NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Clinical Practice – Surveillance Programme

Clinical guideline
Cancer service guidance: Improving outcomes for people with sarcoma

Publication date
March 2006

Previous review dates
None

Surveillance report for GE (post-consultation)
March 2014 (8 year surveillance review)

Key findings

			Potential impact on guidance	
			Yes	**No**
Evidence identified from literature search				✓
Feedback from Guideline Development Group				✓
Anti-discrimination and equalities considerations				✓
No update	Rapid update	Standard update	Transfer to static list	Change review cycle
✓			✓	

Surveillance recommendation
GE is asked to consider the following proposals which were consulted on for two weeks:

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

- The guidance should be transferred to the static list as the guidance meets the following criteria:
    - No evidence was identified that would impact on the current guidance and no major ongoing studies or research has been identified as due to be published in the near future (that is, within the next 3-5 years)

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Surveillance review of cancer service guidance: Improving outcomes for people with sarcoma

Background information

Guideline issue date: 2006
8 year review: 2014

Eight year surveillance review

1. 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.

2. No new evidence was identified which would invalidate the guidance recommendations.

3. The GDG clinical adviser felt that the sarcoma cancer service guidance is up to date and there is no evidence that would change the current recommendations.

On-going research

4. 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 in 2014) therefore it is not possible to determine any potential impact on recommendations.

Anti-discrimination and equalities considerations

5. None identified.

Implications for other NICE programmes

6. A Quality Standard for sarcoma has been referred to NICE with a provisional start date still to be agreed.

Summary of stakeholder feedback

7. In total, seven stakeholders commented on the surveillance review proposal recommendation during the two week consultation period. The table of stakeholder comments can be viewed in Appendix 1.

8. Three stakeholders agreed with the surveillance review proposal to not update the guidance at this time, three stakeholders disagreed and one stakeholder did not state a definitive decision.

9. Two stakeholders agreed with the proposal to transfer the sarcoma cancer service guidance to the static list, one stakeholder disagreed and four stakeholders did not state a definitive decision (but two disagreed with the proposal not to update).

10. The stakeholders that disagreed with the surveillance review proposal commented that the guidance is unclear concerning sarcomas arising in thoracic, abdominal, head and neck, breast, urogenital, retroperitoneal and gynaecological sites and in describing the balance of responsibility between site-specific MDTs and the sarcoma MDT. Currently the guidance recommends that sarcoma MDTs have documented arrangements for linking with other MDTs to ensure coordinated management of patients with sarcomas at specific anatomical sites for which specialist input is required. However, the guidance does not override the responsibility of healthcare professionals and others to make decisions appropriate to the circumstances of each patient, in consultation with the patient and/or their guardian or carer. Similarly, guidance is not designed to be prescriptive, while they assist the practice of healthcare professionals, they do not replace their knowledge and skills.

11. Several stakeholders also indicated that implementation of certain recommendations, such as provision of information for patients, has been variable. However, failure to follow the guidance recommendations is a local implementation issue.

12. No comments were provided by any stakeholders suggesting any areas have been excluded from the original scope or that there are any equality issues.

Conclusion

13. Through the surveillance review of the sarcoma cancer service guidance, no new evidence which may potentially change the direction of guidance recommendations was identified.

Surveillance recommendation

14. GE is asked to consider the proposal to not update the sarcoma cancer service guidance at this time and to move this guidance onto the static list because it fulfils the following criteria:
    - No evidence was identified that would impact on the current guidance and no major ongoing studies or research has been identified as due to be published in the near future (that is, within the next 3-5 years)

Mark Baker – Centre Director
Sarah Willett – Associate Director
Emma McFarlane – Technical Analyst

Centre for Clinical Practice
March 2014

Appendix 1 Surveillance review consultation

Surveillance review consultation comments table
13-24 January 2014

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
Bone Cancer Research Trust	Disagree with the surveillance review proposal to not update the guideline	The Bone Cancer Research Trust disagrees with the proposal not to continue to review the Sarcoma Improving Outcomes Guidance.	Thank you for your comment. Through the surveillance review of the sarcoma cancer service guidance, no new evidence which may potentially change the direction of guidance recommendations was identified. As such, NICE has proposed that the sarcoma cancer service guidance should not be considered for an update at this time and should be transferred to the static guidance list.
		The NICE technology appraisal for Mifamurtide should be included in the guidance, the omission of this critical guidance could have potentially serious consequences if suitable patients are denied access. BCRT believes that all relevant information relating to the treatment of sarcoma should be covered within the Improving Outcomes Guidance, and is concerned about the impact on patients of the omission of specific treatment information.	Thank you for your comment. The scope of the sarcoma cancer service guidance includes the services for diagnosis and staging and treatment services. The only areas of clinical management covered include those which have direct implications for service delivery therefore aspects of drug treatment that are not related to service delivery are outwith the scope of this guidance.
		It is the understanding of BCRT from contact with patients and their families that not all patients are being offered Mifamurtide, despite the NICE technology appraisal, and there is concern about potential “postcode prescribing”. This needs to be addressed, and therefore the Improving Outcomes Guidance should continue to be updated.	Thank you for your comment. The scope of the sarcoma cancer service guidance includes the services for diagnosis and staging and treatment services. The only areas of clinical management covered include those which have direct implications for service delivery therefore aspects of drug treatment that are not related to service delivery are outwith the scope of this guidance.

