

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Clinical Practice – Surveillance Programme

Surveillance review consultation document

8 year surveillance review of cancer service guidance: Improving outcomes for people with sarcoma

Background information

Guideline issue date: 2006

8-year review: 2013

Surveillance review recommendation

Surveillance review proposal put to consultees:

The sarcoma cancer service guidance should not be considered for an update at this time.

The guidance should be transferred to the static guidance list.

Main findings of current (8-year) surveillance review

A literature search for observational studies and systematic reviews was carried out between February 2005 (the end of the search period for the guidance) and October 2013 and relevant abstracts were assessed. Clinical feedback on the sarcoma cancer service guidance was obtained from seven members of the GDG through a questionnaire.

New evidence was identified for the current 8 year surveillance review relating to the following clinical areas within the sarcoma cancer service guidance.

Clinical area 1: Patient perspectives		
Q: In people with sarcoma, is there evidence for the effectiveness of psychosocial interventions?		
Evidence summary	GDG/clinical perspective	Impact
<p>Two observational studies of sarcoma patients found that patient levels of anxiety and depression may differ at different phases of the disease. This could have implications on the efficacy of psychological interventions at different phases of the cancer.^{1,2}</p> <p>The results of this cross-sectional study indicated that a minority of sarcoma patients require mental health services in order to help decrease their emotional distress following the diagnosis, and prevent psychological difficulties during treatment.³</p> <p>A cross-sectional study of 34 people was identified which examined whether psychological distress or posttraumatic stress symptoms are present in an adult cohort of paediatric sarcoma survivors.⁴ The results indicated that psychological distress persisted among the cohort although, as this study was conducted on average 17 years after treatment ended, it is not clear if the psychological distress could be directly attributed to the sarcoma treatment.</p> <p>Lastly, one study was identified which explored the psychosocial characteristics of people living with gastro intestinal stromal tumours (GIST).⁵ Pain was significantly associated with anxiety whilst body image and appearance concerns were expressed by over half of the study participants.</p>	<p>No clinical feedback provided.</p>	<p>New evidence is consistent with current recommendations:</p> <p>In summary, the identified new evidence indicated that people with sarcoma may suffer from psychological distress however, no study specifically explored the efficacy of different psychological interventions to manage these symptoms. In general, the results of these studies support the current recommendation which states that patients should be offered psychological support.</p>
Clinical area 2: Patient perspectives		
Q: What are the information needs of people with sarcoma?		
Evidence summary	GDG/clinical perspective	Impact

<p>A cross-sectional study evaluated expectations of bone cancer patients when receiving information from their doctor.⁶ All respondents indicated that a face-to-face discussion with their doctor, the use of simple language and appropriate words in addition to allocation of time for the patient to ask questions improved the provision of information.</p>	<p>No clinical feedback provided.</p>	<p>New evidence is consistent with current recommendations:</p> <p>The identified new evidence supports the current recommendations which state that a diagnosis or other significant news should be communicated by a senior doctor or specialist nurse who has enhanced skills. Communication should be face to face unless there is specific agreement with the patient about receiving confirmation of a preliminary diagnosis by telephone or in writing.</p>
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Clinical area 3: Diagnosis

Q: For people with lumps suspicious of sarcoma, does referral to a specialist sarcoma unit or MDT improve the rate of pre-operative diagnosis?

Evidence summary	GDG/clinical perspective	Impact
<p>One study was identified which aimed to identify factors which could improve diagnosis of low-grade central osteosarcoma.⁷ Patients who were referred to the specialist centre after initial treatment elsewhere all presented with local recurrence.</p>	<p>Feedback from the GDG suggested that a failure to refer patients to specialist sarcoma units may negatively impact on patient outcomes. Furthermore, the GDG highlighted that the National cancer Intelligence network is conducting research in the early stages of the gynaecological sarcoma diagnostic pathway utilising verified national sarcoma data.</p>	<p>New evidence is consistent with current recommendations:</p> <p>The results of one study indicated that in a subset of patients with low-grade central osteosarcoma, local recurrence occurred when they had not been referred to a specialist centre in the first instance. This is in line with clinical feedback which suggests failure to refer to a specialist sarcoma unit may have a negative impact on patient outcomes. Together this evidence supports the guidance which recommends that anyone with a possible sarcoma should be referred to a diagnostic clinic for biopsy and that biopsy should not be done outside these clinics.</p>

Clinical area 4: Diagnosis

Q: Does diagnosis of sarcoma by a specialist radiologist, compared with a general radiologist, lead to greater diagnostic accuracy?

