs. Without this lead, non-sarcoma MDTs will continue to manage and treat sarcoma patients without referring on. They will have no incentive or requirement to refer to sarcoma MDTs other than patient pressure.
25	Sarcoma UK	1 What it means for patients, service users and carers	The wording in this section is not consistent with the rest of quality statement 1. The phrase "looked after with the help of a sarcoma multi-disciplinary team" is too vague and potentially misleading.
26	Association of Chartered Physiotherapists in Oncology and Palliative Care	2	Core roles in a sarcoma MDT- should include a physiotherapist an occupational therapist. It has been mentioned that AHPs can be seen as a key worker. They have an important role in patient care whatever the patient's age.
27	Bristol Sarcoma Service	2, 4, 7	We are in broad agreement with the quality statements and previous peer review requirements for sarcoma services
28	London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)	2	We agree that this is essential. However recent changes in the Cancer Measures for requirements for core member attendance are in our view not constructive and potentially undermine the viability of MDTs for rare cancers where expertise is limited to a small number of individuals. We would suggest support for a review by the National Cancer Peer Review team which is done in conjunction with reconsideration of the criteria which are used to designate staff as 'extended' MDT members. This role would be more effective in assisting the development of quality services if it was more tightly defined.
29	NHS England	2	The quality statement simply needs to be identical to peer review so remove reference to 'Adapted from' - This statement should be altered so that the MDT requirements are identical to the existing MDT requirements as outlined in the IOG/peer review measures; either reference or specify in full The CRG has discussed recent changes to Cancer Measures which refer to core membership of MDTs and are

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			concerned about the value of these in ensuring compliant appropriately staffed MDTs discussing sufficient numbers of new cases. This QS has a dependency of the Cancer Measures and should therefore be considered in conjunction with concerns about these.
30	North Bristol NHS Trust	2	This statement should reflect current peer review requirements to avoid any confusion
31	Sarcoma UK	2 Statement and rationale	This statement does not reflect situations where treatment could be delivered locally by a 'designated' member of an MDT eg radiotherapy services. Having such treatment locally is of benefit to patients but it is imperative that the designated member is recognised within the MDT structure as an extended member. The statement should be reworded to reflect this situation. There is lack of clarity about the role of peer review and the definitions of MDT core membership currently used. Having different definitions will undermine peer review. The same list should be used.
32	The Royal College of Radiologists (RCR) and the British Society of Skeletal Radiologists (BSSR)	2	The requirement for two specialist sarcoma radiologists per sarcoma MDT is already stated in the NICE Sarcoma guidance: 'Two specialist sarcoma radiologists with a special interest in musculoskeletal or oncological imaging'. However, the RCR/BSSR feel this statement is largely redundant – if they are specialist sarcoma radiologists there is perhaps no need to state the special interest in musculoskeletal or oncological imaging. The RCR/BSSR suggests that what constitutes a specialist sarcoma radiologist is poorly defined – currently, by default, it is the designation for any radiologist regularly attending a sarcoma MDT. Prior to such attendance the minimum expectation would be a consultant that has undertaken pre-CCT training in oncological or musculoskeletal radiology, or its equivalent. There are some radiology fellowship and training posts in centres that have sarcoma services that provide more sarcoma specific training but these are insufficient (and would be proscriptive) to be set as the minimum standard for subsequent designation as a specialist sarcoma radiologist. For the purpose of measuring this Quality Standard, the RCR/BSSR suggest criteria for designation as a specialist sarcoma radiologist could be based on: • Minimum number of sarcoma scans reported per annum. or • Minimum number of image guided sarcoma biopsies performed per annum. (accepting that not all specialist sarcoma radiologists undertake biopsy work) or • Minimum number of sarcoma MDT meetings attended.