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
			Mifamurtide in combination with postoperative multi-agent chemotherapy is recommended in TA235 within its licensed indication as an option for the treatment of high-grade resectable nonmetastatic osteosarcoma after macroscopically complete surgical resection in children, adolescents and young adults. However, NICE does not define how guidance is implemented locally.
		We understand that the recommendations about providing appropriate and timely information as described in the Improving Outcomes Guidance (chapter 2, Patient Perspectives) are not being implemented and this needs to be addressed. Accessible, high quality and accurate information is critical for bone sarcoma patients as this is a rare condition affecting just 500 people per year. Given the rarity of the condition, isolation and fear become exacerbated, and the provision of high quality information can help the patient overcome these feelings.	Thank you for highlighting this issue. The guidance recommends that patients should be provided with relevant information at each stage in the disease and treatment pathway and this should be provided in a variety of formats. Failure to follow the guidance recommendations is a local implementation issue.
		The National Cancer Experience Survey indicates that the experience of sarcoma patients is generally poor, scoring 20-30% points lower than other cancers on many measures, including “being seen as soon as necessary”. The provision of written information is also poor with only 50% of patients receiving appropriate information. Given these results, it is critical that the Sarcoma Improving Outcome Guidance continues to be updated so that patient experience can be improved. The fact that sarcoma patient experience is currently so poor must be addressed, and the Improving Outcomes Guidance is an important tool to facilitate this.	Thank you for highlighting this issue. The decision not to update the guidance and place it on the static list is based on no new evidence being identified through our surveillance process or subsequent consultation with stakeholders. A quality standard on sarcoma has been referred to NICE which will identify key areas for quality improvement. This is currently in development please see the NICE website for further details of this process and how you can be involved in that process.
Clinical Reference Group for Specialised	Disagree with the surveillance review	The Clinical Reference Group for Specialist Commissioning in Sarcoma disagrees with the proposal not to update the guideline. The delivery of sarcoma services is changing, and the guidance should reflect this. Professional and patient	Thank you for your comment. No specific new evidence was offered by the consultee. Through the surveillance review of the sarcoma cancer service guidance, no new evidence which may potentially

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
Commissioning	proposal to not update the guideline	groups are in agreement that the guideline contains ambiguity that prevents consistent delivery of and equitable access to specialist care. The ambiguity will hinder the efficient commissioning of services that the national specialist services model promises. We believe that these ambiguities can be resolved in part by new evidence and also through professional consensus that has been built since the original guideline.	change the direction of guidance recommendations was identified. As such, NICE has proposed that the sarcoma cancer service guidance should not be considered for an update at this time and should be transferred to the static guidance list. A quality standard on sarcoma has been referred to NICE which will identify key areas for quality improvement. This is currently in development please see the NICE website for further details of this process and how you can be involved in that process.
		We believe the present description of the diagnostic pathway is suboptimal. Experience of one-stop diagnostic services with triple assessment indicates that this is not an appropriate or efficient model. There has been limited development of diagnostic centres outside sarcoma treatment centres.	Thank you for your comment. No specific new evidence was offered by the consultee. Through the surveillance review of the sarcoma cancer service guidance no new evidence was identified which would change the direction of the recommendations on diagnosis. NICE is not aware of any important new studies likely to publish over the next few years which would contradict the decision to move this guideline onto the static list. Please note that clinical guidelines placed on the static list will be reviewed every 5 years to determine if they should remain on the static list. However, if you become aware of any new evidence or information from clinical practice that is likely to impact on the guideline, please contact NICE with the appropriate details.
		The guideline is unclear concerning sarcomas arising in thoracic, abdominal, head and neck, breast, urogenital, retroperitoneal and gynaecological sites and in describing the balance of responsibility between site-specific MDTs and the sarcoma MDT. Clear referral guidelines within the IOG for sarcomas in these sites would help meet the first key recommendation that all patients with sarcoma should be treated in or under the supervision of a sarcoma MDT. This	Thank you for your comment. The guidance recommends that sarcoma MDTs have documented arrangements for linking with other MDTs to ensure coordinated management of patients with sarcomas at specific anatomical sites for which specialist input is required (for example, head and neck, uterine, retroperitoneal sarcoma and GIST sarcomas). However, the guidance does not override the

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
		goal is shared by the CRG.	responsibility of healthcare professionals and others to make decisions appropriate to the circumstances of each patient, in consultation with the patient and/or their guardian or carer. NICE is not aware of any important new studies likely to publish over the next few years which would contradict the decision to move this guidance onto the static list. Please note that clinical guidelines placed on the static list will be reviewed every 5 years to determine if they should remain on the static list. However, if stakeholders become aware of any new evidence or information from clinical practice that is likely to impact on the guideline, please contact NICE with the appropriate details.
		Aspects of care delivery described in the guidance continue to be suboptimal (eg M. Venkatesan, C.J. Richards, T.A. McCulloch, A.G.B. Perks, A. Raurell, R.U. Ashford, East Midlands Sarcoma Service, Inadvertent surgical resection of soft tissue sarcomas, European Journal of Surgical Oncology (EJSO), Volume 38, Issue 4, April 2012, Pages 346-351) and therefore thought should be given to recommendations for implementation within the guidance. We now have eight years of experience about what has worked and what has not.	Thank you for highlighting this study. This paper was identified in the surveillance review of the sarcoma cancer service guidance where it was concluded that the new evidence was supportive of the guidance recommendations. Failure to follow the guidance recommendations is a local implementation issue.
		Information in the guidance is outdated: ie Bristol no longer provides a bone tumour service, PCTs have been abolished, a peer review mechanism does exist.	Thank you for your comment. The aim of the guidance is to advise commissioners on how to improve the care of all patients with bone sarcomas and adults with soft tissue sarcomas. We recognise that aspects of the terminology used in the guideline may now be outdated. However, as no evidence was identified that would change the direction of the recommendations, and considering that the terminology is a small aspect of the guidance, this is