Evidence summary	GDG/clinical perspective	Impact
<p>One study correlated radiologists' certainty of the diagnosis of liposarcoma on musculoskeletal magnetic resonance imaging with pathology results.⁸ Fifteen</p>	<p>No clinical feedback provided.</p>	<p>New evidence is unlikely to impact on current recommendations:</p>

(47%) of 32 variable benign or malignant tumours were incorrectly diagnosed as liposarcomas.		One study was identified which compared radiologists' certainty of the diagnosis of liposarcoma on musculoskeletal MRI with pathology results however, no direct comparisons with specialist radiologists were reported. As such, the results of this study are unlikely to impact on the current recommendations.
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Clinical area 5: Diagnosis

Q: In people with soft tissue sarcoma, does early referral improve survival?

Evidence summary	GDG/clinical perspective	Impact
A retrospective review of the North of England Bone and Soft Tissue Tumour Service was identified which aimed to identify reasons for delay in referral of groin sarcoma. ⁹ A 4.4 month delay in presentation to the sarcoma MDT was identified for 9 out of 13 cases. Four patients died; three as a result of distant metastases and one as a result of local recurrence.	No clinical feedback provided.	New evidence is consistent with current recommendations: One small retrospective review of a bone and soft tissue tumour service in England reported poorer outcomes in people who experienced a delay in referral for groin sarcoma. This is unlikely to change the direction of the current recommendation which states that commissioners should ensure that GPs are aware of and comply with the urgent referral criteria in the NICE 'Referral guidelines for suspected cancer'.

Clinical area 6: Diagnosis

Q: Do delays in diagnosis result in poor outcomes for people with sarcoma?

Evidence summary	GDG/clinical perspective	Impact
A retrospective study was identified which aimed to assess the impact of diagnostic delays on the prognosis of osteosarcoma. ¹⁰ Estimated 5- and 10-year overall survival rates were 26% and 10%, respectively following a delay in diagnosis. However, this was a small study making it difficult to estimate the prognostic significance of delay. One study reported on the length of delay in diagnosis in people with symptoms suspicious of osteosarcoma around the knee joint. ¹¹ The mean total delay from	Feedback from the GDG indicated that improvements in early diagnosis of soft tissue sarcoma are required as this is likely to increase survival.	New evidence is consistent with current recommendations: Four studies were identified which described delays in diagnosis of sarcoma. Two of the studies inferred that this delay may have had an impact on survival rates whilst one study concluded that the length of symptoms did not correlate with overall survival. The final study did not report on the association of diagnostic delay on outcomes in the abstract. On the whole, the results of the studies support the view of the GDG that early

<p>onset of symptoms to diagnostic workup and biopsy was 17 (range, 4-55) weeks although no data on the association of this delay on outcomes was reported in the abstract.</p> <p>One study was identified which assessed whether the time from first sarcoma symptom to diagnosis has an impact on survival or disease-free survival.¹² Length of symptoms did not correlate with overall survival or disease-free survival.</p> <p>One observational study focused on the symptoms and diagnostic problems of chest wall chondrosarcoma and factors related to long doctor's delay.¹³ Doctor's delay was >6 months for 40% of the patients evaluated whilst patients who died from chondrosarcoma had longer total delay in diagnosis.</p>		<p>diagnosis of sarcoma is likely to improve patient outcomes. Generally this data is in line with the evidence presented in the guidance which indicates that delays in diagnosis can have an adverse effect on the outcome of people with sarcoma.</p>
<p>Clinical area 7: Diagnosis</p>		
<p>Q: Are current guidelines for early diagnosis of soft tissue sarcoma resulting in improved outcomes for patients?</p>		
<p>Evidence summary</p>	<p>GDG/clinical perspective</p>	<p>Impact</p>
<p>One study reported a cost-effectiveness analysis comparing costs and outcomes when clinicians adhered to guidelines for management of sarcoma and when they did not.¹⁴ Compliance with guidelines was observed for 54% of the patients included in the study. In terms of relapse-free survival, compliance with guidelines was considered to be less costly and more effective than non-compliance.</p> <p>An observational study was identified which assessed the impact of adherence to clinical practice guidelines for loco-regional treatment (surgery and radiotherapy) and chemotherapy on local disease control and survival in sarcoma patients.¹⁵ Patients not treated according to the guidelines were at a higher risk of local recurrence and had a shorter sarcoma-specific survival.</p>	<p>Clinical feedback suggested that education of GPs about sarcoma continues to be a challenge. However, a patient survey by Sarcoma UK was highlighted that suggests GP referral performance is improving.</p>	<p>New evidence is consistent with current recommendations:</p> <p>Two studies identified for this review question indicated that there may be a benefit to sarcoma patients if clinicians adhered to clinical guidelines. In addition, a patient survey was highlighted by the GDG that indicates that GP referral performance is improving. This information supports the guidance which indicates that networks should ensure that GPs and hospital doctors are aware of the diagnostic pathways for patients with signs and symptoms suggestive of bone or soft tissue sarcoma.</p>