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			Post CCT radiologists aspiring to attain sarcoma specialist status could then achieve this by attending MDTs and/or performing supervised sarcoma scan reporting.
33	Bristol Sarcoma Service	3	This standard as written is a little unclear. As occurs currently, we agree the principal that other specialist cancer MDTs, eg head and neck, gynaecology, should be able to continue to manage sarcoma cases as long as they have suitable expertise. However all cases should be discussed at the regional sarcoma MDT to ensure coordination of other aspects of care or access to clinical trials. There should be strong links between the regional sarcoma MDT and other specialist cancer MDTs in the region.
34	London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)	3	We think this QS is vague and, as currently worded, of doubtful value. We do not know of standards that define 'areas of specific expertise' and fear that this is just an opportunity for self-promotion. A different approach would be to recommend that sarcoma services provide outcome data that can be used as comparators.
35	NHS England	3	We acknowledge that some patients are not getting access to the right expertise but sharing information as such an unhelpful and unmeasurable statement. It would be better to focus in on pathways for site specific sarcomas Sarcoma MDTs share information about shared pathways for site specific sarcomas
36	North Bristol NHS Trust	3	Information on all sarcoma mdts and treatment centres should be easily accessible to public and healthcare professionals and the services they each provide, including contact and referral guidelines Will this still be measured by peer review, if this does not continue how will this be monitored/measured? Is it via Peer review that an MDT will be deemed to have met MDT measures, how else can this be measured?
37	Sarcoma UK	3	From a patient perspective, this quality statement should be focused on the establishment of clear pathways to/from site specific or non-sarcoma MDTs to sarcoma MDTs. It is this information that should be clearly shared. A recent Sarcoma UK survey of patients with gynaecological sarcomas found that 50% of respondents were not referred to a sarcoma MDT following their diagnosis; and 50% of respondents who had a further recurrence of sarcoma were not referred to a sarcoma MDT. 90% of respondents were not told that a sarcoma specialist had been consulted to agree a care pathway. This statement also puts the onus on sarcoma MDTs to 'share information' rather than addressing the issue of site-specific and non-sarcoma MDTs taking responsibility for referring sarcoma cases into a sarcoma MDT. In our recent survey of gynaecological sarcoma patients, it was clear that patients themselves had to insist on a referral to a sarcoma MDT as this was not forthcoming or supported by the non-sarcoma MDT. "My mum had a terrible argument to get to see a sarcoma specialist. Only after the second recurrence and after pushing did she see a sarcoma specialist. By then it had spread everywhere."
38	Sarcoma UK	3	Achievement measures should be based on evidence that these pathways are in place, and data to show that they

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		Structure	are being used.
39	London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)	4	We support the principle that all patients with sarcoma should be referred to sarcoma centres where surgery can be undertaken by a team of surgeons with appropriate skills who regularly operate in the retro peritoneum and who are part of a sarcoma MDT. Such centres should also process the requisite support infrastructures for performing such procedures. 'Special expertise' in this quality standard requires definition. We would favour a definition based on centre activity i.e. number of cases, rather than an individual.
40	North Bristol NHS Trust	4	What is the national definition of a retroperitoneal surgeon? Who will designate these surgeons nationally? Should the RP surgeon be a core member of the MDT not just an extended member? Should Retroperitoneal surgery be a recognised sub speciality nationally, how will this be achieved?
41	NHS England	4	We don't believe the QS should focus on the presence of an individual surgeon. We want to endorse that this type of tumour should be treated by a specialist retroperitoneal service which ideally would include more than one surgeon with special expertise in retroperitoneal sarcomas. Can we include minimum numbers that we would expect to be performed to be classed as this type of service? The CRG has suggested that the number should be 25 retroperitoneal (not including GIST or intra abdominal sarcomas not arsing in the retroeritoneum) sarcomas per annum for a retroperitoneal sarcoma service People with retroperitoneal sarcoma are referred to and have their treatment managed by a specialised retroperitoneal sarcoma service. This service should manage a minimum volume of 25 Retroperitoneal sarcomas (not including GISt or intradbominal sarcomas that do not arise in the retroeritoneum)
42	Royal College of Paediatrics and Child Health	4 & 5	The special picking out of retroperitoneal seem un-needed. Bone needs to be different and is arranged as such, but not given its own QS. It may be that examples - of bone & retroperitoneal - are used in QS5.
43	Royal Marsden Hospital	4	Retroperitoneal sarcoma is a rare group of sarcomas occurring in a challenging anatomical area of the body. The best chance of resection with curative intent is at the time of primary presentation. We agree with the Quality Statement 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." There is strong evidence from the literature supporting the concept of concentrating rare and complex operations in high-volume specialist centres leading to improved short term peri-operative and long term oncological outcomes for patients with retroperitoneal sarcomas. Specific questions detailed: The Quality Statement raises the question: "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'?"