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
			not significant enough to warrant updating the guidance at this point. The terminology will be amended if the guidance is considered to require an update in the future.
		The guidance does not refer to new mechanisms for implementation of change and commissioning (eg the CRG service specification)	Thank you for your comment. The aim of the guidance is to advise commissioners on how to improve the care of all patients with bone sarcomas and adults with soft tissue sarcomas. We recognise that aspects of the terminology used in the guideline may now be outdated. However, as no evidence was identified that would change the direction of the recommendations, and considering that the terminology is a small aspect of the guidance, this is not significant enough to warrant updating the guidance at this point. The terminology will be amended if the guidance is considered to require an update in the future.
		The guidance should refer to the NICE technology guidance 235 for mifamurtide, as well as that for imatinib.	Thank you for your comment. The scope of the sarcoma cancer service guidance includes the services for diagnosis and staging and treatment services. The only areas of clinical management covered include those which have direct implications for service delivery therefore aspects of drug treatment that are not related to service delivery are outwith the scope of this guidance.
		The IOG should contain a recommendation in favour of an aggressive surgical approach to the management of retroperitoneal tumours (Bonvalot S, Miceli R, Berselli M, et al. Aggressive surgery in retroperitoneal soft tissue sarcoma carried out at high-volume centers is safe and is associated with improved local control. Ann Surg Oncol. 17(6) 1507-14 (2010)., Gronchi A, Lo Vullo S, Fiore M, et al. Aggressive surgical policies in a retrospectively reviewed single-	Thank you for your comment. The scope of the sarcoma cancer service guidance includes the services for diagnosis and staging and treatment services. The only areas of clinical management covered include those which have direct implications for service delivery therefore aspects of surigical management that are not related to service delivery are outwith the scope of this guidance.

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
		institution case series of retroperitoneal soft tissue sarcoma patients. J Clin Oncol. 27(1) 24-30 (2009).)	
		There is further evidence in favour of high volume centres for retroperitoneal sarcoma (Gutierrez JC, Perez EA, Moffat FL, Livingstone AS, Franceschi D, Koniaris LG. Should soft tissue sarcomas be treated at high-volume centers? An analysis of 4205 patients. Ann Surg. 245(6) 952-8 (2007), Bonvalot S, Rivoire M, Castaing M, et al. Primary retroperitoneal sarcomas: a multivariate analysis of surgical factors associated with local control. J Clin Oncol. 27(1) 31-7 (2009).)	Thank you for the comment. The highlighted study was identified through the surveillance review of the sarcoma cancer service guidance and was found to support a positive relationship between case volume and patient outcome for complex or high-risk surgery. However, as no specific detail on the number of new sarcoma cases seen by the high volume centre was provided in the abstract it was concluded that this new evidence would not challenge the current recommendations on the minimum number of new cases a MDT should have in a year.
		The guidance should emphasise the importance of data collection in the English cancer registration service, for patients treated by NHS and independent sector providers.	Thank you for your comment. The guidance recommends that all sarcoma MDTs should collect data on patients, tumour, treatment and outcome and that cancer registries should act as the data repository of the agreed dataset.
		Advances in molecular diagnostics in sarcoma should be reflected in the guidance, particularly in relation to GIST	Thank you for your comment. 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 identified, 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 identified which would change the direction of this recommendation.
Department		I wish to confirm that the Department of Health has no	Thank you for your comment.

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
of Health		substantive comments to make, regarding this consultation.	
National Cancer Research Institute/Royal College of Physicians/Association of Cancer Physicians	Agree with the surveillance review proposal to not update the guideline	Our experts are not aware of any new data to inform an update	Thank you for your comment.
National Cancer Research Institute/Royal College of Physicians/Association of Cancer Physicians	Agree to place this guideline on the static list	Therefore content for this to move to the static list	Thank you for your comment.
Royal College of Paediatrics and Child Health	Agree with the surveillance review proposal to not update the guideline	Evidence identified provides further support for what is currently standard practice but doesn't suggest that practice should change. In view of these findings I think it is reasonable to move this to the 5 year surveillance list.	Thank you for your comment.
The Royal College of Pathologists	Agree with the surveillance review proposal to not update the guideline		Thank you.
The Royal College of	Agree to place this guideline		Thank you.

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
Pathologists	on the static list		
SARCOMA UK	Disagree with the surveillance review proposal to not update the guideline	Sarcoma UK acknowledges that the literature search carried out as part of this 8 year review indicates that no new information has been published that would bring about significant changes to the existing guidelines. However, evidence of how the guidelines have been implemented and the impact on practice (combined with improved patient experience data), is available. This provides us with important pointers as to where the guideline could be clarified in order to improve outcomes for sarcoma patients. The points made in this consultation relates to the opportunities that NICE have to clarify areas and help improve the implementation of the guideline by ensuring it is relevant to current sarcoma practice.	Thank you for your comment. Failure to follow the guidance recommendations is a local implementation issue. The decision not to update the guidance and place it on the static list is based on no new evidence being identified through our surveillance process or subsequent consultation with stakeholders. A quality standard on sarcoma has been referred to NICE which will identify key areas for quality improvement. This is currently in development please see the NICE website for further details of this process and how you can be involved in that process.
		We were surprised that data from the National Cancer Patient Experience Survey (NCPES) relating to sarcoma was not considered as part of the evidence. Rather, a four-year old Sarcoma UK survey of 80 patients' experiences of referral/diagnosis was highlighted to suggest that GP referral performance is improving. This very small scale survey included people who had been diagnosed a number of years previously and is not current. The NICE comments on the survey do not mention the reservations expressed within the survey about sample size and bias, particularly that it was survivors who responded. At the time it was conducted, the patient survey reflected positively the introduction of the guideline (when there had not previously been one in place). However, the landscape has changed as the guideline has been used and sarcoma services have been developed. The 2013 NCPES indicates: • 64% of sarcoma patients saw their GP no more than twice before referral to hospital in 2013 compared to	Thank you for highlighting the National Cancer Patient Experience Survey. The guidance recommends that GPs comply with the urgent referral criteria in the NICE 'Referral guidelines for suspected cancer'. In addition, patients with a suspected diagnosis of soft tissue sarcoma should be seen within 2 weeks at a diagnositic clinic. Failure to follow the guidance recommendations is a local implementation issue. A quality standard on sarcoma has been referred to NICE which will identify key areas for quality improvement. This is currently in development please see the NICE website for further details of this process and how you can be involved in that process.