Clinical area 8: Pathology		
Q: Does diagnosis by a specialist sarcoma pathologist compared with a general pathologist of sarcomas lead to greater diagnostic accuracy?		
Evidence summary	GDG/clinical perspective	Impact
<p>A retrospective review found concordant primary diagnosis in 28.3% for pathologists in private clinics, 29.6% for hospital pathologists, 36.8% for academic medical centres (university hospitals) and 70.5% for a Department of Pathology.¹⁶ An improvement in diagnosis or confirmation of the correct primary diagnosis by a second opinion was seen in 73.1% of the patients; in 2.5%, the second opinion was false.</p> <p>A cross-sectional study aimed to determine the importance of a second opinion in pathological diagnosis of soft tissue lesions.¹⁷ During the study period, 34 cases of soft tissue lesions were received for review and second opinion. Concurrence between the review and initial diagnosis was seen in 18 (53%) cases whilst discrepancy in the diagnosis at review and initial consultation was seen in 16 (47%) cases.</p>	No clinical feedback provided.	<p>New evidence is unlikely to impact on current recommendations:</p> <p>There is consistent observational evidence that a histopathological diagnosis of sarcoma is often changed on expert review. This is in line with the evidence presented in the guidance and is unlikely to impact on the recommendation which states that all patients with a possible diagnosis of bone or soft tissue sarcoma should have the diagnosis confirmed by a specialist sarcoma pathologist.</p>
Clinical area 9: Pathology		
Q: What is the clinical utility of cytogenetic testing and molecular pathology in people with sarcoma?		
Evidence summary	GDG/clinical perspective	Impact
<p>Nine studies were identified evaluating expression of a number of genes in a range of sarcomas.</p> <p><i>Gastrointestinal stromal tumours</i> One observational study indicated that DOG1 and KIT are sensitive and specific markers for GIST.¹⁸</p> <p>A review of 9 patients with tumours considered to be GIST revealed expression of CD117 and/or CD34 in 5 of 6 tumours, expression of actin in 3 of 6 tumours, and expression of desmin in 1 of 6 tumours.¹⁹ However, five patients underwent surgical excision, and the GIST diagnosis was confirmed in 3 patients, whereas 1</p>	Clinical feedback from the GDG indicated that genetic analysis is increasingly being used to determine translocations and mutations although it was felt that only selected centres offer mutation analysis. There was a view that mutational testing of primary tumours should be mandatory to enable more personal treatment to be given.	<p>New evidence is unlikely to impact on current recommendations:</p> <p>Evidence was identified indicating the potential of cytogenetic testing in people with sarcoma. This was also confirmed by GDG feedback. However, no data on outcomes according to gene expression was reported in the abstract of any of the studies therefore it is not clear if the tested genes could be useful prognostic markers. The guidance currently recommends that specialist sarcoma pathologists should have ready access to molecular pathology and/or cytogenetics facilities and no new evidence or clinical feedback was</p>