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			In practice we feel that the term “special expertise” should be defined by two measures: The first requirement to define “special expertise” should necessitate that the surgeon performing the surgery is a core member of the sarcoma MDT. This will ensure that the surgeon has the sarcoma oncology knowledge and experience in the biologic behaviour, response to treatment and clinical outcomes of retroperitoneal sarcoma which varies according to histological subtype and grade. The sarcoma MDT with the surgeon/s involvement can therefore formulate a management plan, including extent of resection and neoadjuvant strategies with a clear understanding of the disease biology. It is essential that the surgeon performing the surgery has a full understanding of the biological behaviour and disease process and not only has the anatomical expertise and practical skills of performing surgery in the retroperitoneum. The second requirement to define “special expertise” should necessitate a minimum number of new patients with retroperitoneal sarcoma managed in the designated sarcoma MDT. High surgeon-volume and hospital-volume has been shown in all fields of complex surgical oncology to lead to improved patient outcome. We would propose that annually at least 25 new cases of retroperitoneal sarcoma excluding gastrointestinal stromal tumour (GIST) should be the minimum number required to be managed by a sarcoma MDT to provide the “special expertise” to improve outcome for patients with retroperitoneal sarcomas.
44	Sarcoma UK	4	Sarcoma UK supports the rationale that concentrating retroperitoneal sarcoma cases in a small number of specialist centres may improve outcomes. However, the rest of this quality statement does not fit with this rationale. It refers to “a designated surgeon with special expertise in managing this type of tumour”. This is at odds with the recommendation of having a small number of specialist centres where expertise is concentrated – having one designated surgeon implies a lone worker. We are in support of bringing retroperitoneal sarcoma expertise into specialised retroperitoneal sarcoma services. This provides sarcoma patients with access to the full range of sarcoma treatments and services, as well as reassurance that the centre is able to provide the best quality care and access to treatments. We believe that patients will welcome this development, and will be reassured that they are being treated by the best team. We acknowledge that there are issues with travel and cost for patients, however our experience is that the majority of patients want to be treated by a team that will give them the greatest chance of recovery/survival even if this means travelling for initial treatment. For this quality statement to work in practice, there needs to be a minimum number of cases that each centre must see in order to treat retroperitoneal sarcoma.
45	British Association of Oral and Maxillofacial Surgeons	5	“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. (page 5 out of 34).

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			This statement is also repeated on Page 16 under the heading “rationale” – “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 tumour”. We feel it should be more specific in these statements as sarcoma operations have to be delivered by site-specific cancer specialists in conjunction with the sarcoma MDT. Age specification alone cannot be considered as an adequate and exclusive pre-requisite given that the age specific specialist may not have experience in oncological surgery, therefore despite the appropriate age specific skills he may not be surgically competent to deliver an oncologically safe operation.
46	Children's Cancer and Leukaemia Group	5	Who does the surgery is already covered in the statement (that it can be a surgeon with age-appropriate skills), but again should emphasise (as per comment above) for children and young people it is discussed at the paediatric oncology diagnostic and treatment MDT and then referred as appropriate to the sarcoma MDT.
47	London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)	5	Surgery for sarcoma should be planned operations undertaken by surgeons who are members of sarcoma MDTs. The addition of ‘or by a surgeon with tumour site-specific or age-appropriate skills in consultation with the sarcoma MDT.’ removes clarity, adds ambiguity and could be used to support sub-optimal practice.
48	National Cancer Intelligence Network Gynaecology SSCRG	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.” This section does not recognise the fact that the majority of gynaecological sarcomas are uterine, and when they occur in pre-menopausal or perimenopausal women they are frequently mistaken pre-operatively for benign fibroids. Therefore, a significant proportion of major resections for uterine sarcoma are performed out with an institution hosting a specialist sarcoma MDT and often out with a specialist gynaecological oncology centre. Whilst it is appropriate for cases of suspected uterine sarcoma to be referred to a gynaecological cancer centre for assessment and surgery, many of these will prove benign on post-op hysterectomy histology. Cases of sarcoma in younger women which are not suspected pre-operatively will continue to have primary surgery (hysterectomy) by general gynaecologists, who perform identical surgery on other women with uterine fibroids. Once the histology is known, the case should be referred to the regional specialist gynaecological cancer centre for MDT review, and then to the regional sarcoma MDT for histology review and advice regarding the need for further staging and adjuvant treatment.