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
		62% in 2012. • The number of sarcoma patients who felt they were seen as soon as necessary decreased from 73% in 2012 to 72% in 2013. Sarcoma patients are still experiencing delays in referral for investigations leading to diagnosis. Over a third of sarcoma patients had to see their GP three times or more before referral. This is not enough to indicate a change in behaviour that may lead to more positive future outcomes. In terms of patients feeling they were seen as soon as necessary, sarcoma has consistently come bottom of the rankings indicating this is an area in great need of improvement. An update of the guideline should be carried out that takes into consideration the latest data relating to sarcoma patient experiences identified in the NCPES	
		The guideline is used as the basis for sarcoma service specifications and cancer peer review. As sarcoma services, treatments and techniques have developed in the past 8 years the guidelines are not as relevant as they could be. In particular, they only contain limited reference to GIST, gynaecological, retroperitoneal and head & neck sarcomas. These are areas where sarcoma clinicians and patients have identified inconsistencies around pathways and responsibility for care which are impacting adversely on patients and limiting the ability to improve outcomes. These inconsistencies are due in part to lack of clarity in the guideline and this need to be addressed urgently. The guideline should be updated to give clearer recommendations around these areas of inconsistency.	Thank you for your comment. The guidance recommends that sarcoma MDTs have documented arrangements for linking with other MDTs to ensure coordinated management of patients with sarcomas at specific anatomical sites for which specialist input is required (for example, head and neck, uterine, retroperitoneal sarcoma and GIST sarcomas). However, the guidance does not override the responsibility of healthcare professionals and others to make decisions appropriate to the circumstances of each patient, in consultation with the patient and/or their guardian or carer. NICE is not aware of any important new studies likely to publish over the next few years which would contradict the decision to move this guideline onto the static list. Please note that clinical guidelines placed on the static list will be reviewed every 5 years to determine if they should

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
			remain on the static list. However, if stakeholders become aware of any new evidence or information from clinical practice that is likely to impact on the guideline, please contact NICE with the appropriate details.
		This surveillance review (Clinical area 3: Diagnosis) contains reference from the Guidelines Development Group around problems with gynaecological sarcoma pathways but fails to discuss the impact of this. Recent data presented at the Connective Tissue Oncology Society conference (Nov 13) highlighted major problems around inappropriate treatment of patients with gynae sarcoma by gynaecologists, leading to patients dying prematurely. Similar studies are underway in centres in the UK to assess the scale of the problem and the findings could impact significantly on the guideline, requiring a much stronger recommendation in order to improve the outcomes for patients with gynae sarcomas.	Thank you for your comment. The scope of the sarcoma cancer service guidance includes the services for diagnosis and staging and treatment services. The only areas of clinical management covered include those which have direct implications for service delivery therefore aspects of treatment that are not related to service delivery are outwith the scope of this guidance.
		In summary: Sarcoma UK believes that the guideline should be considered for updating because the sarcoma landscape is changing. Updating it is key to improving outcomes for patients and will help retain the credibility of the guideline amongst professionals and patients.	Thank you for your comment. Having carried out a surveillance review of the sarcoma cancer service guidance we do not feel that the evidence base is substantially evolving in this area at this time. By moving the guidance to the static list it will continue to be reviewed periodically, but less frequently than other guidelines. However, NICE would welcome being informed of the publication of any additional new evidence or guidelines that impact on the recommendations within the guideline before the next 5 year review.
SARCOMA UK	Disagree to place this guideline on the static list	There is recognition at the highest level within the NHS that change must happen in order to improve outcomes for sarcoma patients. The National Cancer Patient Experience Survey shows that sarcoma patients consistently have some of the worst experiences of any cancer patients in the NHS.	Thank you for your comment. Having carried out a surveillance review of the sarcoma cancer service guidance we do not feel that the evidence base is substantially evolving in this area at this time. By moving the guidance to the static list it will continue

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
		The establishment of a sarcoma-specific Clinical Reference Group as part of the restructure of NHS England provides evidence that sarcoma is viewed as a priority area.	to be reviewed periodically, but less frequently than other guidelines. However, NICE would welcome being informed of the publication of any additional new evidence or guidelines that impact on the recommendations within the guideline before the next 5 year review. A quality standard on sarcoma has been referred to NICE which will identify key areas for quality improvement. This is currently in development please see the NICE website for further details of this process and how you can be involved in that process.
		One of the main pieces of work of the Sarcoma CRG is to review and develop a new sarcoma service specification for commissioning sarcoma services. As a member of the CRG (representing Sarcoma UK), evidence is emerging from other members that there are ambiguities in the original guidance. This is particularly noticeable around diagnostic pathways and appropriate/ timely referral by GPs into specialist services. Improved data collection by the NCIN is providing evidence that, for example, 40% of sarcoma patients are still not treated under the care of a sarcoma MDT. The development of this new service specification for commissioning sarcoma services means that areas of the guidance will need to be updated to reflect this.	Thank you for your comment. The guidance recommends that patients with a suspected diagnosis of soft tissue sarcoma should be seen within 2 weeks at a diagnositic clinic. Furthermore, it is recommended that all patients with a confirmed diagnosis of bone sarcoma, or adults with a soft tissue sarcoma, should have their care supervised by or in conjunction with a sarcoma MDT. The recognition and management of suspected cancer in children, young people and adults guideline is currently undergoing an update and will cover the immediate referral to secondary care using the existing fast-track (2-week wait) referral system as part of the update.
		There is a lack of clarity around pathways and management of site specific sarcomas such as gynaecological, retroperitoneal, and head and neck sarcomas. The current guidance does not offer sufficient clarity about how and where these types of sarcoma should be treated, resulting in inconsistencies that the sarcoma Clinical Reference Group is attempting to address.	Thank you for your comment. The guidance recommends that sarcoma MDTs have documented arrangements for linking with other MDTs to ensure coordinated management of patients with sarcomas at specific anatomical sites for which specialist input is required (for example, head and neck, uterine, retroperitoneal sarcoma and GIST sarcomas).