<p>tumour proved to be neurofibroma, and another tumour was leiomyoma. As such, it is not clear if expression of CD117, CD34, actin or desmin are specifically relevant to GIST and no data on outcomes according to gene expression was reported.</p> <p><i>Sarcoma</i> One study indicated that a combination of CAM5.2, WT1, and AE1/AE3 may be useful for routine pathological diagnosis and differentiating sarcomatoid mesothelioma from true sarcoma.²⁰</p> <p><i>Dermatofibrosarcoma protuberans</i> One study reported that COL1A1/PDGFB translocation was detected in 93% of dermatofibrosarcoma protuberans.²¹ However, no data on outcomes according to gene expression was reported in the abstract therefore it is not clear if this could be a useful prognostic marker.</p> <p><i>Liposarcoma</i> One study assessed the utility of immunohistochemistry for CDK4, MDM2, and p16 in the routine histopathologic diagnosis of well-differentiated liposarcoma (WDL) from dedifferentiated liposarcoma (DDL) from other adipocytic tumours.²² The sensitivity and specificity of the three genes for detecting WDLs/DDLs were 71% and 98%, respectively. The sensitivity and specificity of CDK4 for detecting WDLs/DDLs were 86% and 89%, those of MDM2 were 86% and 74%, and those of p16 were 93% and 92%, respectively.</p> <p>One study evaluated the ability of MDM2 immunohistochemistry and MDM2 fluorescence in situ hybridisation (FISH) to discriminate benign lipomatous tumours from well-differentiated liposarcoma on core needle biopsies.²³ MDM2 FISH had a higher sensitivity (100%) and specificity (100%) compared with MDM2</p>		<p>identified which would change the direction of this recommendation.</p>
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<p>immunohistochemistry (65 and 89%) in core needle biopsies, respectively.</p> <p><i>Bone sarcoma</i></p> <p>One study was identified which aimed to determine whether ezrin could be a useful diagnostic marker in bone pathology.²⁴ Conventional chondrosarcomas, whatever their grade, were negative, while ten of 16 chondroblastic osteosarcomas were positive for ezrin.</p> <p>One study explored the use of MDM2 and CDK4 immunohistochemistry for the histological diagnosis of low-grade osteosarcoma.²⁵ All low-grade osteosarcomas expressed one or both markers (100%), with 13 cases (57%) expressing both.</p> <p>One study evaluated whether MDM2/CDK4 expression may help separate dedifferentiated osteosarcoma from the conventional type.²⁶ MDM2 and CDK4 coexpression was identified in 7 cases, an additional 11 cases expressed either marker alone, whereas the remaining 89 cases were negative for both markers.</p>		
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Clinical area 10: Multidisciplinary sarcoma teams and centralisation of treatment

Q: Should all people with sarcoma be reviewed by a specialist MDT?

Evidence summary	GDG/clinical perspective	Impact
<p>One study was identified which considered the inclusion of plastic surgery expertise as important in an extremity sarcoma MDT.²⁷</p> <p>Retrospective reviews of the management of dermatofibrosarcoma protuberans or head and neck sarcomas reported the benefit of using a multidisciplinary management approach.^{28,29}</p> <p>One study was identified which reported outcomes after unplanned resection of a sarcoma chosen by a</p>	<p>Potential issues with implementation of the recommendations were highlighted by the GDG as there was a view that gastrointestinal, gynaecological and head and neck MDTs do not always refer people with sarcoma to the sarcoma MDT as recommended in the guidance.</p>	<p>New evidence is consistent with current recommendations:</p> <p>Generally, the included new evidence supports the use of MDTs for management of patients with sarcoma. However, as studies did not compare outcomes in patients who had been reviewed by an MDT compared with those who had not, it is not possible to determine if the treatment pathway explored in the studies directly contributed to the outcomes observed. Overall, this new evidence is unlikely to change the direction of the</p>

<p>general physician.³⁰ Similarly, a report from the North of England Bone and Soft Tissue Tumour Service presented experience of managing patients with angiosarcoma.³¹ As outcomes were not compared with patients who had been reviewed by an MDT in these studies it is not possible to determine if the treatment pathway explored directly contributed to the outcomes observed.</p> <p>One study reported the results of a physician survey which collated responses regarding the multidisciplinary management of soft tissue sarcoma.³² There was a trend towards biased views on treatment approaches for sarcoma based on the clinician speciality which may support the importance of multidisciplinary teams and consensus decision making for sarcoma patients.</p>		<p>current recommendation which states that patients with a confirmed diagnosis of sarcoma should have their care supervised by or in conjunction with a sarcoma MDT. However, the GDG indicated that this recommendation may not have been implemented fully.</p>
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Clinical area 11: Multidisciplinary sarcoma teams and centralisation of treatment

Q: Does hospital case volume have an effect on outcomes for patients with sarcoma?