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			Ovarian sarcomas present in the same manner as epithelial ovarian tumours and primary surgery for these cases should be performed by subspecialist gynaecological oncologists working within specialist gynaecological cancer centres. Again, referral should be made post-operatively to the regional sarcoma MDT. Cases of metastatic gynaecological sarcoma diagnosed prior to primary surgery (e.g. from biopsy of metastatic deposit) should be referred to the regional sarcoma MDT for management planning prior to surgery, which if considered appropriate could then be performed by the specialist sarcoma surgeons or the gynaecological oncologists depending on the nature of surgery undertaken and local preference. These issues were highlighted in the collaboration between the NCIN gynaecology SSCRG and sarcoma SSCRG during the preparation of recent publications on the incidence and management of gynaecological sarcomas in the UK.
49	NHS England	5	The CRG supports the underlying principle of this QS, that surgery for sarcoma should be planned and undertaken by specified surgeons working as team members of a sarcoma service. The second part of the QS is ambiguous and not specific “or by a surgeon with tumour site-specific or age-appropriate skills in consultation with the sarcoma MDT.” We recommend that this is omitted and instead reference made to core and extended MDT members. There is little value in the term age appropriate which, in itself, does not denote skills relating to sarcoma which are important in all age groups, including adolescent and paediatric patients and the elderly. A tighter definition of ‘extended’ members of MDTs from the National Peer Review team is desirable. People who have resection of their sarcoma have it performed in a specialist sarcoma centre by a surgeon who is a core member of the MDT, or by a tumour site specific surgeon who is an extended member of the MDT
50	North Bristol NHS Trust	5	Soft tissue sarcoma patients need the expertise of specialist soft tissue surgeons ie plastic surgeons. It is not a requirement that a core member of the sarcoma MDT is a plastic surgeon, given the complex reconstructions often needed should this be changed? Is unclear how amputation rates will be affected by this measure and may be difficult to measure
51	Sarcoma UK	5	We support the aim of this quality statement and recognise the importance of minimising the number of resections carried out by general or non-sarcoma specialist surgeons. However, the current wording of this statement is too loose and open to interpretation. We believe that all sarcoma patients who have a resection should have their operation in a specialist sarcoma centre by a surgeon who is a core member of the MDT. If it is appropriate for surgery to be delivered by a tumour-specific surgeon, they should be an extended member of the sarcoma MDT.
52	Association for Palliative Medicine of Great Britain	6 Table 3	Mentions that “generic” information on palliative care and pain control will be given to patients when no treatment other than palliative is available and this should be done by the sarcoma centre or palliative care centre. It should be

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	and Ireland		made clearer what palliative care services can offer, that their expertise may be of benefit at various points in the illness. It does not make sense to say that this information should be given by the palliative care centre – perhaps it should be a leaflet specific to potentially likely events in sarcoma that palliative care may be able to help with and should be given to patients at the sarcoma centre. It can't be given out at the palliative care centre – the patient would need to know why they were going there first
53	Association of Chartered Physiotherapists in Oncology and Palliative Care	6 Page 20 – Information Pathway	Confirming referral to sarcoma treatment centre: Information on practical issues and pre-habilitation and rehabilitation services.
54	Association of Chartered Physiotherapists in Oncology and Palliative Care	6 Page 20 – Information Pathway	On referral to another sarcoma treatment centre: Information on practical issues and prehabilitation/rehabilitation. Liaison and communication between centres of planned ongoing care.
55	Association of Chartered Physiotherapists in Oncology and Palliative Care	6 Page 20 – Information Pathway	At diagnosis – Information on how and when to get a referral to specialist allied health professionals for assessment if high risk and rehabilitation.
56	London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)	6	Clear comprehensive information is essential and valued by patients. The challenge of producing information that matches the heterogeneity of sarcoma patient experience is however formidable. We were unclear why either diagnosis or stage is included. Surely both?
57	North Bristol NHS Trust	6	Local information is of course important but this should not be limited to referral point only. Appropriate information in varied formats should be provided at all stages of the sarcoma pathway. Who provides this information is also important to patients experience
58	Sarcoma UK	6	This quality statement only addresses a small part of the problem of appropriate information about sarcoma provided to patients throughout their sarcoma diagnosis and treatment. Patients need information at every stage, from diagnosis through to end of life care, as set out in Table 3 The Information Pathway. However, the wording of this quality statement appears to relate only to the early stages of diagnosis.
59	Sarcoma UK	6 Rationale	Our experience is that patients receive some information about sarcoma but it doesn't meet all their needs. Sarcoma UK provides Information Standard-accredited patient information and personalised information via email and phone. People contact the charity even before their first visit to a diagnosis clinic, after having independently searched for sarcoma on the internet. They frequently report that the information they have been given by the clinic or treatment centre is not sufficient to answer their questions. Patient experiences would be significantly improved if they were told