Stakeholder	Agree?	Comments Please insert each new comment in a new row	Response
			However, the guidance does not override the responsibility of healthcare professionals and others to make decisions appropriate to the circumstances of each patient, in consultation with the patient and/or their guardian or carer. NICE is not aware of any important new studies likely to publish over the next few years which would contradict the decision to move this guideline onto the static list. Please note that clinical guidelines placed on the static list will be reviewed every 5 years to determine if they should remain on the static list. However, if stakeholders become aware of any new evidence or information from clinical practice that is likely to impact on the guideline, please contact NICE with the appropriate details.
		Specialist centres can interpret the current guidance in their own way and develop their own protocols, resulting in inconsistencies in practice and management. The improvements that patients need cannot come about if the guidance is not clear enough with its recommendations, or regularly reviewed, and ultimately updated.	Thank you for your comment. The sarcoma cancer service guidance does not intend to cover treatment protocols. It is guidance for commissioners on the organisation of services.
		In summary, Sarcoma UK believes that the guidance must continue to be regularly reviewed to ensure that new evidence and clarification around new and best practice can be incorporated quickly. Without this underpinning from NICE successful outcomes will remain a matter of chance for a significant proportion of patients. There will also be the need to update the guidance as a result of the work of the sarcoma CRG and to address inconsistencies. If the guidance goes onto the static list, there is a risk that it will fall behind the changes that are happening in service delivery.	Thank you for your comment. By moving the guideline to the static list it will continue to be reviewed periodically, but less frequently than other guidelines. However, NICE would welcome being informed of the publication of any additional new evidence before its next review in 5 years.

Appendix 2 Decision matrix

The table below provides summaries of the evidence for key questions for which studies were identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
CSG:S – 01 What are the views of patients with cancer on travelling for specialist treatment or diagnosis?			
Ten studies were included for this review question (5 cross-sectional studies, 3 case series, 1 systematic review and 1 qualitative study). The evidence suggested that, when confronted with different treatment options, travel time is a consideration in a person's choice of treatment.	No studies identified.	Clinical feedback from the GDG indicated that some cancer centres / networks have chosen not to develop a local diagnostic service which means that some patients may have to travel a long distance in order to obtain the necessary biopsy or scan.	No relevant evidence identified.
CSG:S – 02 In people with sarcoma, is there evidence for the effectiveness of psychosocial interventions?			
The following studies were included: 2 intervention studies and 1 cross-sectional study which reported the views of people with sarcoma on the effectiveness of psychosocial interventions. No studies designed to measure the effectiveness of psychosocial interventions for people with sarcoma were identified. The NICE guidance on Improving Supportive and Palliative Care for	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 of the types of psychological interventions as adaptation of these at different phases of the cancer may improve efficacy (Paredes et al., 2011; Paredes et al., 2012a). The results of a cross-sectional study	No clinical feedback provided.	New evidence is consistent with guideline recommendations: In summary, several studies were identified which 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

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
Adults with Cancer contains a comprehensive review of the effectiveness of psychosocial interventions for people with cancer and this evidence was used for the recommendations. The sarcoma specific evidence suggested patients report psychosocial interventions as beneficial. Stronger evidence reviewed in NICE guidance on Improving Supportive and Palliative Care in Adults with Cancer indicates such interventions are useful in the reduction of anxiety in people with cancer. There was insufficient evidence, however, to strongly recommend any specific psychosocial intervention in this patient group.	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 treatments (Paredes et al., 2012b). 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 pediatric sarcoma survivors (Wiener et al., 2006). 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 can be directly attributed to the sarcoma treatment. Lastly, one study was identified which explored the psychosocial characteristics of people living with GIST (Wiener et al., 2012). Pain was significantly associated with anxiety whilst body image and appearance concerns were expressed by over half of the study participants.		support the current recommendation which states that patients and carers should be offered psychological support.
CSG:S – 03 What are the information needs of people with sarcoma?			