Evidence summary	GDG/clinical perspective	Impact
<p>An observational study was identified which evaluated the prognostic significance of surgical centre case volume on outcome for soft tissue sarcoma.³³ On multivariate analysis, treatment at a high-volume centre was a significant independent predictor of improved survival and functional outcomes.</p>	<p>No clinical feedback provided.</p>	<p>New evidence is unlikely to impact on current recommendations:</p> <p>In summary, the new evidence supports a positive relationship between case volume and patient outcome for complex or high-risk surgery. No specific detail on the number of new sarcoma cases seen by the high volume centre was provided in the abstract therefore no new evidence was identified which would challenge the current recommendations on the minimum number of new cases a MDT should have in a year.</p>

Clinical area 12: Treatment of patients with sarcoma

Q: Are outcomes (surgical margins, local control, patient experience and survival) better for people with suspected limb, limb girdle or truncal soft tissue sarcoma treated in specialist sarcoma units than for those treated in non-specialist units?

Evidence summary	GDG/clinical perspective	Impact
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<p>A review of the East Midlands Sarcoma Service identified 42 patients presenting to the specialist centre after unplanned excision of soft tissue sarcomas.³⁴ In 40 cases resection was undertaken to achieve clear margins. In this study, however, there was no comparison of outcomes in people who had all their treatment in a specialist sarcoma unit.</p> <p>One study reported a 10-year, single-institution review of curative surgery on outcome, with a special emphasis on surgery before referral.³⁵ Forty nine percent of the patients included in the analysis underwent surgery contrary to current clinical guidelines before referral, most (73%) at primary care units. No influence on survival was observed although this pathway was considered to lead to an unfavourable clinical course.</p>	<p>GDG feedback indicated that patients referred to a sarcoma MDT following surgery at a non-expert centre are almost always non-salvageable.</p> <p>Furthermore, it was felt that there is variation in practice over management of sarcomas not in limbs. For example, there remains controversy over who should manage retroperitoneal, head and neck and gynaecological sarcomas.</p>	<p>New evidence is consistent with current recommendations:</p> <p>The identified new evidence and clinical feedback is in line with the evidence identified for the guidance and is therefore supportive of the current recommendations.</p>
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Clinical area 13: Patients with soft tissue sarcoma requiring shared management

Q: What is the role for PET in the management of people with sarcoma?

Evidence summary	GDG/clinical perspective	Impact
<p>In total, 18 studies were identified which evaluated the role of PET in management of sarcoma:</p> <p><u>Diagnosis</u> One study was identified which compared whole body 2-deoxy-2-18F-FDG-PET/CT with 18F-FDG PET/CT alone for detection of bone lesions.³⁶ Bone imaging was found not to provide an added diagnostic value over (18)F-FDG-PET/CT.</p> <p><u>Staging</u> Nine studies assessed the use of FDG-PET/CT for staging of sarcoma.</p> <p><u>Bone and soft tissue sarcoma</u> One study evaluated the impact of FDG-PET/CT on</p>	<p>Clinical feedback highlighted that PET imaging in patient assessment pre-operatively and at the time of recurrence is increasingly being used.</p>	<p>New evidence is unlikely to enable a specific recommendation on the use of PET for sarcoma to be made:</p> <p>From an assessment of the abstracts, the identified new evidence inferred that FDG-PET/CT may have a role in diagnosis, staging, treatment evaluation and follow up in people with sarcoma. Furthermore, clinical feedback from the GDG indicated that PET imaging is increasingly used in management of sarcoma. However, limited studies reported specificity in the abstract or indicated that they compared FDG-PET/CT against a reference standard whilst only one study stated an impact on outcomes after using FDG-PET/CT. Studies were generally very small and retrospective in nature. Furthermore, no study</p>