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			at the earliest possible opportunity about sources of high quality accredited information and support from national patient organisations. Sarcoma UK's website is increasingly being used by patients as one of the main sources of information about sarcoma. In 2013/14, 72,000 people visited the site, with the About Sarcoma information pages most looked at. This compares to 38,000 the previous year. In addition, visits to our Support pages where patients can order information and find sources of support increased by 74%. We recommend that the statement is broadened to state that "People who are referred to a sarcoma diagnostic clinic or treatment centre are given information specific to the clinic/centre, but also details of the national patient organisations that can provide further information and support throughout their diagnosis, treatment and discharge." It is very important that patients are given local information and that the information is tailored to their experience in the specific clinic or centre. However, our evidence is that patients also want independent high quality information from patient organisations/national charities alongside local information. Sarcoma UK's Information Toolkit provides local treatment centres and clinics with the opportunity to combine local information with high quality sarcoma patient information.
60	NHS England	7	We support the QS emphasising the importance of the key worker. Allocation needs to be followed by provision of support. We want key workers to be actively and proactively involved. All patients with sarcoma will have a key worker who will provide support during all stages of their diagnosis, treatment and follow up pathway
61	London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)	7	We support this QS.
62	North Bristol NHS Trust	7	Key worker should be replaced with clinical nurse specialist, key worker is vague and does not reflect the national trend towards key workers being specialist nurses. Giving contact details is not sufficient, many patients will not ring if just given contact details, patients should meet their key worker personally. Key worker should be present with patients at key stages of pathway eg diagnosis, recurrence, end of treatment. Some expectation of what key worker provides should also be specified; some is detailed in peer review documentation but is not comprehensive. Level of knowledge and expertise is important to specify, more experience and knowledge results in better service and improved patient experience Cover for key worker should be from another with similar sarcoma knowledge or expertise, not just a tick box exercise for another key worker from a different cancer site to cover in their absence or a clerical worker
63	Royal College of	7	Key workers are magnificent and should certainly stay.

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	Paediatrics and Child Health		
64	Sarcoma UK	7	Evidence from the National Cancer Patient Experience Survey shows that patient experience is maximised through contact with a sarcoma **clinical nurse specialist**, and Sarcoma UK's patient networks also confirm this. Whilst the definition of terms in quality statement 7 sets out that key workers are 'usually' clinical nurse specialists or allied healthcare professionals with specialist knowledge of sarcoma, we believe this should be emphasised within the quality statement wording itself. The second part of the quality statement is too passive. It is not sufficient that patients are just "provided with their key worker's name and contact details". The quality statement should set out the expectation that the CNS will make personal contact with the patient and be present during key stages of a patient's diagnosis and treatment. A name on a piece of paper requires effort from patients who may already be emotionally drained and may not feel able to take the step to contact someone they don't know (and reach an answerphone). However, a call/meeting generated by the CNS would establish a relationship and provide reassurance to the patient. We acknowledge current resource limitations within specialist nursing, but feel that this amendment to the quality statement would help to ensure resources are allocated to providing sarcoma clinical nurse specialist cover.
65	Sarcoma UK	7 Definition of terms	We would question the use of the term 'usually' to describe specialist nurses or allied healthcare professionals as key workers. The key worker should be a core member of the sarcoma MDT, and quality statement 2 clearly sets out the core membership of the MDT.
66	Sarcoma UK	7 Rationale	We question why the very important issue of rehabilitation is only included in the rationale for key workers. We strongly recommend that a further quality statement relating to discharge and care pathways is included in the overall Quality Standard, covering access to rehabilitation services. Without this, the overall Quality Standard is not accurately reflecting the key areas for quality improvement.
67	Christie NHS Trust	Consultation question 1	Key areas for quality improvement correctly identified. It would however be interesting to review histology diagnoses across each sarcoma MDT. For instance some MDTs classify many more sarcomas as pleomorphic sarcomas whilst others use this terminology much less. One would expect reasonable consistency between different reporting pathologists at different MDTs. Simple reporting of the frequency of the more common histological variants would go some way to address this
68	NHS England	Consultation question 1	Yes these are good standards to drive quality improvement. I would also add that all cases of sarcoma must be included in prospective audit and every MDT should review their audited outcomes regularly
69	North Bristol NHS Trust	Consultation question 1	Many specialities are not represented that are of equal importance eg gynaecology, head and neck, thoracics, reconstruction
70	Plymouth Hospital NHS	Consultation	Yes, but also improving the general public's and GP's awareness of sarcoma and best practice treatment goals would