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
Evidence included five observational studies, all of poor quality, and two qualitative studies. Recommendations about the development and dissemination of patient information were informed by the generic evidence reviewed in The NICE guidance on Improving Supportive and Palliative Care for Adults with Cancer. The evidence suggested a demand for websites with sarcoma information. Several themes relating to information needs were identified in qualitative reports. Fear of the unknown was a source of anxiety for people with sarcoma.	A cross-sectional study evaluated expectations of bone cancer patients when receiving information from their doctor (Cheah et al., 2012). 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.	No clinical feedback provided.	New evidence is consistent with guideline recommendations: The results of a cross-sectional study 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. This 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.
CSG:S – 04 For people with lumps suspicious of sarcoma, does referral to a specialist sarcoma unit or MDT improve the rate of pre-operative diagnosis?			
Eight observational studies (7 case series and a clinical audit) compared the preoperative management of people with sarcoma in specialist and	One study was identified which aimed to identify factors which could improve diagnosis of low-grade central osteosarcoma (Malhas et al., 2012).	Feedback from the GDG suggested that a failure to refer patients to specialist sarcoma units may negatively impact on	New evidence is consistent with guideline recommendations: The results of one study indicated

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
non-specialist settings. The evidence suggested that an accurate and safe pre-operative diagnosis of sarcoma is more likely at a specialist centre. The diagnostic clinic for STS closely affiliated to (but geographically separate from) the specialist sarcoma MDT is a new service model and no direct evidence was identified.	Patients who were referred to the specialist centre after initial treatment elsewhere all presented with local recurrence.	patient outcomes. The GDG highlighted that the NCIN is conducting research in the early stages of the gynaecological sarcoma diagnostic pathway utilising verified national sarcoma data.	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 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.
CSG:S – 05 In people with suspected osteosarcoma, does an urgent referral for an X-ray result in an earlier accurate diagnosis?			
Six case series were identified. Limited, but consistent, evidence supported the early ordering of a radiograph in people with suspected osteosarcoma. Complex imaging studies (CT, MRI or bone scan) ordered by referring physicians for putative bone sarcomas were often inappropriate or inadequate, and were a potential source of referral delay.	No studies identified.	No clinical feedback provided.	No relevant evidence identified.
CSG:S – 06 Does diagnosis of sarcoma by a specialist radiologist, compared with a general radiologist, lead to greater diagnostic accuracy?			
Six case series were identified. There was some evidence to suggest shortcomings in radiological	One study correlated radiologists' certainty of the diagnosis of liposarcoma on musculoskeletal MRI with pathology	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
assessment of people with sarcoma in referring hospitals, but no direct comparisons with specialist radiologists were reported. Three observational studies found the technical adequacy of CT or MRI imaging performed at referral centres was often poor. A tendency towards excessive imaging was also observed.	results (Lee et al., 2011). Fifteen (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.
CSG:S – 07 In people with STS, does early referral improve survival?			
No studies addressed the question directly, although a case series from the Scandinavian Sarcoma Group included a historical comparison of referral practices and patient outcomes. Other evidence was included (five case series and a cross-sectional study) to help estimate referral delay in STS. The observational evidence suggested that diagnostic uncertainty at the point of consultation to primary or secondary care can result in a delay in referral to the appropriate treatment centre. There was limited observational evidence that indicated that on average approximately five visits are	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 (Collin et al., 2010). 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 guideline 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 guideline 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'.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
made to a GP before a patient with sarcoma is referred elsewhere.			
CSG:S – 08 Do delays in diagnosis result in poor outcomes for people with sarcoma?			
No population based studies of diagnostic delay and outcome in people with sarcoma were identified. Nine observational studies (case series) analysed diagnostic delay in terms of disease stage at diagnosis. Evidence relating diagnostic delay to patient outcomes in sarcoma was limited in quantity and observational in nature. The studies tended to include small numbers of heterogeneous patients, making it difficult to estimate the prognostic significance of delay. Seven other studies were identified, two of which evaluated tumour size as a prognostic factor. UK studies reporting the early management of people with sarcoma expressed the opinion that diagnostic delay has a detrimental effect on treatment options and outcomes.	A retrospective study was identified which aimed to assess the impact of diagnostic delays on the prognosis of osteosarcoma (Kim et al., 2009). 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 (Pan et al., 2010). The mean total delay from 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. One study was identified which assessed whether the time from first sarcoma symptom to diagnosis has an impact on survival or disease-free	Feedback from the GDG indicated that a better system for early diagnosis of soft tissue sarcoma is badly needed as this is likely to improve survival.	New evidence is consistent with guideline recommendations: Four studies were identified which described delays in diagnosis of sarcoma. Two of the studies inferred that this delay may had 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. Generally this data is in line with the evidence presented in the guideline which indicates that delays in diagnosis can have an adverse effect on the outcome of people with sarcoma.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
	survival (Rougraff et al., 2012). Length of symptoms did not correlate with overall survival or disease-free survival. One observational study focused on the symptoms and diagnostic problems of chest wall chondrosarcoma and factors related to long doctor's delay (Widhe et al., 2011). Doctor's delay was >6 months for 40% of the patients evaluated whilst patients who died from chondrosarcoma had longer total delay in diagnosis.		
CSG:S – 09 Are current guidelines for early diagnosis of STS resulting in improved outcomes for patients?			
Two case series of good to poor quality, described the introduction of the Scandinavian Sarcoma Group (SSG) referral guidelines and the associated changes in referral practices and patient outcomes. A paper describing the development and dissemination of the SSG guidelines was also included. One systematic review, two case series and an audit were also included. There was limited evidence, from the Scandinavian Sarcoma Group, to suggest that the introduction of referral guidelines may improve outcomes.	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 (Perrier at al., 2012). 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. An observational study was identified which assessed the impact of adherence to clinical practice guidelines	Clinical feedback suggested that education of GPs about sarcoma continues to be a challenge. Although, a patient survey by Sarcoma UK was highlighted that suggests GP referral performance is slowly improving.	New evidence is consistent with guideline recommendations: Two studies identified for this review question indicated that there may be a benefit to sarcoma patients if clinicians adhered to clinical guidelines. This information supports the guideline 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.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
	for loco-regional treatment (surgery and radiotherapy) and chemotherapy on local disease control and survival in sarcoma patients (Rossi et al., 2013). Patients not treated according to the guidelines were at a higher risk of local recurrence and had a shorter sarcoma-specific survival.		
CSG:S – 10 Does diagnosis by a specialist sarcoma pathologist compared with a general pathologist of sarcomas lead to greater diagnostic accuracy?			
16 case series examined expert pathological review and diagnostic accuracy in sarcoma. Four of the studies included people with bone sarcomas only, seven studies included people with STS only and five included people with either bone or soft tissue sarcoma. Most studies did not define expert or specialist pathologist. The diagnostic accuracy of the expert pathologists was not assessed, but was assumed to be the gold standard, and the expert pathologist was assumed to be correct in any disagreement in diagnosis. There was consistent observational evidence that a histopathological diagnosis of sarcoma is often changed on review by an expert pathologist.	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 (Lehnhardt et al., 2008). An improvement in diagnosis or confirmation of the correct primary diagnosis by the second opinion was seen in 73.1% of the patients; in 2.5%, the second opinion was false. A cross-sectional study aimed to determine the importance of second opinion in pathological diagnosis of soft tissue lesions (Sharif et al., 2010). During the study period, 34 cases of soft tissue lesions were received for review and second opinion. Concurrence between the review and initial diagnosis	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations: 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.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
	was seen in 18 (53%) cases whilst discrepancy in the diagnosis at review and initial consultation was seen in 16 (47%) cases.		
CSG:S – 11 What is the clinical utility of cytogenetic testing and molecular pathology in people with sarcoma?			
Evidence included 11 case series, 1 systematic review and 2 consensus statements. No studies were identified which compared outcomes in people who received genetic testing with those who did not. Two position papers by European and US expert sarcoma pathologists reported consensus about the clinical utility of such techniques in the diagnosis of sarcoma. A number of case series analysed the outcomes of patients according to type of fusion gene in synovial sarcoma, Ewing's sarcoma or myxoid liposarcoma, or according to the type of *KIT* mutation in GIST. Consensus statements by expert sarcoma pathologists in Europe and America described the clinical usefulness of data from genetic tests. They suggested that such testing is likely to be mandatory in the diagnosis of certain types of sarcoma and should	One observational study indicated that DOG1 and KIT are sensitive and specific markers for GIST (Hwang et al., 2011). 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 (Kushitani et al., 2008). A review of 9 patients with tumours considered to be GIST revealed expression of CD117 and/or CD34 in 5 of 6 tumors, expression of actin in 3 of 6 tumors, and expression of desmin in 1 of 6 tumors (Logrono et al., 2006). However, five patients underwent surgical excision, and the GIST diagnosis was confirmed in 3 patients, whereas 1 tumor proved to be neurofibroma, and another tumor was leiomyoma. As such, it is not clear if	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. Lastly, there was a view that mutational testing of primary tumours should be mandatory to enable more personal treatment to be given.	New evidence is unlikely to impact on guideline recommendations: Evidence was identified indicating the potential of cytogenetic testing in people with sarcoma. 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 SSPs should have ready access to molecular pathology and/or cytogenetics facilities and no new evidence was identified which would change the direction of this recommendation.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
be available in all specialist centres. There was observational evidence that analysis of KIT mutation may provide prognostic information for people with GIST and predict response to imatinib therapy.	expression of CD117, CD34, actin or desmin are specifically relevant to GIST and no data on outcomes according to gene expression was reported. One study was identified which aimed to determine whether ezrin could be a useful diagnostic marker in bone pathology (Salas et al., 2009). Conventional chondrosarcomas, whatever their grade, were negative, while ten of 16 chondroblastic osteosarcomas were positive for erzin. One study reported that COL1A1/PDGFB translocation was detected in 93% of dermatofibrosarcoma protuberans (Salgado et al., 2011). The study indicated that this gene fusion should be detected using fluorescence in situ hybridization. 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. One study assessed the utility of immunohistochemistry for CDK4, MDM2, and p16 in the routine		