<p>initial staging, restaging, and evaluating treatment response in bone and soft tissue sarcomas.³⁷ All results were confirmed either by pathology, or by clinical follow-up. FDG-PET was found to be more accurate than CT whilst combined PET/CT had higher accuracy than either alone. Furthermore, the accuracy of FDG-PET/CT for initial staging of bone and soft tissue sarcomas was reported in a number of studies although only one study described the use of a reference standard in the abstract.³⁸⁻⁴¹</p> <p><i>Rhabdomyosarcoma</i> FDG-PET/CT for staging of rhabdomyosarcoma was investigated in four studies.⁴²⁻⁴⁵ Generally sensitivity was high, but specificity was only reported in one abstract whilst not all the studies included a reference standard which may have resulted in inflated estimates of diagnostic test accuracy.</p> <p><i>Ewing sarcoma</i> One study was compared PET/CT with PET alone in the staging and restaging of patients with Ewing tumour.⁴⁶ PET/CT was found to be significantly more accurate than PET alone for the detection and localisation of lesions in patients with Ewing tumour.</p> <p><u><i>Treatment evaluation</i></u> The impact of FDG-PET/CT on treatment evaluation was assessed in two studies. One study compared diffusion-weighted imaging (DWI) and PET/CT for treatment response evaluation and response prediction in patients with GIST.⁴⁷ The results indicated that DWI can provide a quantitative assessment comparable with PET/CT in GIST lesion characterisation, treatment response evaluation and response prediction. The second study aimed to determine whether FDG-PET/CT could be used to determine whether changes in tumour FDG uptake predict histopathologic treatment responses in high-grade soft tissue sarcoma</p>		<p>specifically focused on the role of FDG-PET/CT in discriminating between low-grade sarcomas and benign tumours.</p> <p>Imaging is already recommended for diagnosis and follow up however additional robust studies are required to confirm the role of PET in the management of people with sarcoma.</p>
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<p>after the initial cycle of neoadjuvant chemotherapy.⁴⁸ A 35% reduction in tumour FDG uptake at early follow-up resulted in a sensitivity and specificity of FDG-PET for histopathologic response of 100% and 67%, respectively.</p> <p><u>Follow-up</u> The role of FDG-PET/CT in follow up of people with sarcoma was investigated in two studies. One study compared FDG-PET/CT with contrast enhancement computed tomography (CECT) in the early follow-up of patients who had undergone treatment for primitive retroperitoneal sarcomas.⁴⁹ Compared with the McNemar test, the sensitivity and specificity of FDG-PET/CT were 66.7 and 100% and those for CECT were 58.3 and 50%, respectively. In addition, a small study of 11 patients reported the utility of pre- and post-radiotherapy functional imaging with FDG-PET.⁵⁰ Sensitivity of FDG-PET imaging was 100% but specificity was not reported.</p> <p><u>Detection of recurrence</u> Three studies assessed the role of FDG-PET/CT in the detection of recurrence of uterine sarcoma.⁵¹⁻⁵³ All three studies reported high sensitivity (> 85%) and high specificity (100%) although only one study reported a reference standard in the abstract which may have resulted in inflated estimates of diagnostic test accuracy.</p>		
Clinical area 14: Treatment support staff		
Q: Do limb prostheses, as currently prescribed, suit patients' needs? (as measured by outcomes including function, quality of life and complications)		
Evidence summary	GDG/clinical perspective	Impact
A small retrospective review of patients with extremity sarcomas indicated that children who received limb salvage with an expandable endoprosthesis showed high emotional satisfaction with their outcome. ⁵⁴ From	No clinical feedback provided.	New evidence is unlikely to impact on current recommendations: In summary, a small retrospective review reported

<p>an assessment of the abstract, however, no information on prosthetic usefulness (such as range of motion) and satisfaction with daily use was reported.</p>		<p>emotional satisfaction among patients provided with an expandable endoprosthesis after limb salvage. However, additional evidence on the usefulness of limb prostheses and satisfaction with daily use is required.</p>
<p>Clinical area 15: Follow up</p>		
<p>Q: For how long should people with sarcoma be followed up and by what method?</p>		
Evidence summary	GDG/clinical perspective	Impact
<p>The impact of frequency of surveillance imaging on disease-specific survival in patients with extremity soft tissue sarcoma was evaluated in one study.⁵⁵ More frequent follow up was associated with improved survival in high-risk relapsing patients with extremity soft tissue sarcoma.</p> <p>The efficacy of a follow up regime for patients with sarcoma of the extremities was evaluated in one study.⁵⁶ However, no detail about the follow-up policy was specified in the abstract.</p> <p>One study was identified which found that people at high-risk of GIST recurrence (risk stratification not described in the abstract) were more likely to suffer relapse (58% relapses occurred within 1 year and 84% within 3 years; n = 19).⁵⁷</p> <p>Lastly, a study was identified which compared patients with GIST who developed recurrence before 5 years and patients who developed recurrence 5 years after the excision of the primary tumour.⁵⁸ The study was unable to conclude an optimum duration of follow up for radically excised patients with GIST.</p>	<p>No clinical feedback provided.</p>	<p>New evidence is unlikely to impact on current recommendations:</p> <p>In summary, the identified new evidence was heterogeneous and evaluated different aspects of follow up. There is insufficient conclusive new evidence on timing and protocols for follow-up for different sarcoma types which would facilitate a more specific recommendation on follow up protocols to be made.</p>
<p>Clinical area 16: Follow up</p>		
<p>Q: What is the impact of follow up of people with sarcoma on their survival and disease recurrence?</p>		
Evidence summary	GDG/clinical perspective	Impact