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	Trust	question 1	also drive up the results of care substantially.
71	The Royal College of Radiologists (RCR) and the British Society of Skeletal Radiologists (BSSR)	Consultation question 1	The RCR feels that the key areas for quality improvement are correctly identified. It would, however, be interesting to review histology diagnoses across each sarcoma MDT. The RCR believes that some MDTs classify many more sarcomas as pleomorphic sarcomas whilst others use this terminology much less. One would expect reasonable consistency between different reporting pathologists at different MDTs. Simple reporting of the frequency of the more common histological variants would go some way to address this.
72	Christie NHS Trust	Consultation question 2	Unfortunately the systems and structures for this level of data collection are not in place and to be fair are some way short. Most of the proposed data collection should be collectable with proper investment in data collection. Most of this is likely to fall upon the MDT meeting and it must be appreciated that this resource is already stretched and over burdening the MDT meeting with this could lengthen MDT meetings and leave less time for the core role which is to best plan patient management.
73	NHS England	Consultation question 2	It should be reasonably straight-forward to collect data on these Quality Statements, although the one difficult one is number 3 on liaising with other cancer services
74	North Bristol NHS Trust	Consultation question 2	Systems and structures would need to be supported locally and nationally, if done this could be collected
75	Plymouth Hospital NHS Trust	Consultation question 2	Yes. A secure internet based common database would facilitate this and ensure all were working from the same dataset; keen to assist….
76	The Royal College of Radiologists (RCR) and the British Society of Skeletal Radiologists (BSSR)	Consultation question 2	The RCR notes that, unfortunately, the systems and structures for this level of data collection are not in place and, indeed, may be some way short. Most of the data proposed for collection should be collectable with proper investment. Most of this is likely to fall upon the MDT meeting and it must be appreciated that this resource is already stretched. Over-burdening the MDT meeting with this data collection could lengthen MDT meetings and leave less time for the core role - which is to best plan patient management.
77	North Bristol NHS Trust	Consultation question 3	QS1 a national sarcoma website with all sarcoma centres, contact and referral details and services provided should be accessible to public and health care professionals Education of public and GP, non sarcoma health care professionals of key importance More evidence needed that specialist centres deliver better outcomes, this could be supported by better data collection
78	NHS England	Consultation question 3	Improvement must be supported by mandatory prospective audit (the provider doesn't get paid for a case before submits appropriate data to the national audit). In addition all doctors in sarcoma MDTs must include their audited sarcoma outcomes in their annual appraisals
79	North Bristol NHS Trust	Consultation question 3	QS2 succession planning and training for all core roles in sarcoma MDT of huge importance
80	North Bristol NHS Trust	Consultation	QS3. National database of all sarcoma patients, treatment and outcomes would help this QS be measured

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		question 3	
81	North Bristol NHS Trust	Consultation question 3	QS4 nationally agreed definition of what constitutes a retroperitoneal surgeon would be very helpful, with nationally available list of who and where they work to inform healthcare professionals and public and prevent unnecessary travelling and appropriate referrals
82	North Bristol NHS Trust	Consultation question 3	QS5 should be as per peer review, shared care pathways readily available, avoids excessive travelling and inappropriate referrals
83	North Bristol NHS Trust	Consultation question 3	QS6 Nationally produced information for sarcoma patients at all stages of their sarcoma pathway as well as local specific information. Can be measured in national and local patient experience surveys, peer review
84	North Bristol NHS Trust	Consultation question 3	QS7 surveys, peer review, national definition of what sarcoma expertise and training needed to fulfil role and level key worker should have and agreed expectations of what the service provides. Key worker should be present at key points in pathway and work with extended key workers to ensure specific sarcoma information also given
85	Plymouth Hospital NHS Trust	Consultation question 3 / Statement No 1	Early referral; education of the general public and primary care
86	Plymouth Hospital NHS Trust	Consultation question 3 / Statement No 2	Institutional investment in Sarcoma services
87	Plymouth Hospital NHS Trust	Consultation question 3 / Statement No 3	Generic unified information produced by the CRG perhaps published on a website
88	Plymouth Hospital NHS Trust	Consultation question 3 / Statement No 4	Faster diagnosis and education of secondary care/tertiary care surgeon
89	Plymouth Hospital NHS Trust	Consultation question 3 / Statement No 5	Education of general public, primary and secondary care. Educating the general public will ensure they request treatment in a specialist centre
90	Plymouth Hospital NHS Trust	Consultation question 3 / Statement No 6	Ensuring continued production of accurate information as per IOG outcome and peer review