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
	histopathologic diagnosis of well-differentiated liposarcoma (WDL) from dedifferentiated liposarcoma (DDL) from other adipocytic tumors (Thway et al., 2012). 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. One study evaluated the ability of MDM2 immunohistochemistry and MDM2 fluorescence in situ hybridisation (FISH) to discriminate benign lipomatous tumors from well-differentiated liposarcoma on core needle biopsies (Weaver et al., 2010). MDM2 FISH had a higher sensitivity (100%) and specificity (100%) compared with MDM2 immunohistochemistry (65 and 89%) in core needle biopsies, respectively. One study explored the use of MDM2 and CDK4 immunohistochemistry for the histological diagnosis of low-grade osteosarcoma (Yoshida et al., 2010). All		

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
	low-grade osteosarcomas expressed one or both markers (100%), with 13 cases (57%) expressing both. One study evaluated whether MDM2/CDK4 expression may help separate dedifferentiated osteosarcoma from the conventional type (Yoshida et al., 2012). 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.		
CSG:S – 12 Should all people with sarcoma be reviewed by a specialist MDT?			
Evidence included: 4 case series, 1 clinical audit and 1 retrospective cohort study. Five observational studies used cancer registries and/or hospital records to compare the outcomes of patients reviewed by a sarcoma MDT with those not reviewed by such an MDT. Four studies, two from Scandinavia and one each from Canada and the UK included only people with STS of the limb, limb girdle or trunk. A French audit contained a majority of patients with extremity or truncal STS but also some patients with STS at other	One study was identified which considered the inclusion of plastic surgery expertise as important in an extremity sarcoma MDT (Agrawal et al., 2013). Retrospective reviews of the management of dermatofibrosarcoma protuberans or head and neck sarcomas reported the benefit of using a multidisciplinary management approach (Buck et al., 2012 and Colville et al., 2005 respectively). One study was identified which reported	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 guideline.	New evidence is consistent with guideline recommendations: 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