<p>The results of a retrospective review indicated that long-term follow up of soft tissue sarcoma may potentially enable disease control if relapse occurs.⁵⁹</p> <p>A small retrospective chart review was identified which evaluated whether regular follow up improves overall survival of children with recurrent sarcomas.⁶⁰ The study concluded that regular follow up with imaging does not influence overall survival of children with sarcomas and that other diagnostic and treatment approaches are needed to improve the survival of children with recurrent sarcomas.</p>	<p>No clinical feedback provided.</p>	<p>New evidence is unlikely to impact on current recommendations:</p> <p>In summary, the identified new evidence was heterogeneous and reported conflicting results on the impact of follow up. There is insufficient conclusive new evidence on the impact of follow up of people with sarcoma on their survival and disease recurrence which would change the direction of the guideline recommendation which states that resources should be made available for regular imaging of patients at high risk of recurrence.</p>
<p>Clinical area 17: Improving knowledge</p>		
<p>Q: Is the outcome for people with sarcoma improved by the use of national cancer datasets and disease-based cancer registries?</p>		
<p>Evidence summary</p>	<p>GDG/clinical perspective</p>	<p>Impact</p>
<p>One study was identified which aimed to determine patient outcomes after different surgical approaches for gastrointestinal sarcomas, including GIST, utilising a large prospective cancer registry from 1991 to 2002.⁶¹ The results indicated that therapies such as surgical resection and treatment with imatinib are likely to be of benefit in this population. This information can be used to determine future treatment options which would be of most benefit for patients with gastrointestinal sarcomas.</p>	<p>Clinical feedback suggested that it should be mandatory for patients to be asked for consent for their samples to be saved in the new GIST tissue bank as this could help facilitate future research into GIST.</p>	<p>New evidence is consistent with current recommendations:</p> <p>In summary, a study reporting results from a large prospective cancer registry highlighted the treatments people with GIST had received and median survival rates for different treatments. This information may potentially be useful in assessing predictors of survival. Furthermore, GDG feedback on the use of tissue banks was positive. As such, this new evidence does not change the direction of the current recommendation which states that cancer registries should act as a data repository for an agreed dataset.</p>

For the following areas of the guideline no evidence was identified:

- The views of patients with cancer on travelling for specialist treatment or diagnosis
- Urgent referral for an X-ray in people with suspected osteosarcoma
- The impact of a 'hub and spoke' structure for delivery of care on patient outcomes

- The impact on patient outcomes in people with suspected bone sarcoma or abdominal / pelvic soft tissue sarcoma treated in specialist sarcoma units compared with non-specialist units
- The utility of shared management, between site specific and specialist sarcoma MDTs, for people with soft tissue sarcoma
- The role of a key worker for people with sarcoma
- Limb fitting services for people with sarcoma
- The impact of specialist rehabilitation (physiotherapy and occupational therapy) in improving outcomes for people with sarcoma
- Palliative care for people with sarcoma
- The use of surveillance in improving outcomes for people predisposed to sarcoma
- The impact of clinical trials in improving outcomes for people with sarcoma

Ongoing research

A research project funded by Sarcoma UK is currently on going which is prospectively collecting data on the quality of life of people with advanced sarcoma who are on a terminal pathway. The results of this trial have not been published at this time (study is expected to publish early 2014) therefore it is not possible to determine any potential impact on recommendations. However, data from this study may contribute towards the evidence base relating to palliative care for people with sarcoma in future surveillance reviews.

Anti-discrimination and equalities considerations

None identified.

Conclusion

Through the 8 year surveillance review of the cancer service guidance: Improving outcomes for people with sarcoma no new evidence which may potentially change the direction of guideline recommendations was identified. The proposal is not to update the sarcoma cancer service guidance at this time and to move this guidance onto the static list. Clinical guidelines placed on the static list will be reviewed every 5 years to determine if they should remain on the static list. Consideration to transfer a clinical guideline back to the active surveillance list may occur in the following circumstances:

- The high level review at 5 years yields new evidence which may impact on the guidance
- Stakeholders notify NICE of relevant new evidence which may impact on guidance at any time point, for example safety data.

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