ID	Stakeholder	Statement No	Comments[1]
91	Plymouth Hospital NHS Trust	Consultation question 3 / Statement No 7	Investment in the Sarcoma service such that CNSs have dedicated time for all parts of pathway
92	NHS England	Consultation question 4	I don't have a good answer – would seek examples from the current sarcoma services We don't believe the QS should focus on the presence of an individual surgeon. We want to endorse that this type of tumour should be treated by a specialist retroperitoneal service which ideally would include more than one surgeon with special expertise in retroperitoneal sarcomas. Can we include minimum numbers that we would expect to be performed to be classed as this type of service? The CRG has suggested that the number should be 25 retroperitoneal (not including GIST or intra abdominal sarcomas not arsing in the retroeritoneum) sarcomas per annum for a retroperitoneal sarcoma service People with retroperitoneal sarcoma are referred to and have their treatment managed by a specialised retroperitoneal sarcoma service. This service should manage a minimum volume of 25 Retroperitoneal sarcomas (not including GISt or intradbominal sarcomas that do not arise in the retroeritoneum)
93	North Bristol NHS Trust	Consultation question 4	Must be nationally agreed for each speciality eg surgeon, pathologist, nurse
94	Plymouth Hospital NHS Trust	Consultation question 4	Specific areas of expertise would become apparent from the national database as mentioned in the answer to Q2
95	Christie NHS Trust	Consultation question 4 & 5	The sarcoma MDT is already required to write detailed guidelines highlighting its interaction with other site specific MDTs by the NICE guidance. Such guidelines should be submitted detailing at what point a suspected sarcoma should be highlighted to the sarcoma MDT and a clear statement of the specific roles and responsibilities of the sarcoma MDT and the site specific team. This should make it clear to other teams the "specific area of expertise" that is accessible via the sarcoma MDT.
96	The Royal College of Radiologists (RCR) and the British Society of Skeletal Radiologists (BSSR)	Consultation question 4 & 5	The RCR notes that the NICE guidance already requires the sarcoma MDT to write detailed guidelines highlighting its interaction with other site-specific MDTs. Such guidelines should be submitted detailing at what point a suspected sarcoma should be highlighted to the sarcoma MDT and a clear statement of the specific roles and responsibilities of the sarcoma MDT and the site-specific team. This should make it clear to other teams the "specific area of expertise" that is accessible via the sarcoma MDT.
97	NHS England	Consultation question 5	Ideally each sarcoma MDT creates an electronic info sheet about their services and the hospital IT system is set up so every imaging and pathology report that suggests a new sarcoma diagnosis gets this info sheet automatically appended to it ("just in time knowledge")

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98	North Bristol NHS Trust	Consultation question 5	Website information, patient surveys, national website availability, GP knowledge of local sarcoma service to them
99	Plymouth Hospital NHS Trust	Consultation question 5	National database and audit of such.
100	Christie NHS Trust	Consultation question 6	The retroperitoneal pathways are quite different to the other sarcoma pathways and warrant a separate quality statement
101	North Bristol NHS Trust	Consultation question 6	Does duplicate and overlap
102	Plymouth Hospital NHS Trust	Consultation question 6	Statement 4 is a subset of statement 5
103	The Royal College of Radiologists (RCR) and the British Society of Skeletal Radiologists (BSSR)	Consultation question 6	The RCR notes that the retroperitoneal pathways are quite different to the other sarcoma pathways and warrant a separate quality statement.
104	Christie NHS Trust	Consultation question 7	The surgical specialties involved in retroperitoneal sarcoma surgery in the UK are quite varied and such expertise is currently offered through urology, general surgery and hepato-biliary services. To define surgical expertise the named surgeons should demonstrate experience both in the total number of retroperitoneal operations performed per year, and also demonstrate experience in sarcoma by stating the number of sarcomas operated on per year. In addition teams should show close working with the sarcoma MDT by demonstrating written guidelines on shared pathway involving relevant members of the sarcoma MDT (e.g. oncologists and pathologists). In addition should the designated centres not have 2 surgeons to cover for leave etc. In terms of data collected this could also include local recurrence rates, and number of operations per patient
105	NHS England	Consultation question 7	A surgeon with ‘special expertise’ in managing retroperitoneal sarcoma is a consultant with CCT in general surgery who has spent time either as a senior trainee or as a consultant in theatre with a surgeon already recognised as an expert in this field (experience, prospective audit) assisting with the operations, and then who maintains a link to such a person as a mentor as they develop their own practice. They must be part of a sarcoma MDT (there is pressure for colorectal surgeons and others in DGHs to take on retroperitoneal sarcoma cases and this must be resisted) and must commit to auditing their work prospectively and comparing with benchmarks and including results in annual appraisal and revalidation reviews. Ideally a surgeon with special expertise would do a certain minimum number of cases a year, but this is hard to set given the small number of new patients. Ideally there should be more than one surgeon with such special expertise in a centre and two should operate together to optimise good patient care and surgical experience

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106	North Bristol NHS Trust	Consultation question 7	Should be nationally agreed, ?measured in hours of operating time achieved or by surgical standards already set?
107	North Bristol NHS Trust	Consultation question 7	‘What defines a retroperitoneal surgeon?’ – we have pondered this in Bristol for many years. Retroperitoneal Sarcoma surgery in Bristol has evolved from a collective of general surgeons, urologists, vascular and plastic surgeons into a sub-speciality in its own right. Where the surgeons primary practice is surgical resection of retroperitoneal disease then this seems like a sensible starting point for a definition. The procedures commonly fitting this category would include (but are not exclusively) large renal cancer surgery (especially that involving caval and nodal surgery), retroperitoneal lymph node dissection for germ cell malignancy and other cancers (melanoma for example), sarcoma excision and complex colonic surgery. The techniques involved in these procedures share a commonality which means that competency in one operation leads adds to the individuals overall experience in the shared ground of ‘retroperitoneal surgery’. There will be a temptation to define competency in retroperitoneal surgery by arbitrarily selecting an indicative number of procedures performed per annum. I would suggest that this is considered as a whole surgical years’ experience in retroperitoneal surgery, not just in primary resection of retroperitoneal sarcoma. We know that retroperitoneal sarcomas can arise from the colon and its mesentery, from the soft tissues surrounding the great vessels, from the kidney etc. etc. Each of the operations to remove these sarcomas needs an individualised approach from a surgeon who can (within his or her capability) accommodate vascular, renal, lymphatic, bowel and soft tissue surgical procedures – supported by a wider team of surgeons when required. By developing retroperitoneal surgery as a stand-alone speciality within surgery we now have 2 surgeons providing retroperitoneal lymph node, renal and sarcoma surgery. We would be delighted to be further involved in helping NICE with the definition of the retroperitoneal sarcoma surgeon. We would support the use of indicative numbers if they were to include the whole range of complex retroperitoneal procedures we have described. We would suggest that retroperitoneal surgery is formally acknowledged as a sub-speciality and encourage the development of a National professional group.
108	Plymouth Hospital NHS Trust	Consultation question 7	This is a very contentious subject. Bare number counting is too blunt a tool to assess expertise. It is possible for a surgeon to perform over 25 cases a year but to a lower standard than one who performs fewer than 25 but may have a large non sarcoma retroperitoneal practice; the same argument holds for non-retroperitoneal sarcomas. Audit of outcomes would help; national database
109	The Royal College of Radiologists (RCR) and the British Society of Skeletal Radiologists (BSSR)	Consultation question 7	The RCR notes that the surgical specialties involved in retroperitoneal sarcoma surgery in the UK are quite varied and such expertise is currently offered through urology, general surgery and hepato-biliary services. To define surgical expertise the named surgeons should demonstrate experience in the total number of retroperitoneal operations performed per year, and also demonstrate experience in sarcoma by stating the number of sarcomas operated on per year. In addition teams should show close working with the sarcoma MDT by demonstrating written guidelines on shared pathway involving relevant members of the sarcoma MDT (eg, oncologists and pathologists).

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			In addition, the RCR suggests that the designated centres should have 2 surgeons to cover for leave, etc. In terms of data collected, the RCR suggests this could also include local recurrence rates, and number of operations per patient.

Stakeholders who submitted comments at consultation

- Alder Hey Children’s NHS Foundation Trust
- Association of Chartered Physiotherapists in Oncology and Palliative Care
- Association for Palliative Medicine of Great Britain and Ireland
- Bristol Sarcoma Service
- British Association of Oral and Maxillofacial Surgeons
- British Gynaecological Cancer Society
- Children's Cancer and Leukaemia Group
- Christie NHS Trust
- Department of Health
- GlaxoSmithKline
- London Sarcoma Service (University College Hospital and Royal National Orthopaedic Hospital)
- National Cancer Intelligence Network Gynaecology SSCRG
- NHS England
- North Bristol NHS Trust
- Plymouth Hospital NHS Trust

- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal Marsden Hospital
- Sarcoma UK
- The Royal College of Radiologists (RCR) and the British Society of Skeletal Radiologists (BSSR)
- The Royal College of Surgeons of Edinburgh