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
anatomical sites. The UK study was the only one to adjust for differences in case mix in its analyses. Evidence about MDT management for people with bone sarcomas was limited to a UK study of patterns of care and survival in people younger than 40 years with bone sarcoma. There was consistent evidence from observational studies that outcomes are better in patients managed by an STS MDT, but it was unclear to what extent MDT management is responsible for this difference. Multidisciplinary sarcoma teams tend to be located in specialist centres which in turn treat the greatest numbers of people, and it is difficult to estimate the contribution of the MDT service model to better patient outcomes. There was evidence of an overall survival advantage for those people with STS reviewed by a sarcoma MDT, in the three studies that reported this outcome. The four studies that considered disease-free survival found an advantage for those patients who were treated by a	outcomes after unplanned resection of a sarcoma chosen by a general physician (Hoshi et al., 2008). Similarly, a report from the North of England Bone and Soft Tissue Tumour Service presented experience of managing patients with angiosarcoma (Lewis et al., 2011). 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. One study reported the results of a physician survey which collated responses regarding the multidisciplinary management of soft tissue sarcoma (Wasif et al., 2013). 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.		the direction of the guideline recommendation which states that patients with a confirmed diagnosis of sarcoma should have their care supervised by or in conjunction with a sarcoma MDT.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
sarcoma MDT.			
CSG:S – 13 Does hospital case volume have an effect on outcomes for patients with sarcoma?			
Evidence included: 1 clinical audit, 2 case series and 1 cohort study. Evidence about hospital case volume and outcome in people with sarcoma was limited to two population based observational studies and a cohort study. An observational study examined hospital case volume and compliance with clinical guidelines for patients with sarcoma. There was insufficient evidence to draw conclusions about the impact of hospital case volume on outcomes of people with sarcoma. The few studies identified were unlikely to answer the question; due to the rarity of sarcoma there are few truly high case volume hospitals or surgeons, so most studies made comparisons between low volume centres. In the absence of evidence to indicate the appropriate case load for a sarcoma unit or surgeon, definitions of 'high case volume' were not defined *a priori* but derived from study results, ranging	An observational study was identified which evaluated the prognostic significance of surgical centre case volume on outcome for soft tissue sarcoma (Gutierrez et al., 2007). On multivariate analysis, treatment at a high-volume centre was a significant independent predictor of improved survival and functional outcomes.	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations: 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.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
from one patient per year to ten or more patients per year. Evidence from studies of other cancers suggests there is a positive relationship between case volume and patient outcome for complex or high-risk surgery (NICE *Improving Outcomes in Colorectal Cancer*).			
CSG:S – 14 Is there any evidence that a 'hub and spoke' structure for delivery of care affects patient outcome?			
Two systematic reviews were included. No evidence from studies of people with sarcoma was found. Due to the scarcity of research in this area the scope of the question was widened to include any evaluation of hub and spoke healthcare delivery models. A systematic review and modelling study of high quality compared patient outcomes in 'hub and spoke', centralised and localised service delivery models for vascular services. One systematic review of good quality examined accessibility and patient outcomes in cancer services. In a study comparing centralised, hub and spoke, and localised vascular	No studies identified.	No clinical feedback provided.	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
services models, both centralised and hub and spoke models were associated with improved patient outcomes when compared to the localised model. The argument that specialisation and case volume are associated with improved outcomes supports the hub and spoke model although such arguments also favour the fully centralised service model. Reduction of the patient's burden of travel is a major advantage of the hub and spoke model over a fully centralised service.			
CSG:S – 15 Are outcomes (local control, surgical margins, patient experience and survival) better for people with suspected bone sarcoma treated in specialist sarcoma units than for those treated in non-specialist units?			
Evidence included: 1 cohort study and 2 case series. A UK cohort study included a partially case mix adjusted analysis comparing the overall survival of people younger than 40 years with bone sarcoma initially treated at specialist centres with those treated elsewhere. An observational study reported case-mix adjusted analyses of the overall and disease free survival of patients treated at a specialist centre and at non-specialist centres	No studies identified.	No clinical feedback provided.	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
whilst a small observational study compared the surgical margins achieved by specialist unit. No relevant studies reporting comparisons of local control or patient experience were identified. The limited evidence suggested that overall survival was better for patients treated in specialist centres.			
CSG:S – 16 Are outcomes (surgical margins, local control, patient experience and survival) better for people with suspected limb, limb girdle or truncal STS treated in specialist sarcoma units than for those treated in non-specialist units?			
Evidence included: 9 case series and 1 clinical audit. Six observational studies, from the UK, Australia, France and Sweden, reported comparisons of surgical margins in specialist and non-specialist settings. Two studies, from the UK and USA, reported a comparison of specialist and non-specialist determination of surgical margins in STS. Four observational studies, from the UK, Sweden, Finland and France, included comparisons between the local recurrence of STS in people treated in specialist and non-specialist settings. None of these analyses was adjusted for case mix. Four observational studies, from the	A review of the East Midlands Sarcoma Service identified 42 patients presenting to the specialist centre after unplanned excision of soft tissue sarcomas (Venkatesan et al., 2012). 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. One study reported a 10-year, single-institution review of curative surgery on outcome, with a special emphasis on surgery before referral (Zacherl et al., 2012). Forty nine percent of the patients included in the analysis underwent	GDG feedback indicated that patients referred to a sarcoma MDT following surgery at a non-expert centre are almost always non-salvageable. 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.	New evidence is consistent with guideline recommendations: The identified new evidence is in line with the evidence identified for the guidance and is therefore supportive of the current guideline recommendations.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
UK, Sweden and Canada, included comparisons of the overall survival of patients treated in specialist and non-specialist settings. No relevant studies reporting patient's perspectives on specialist and non-specialist treatment settings were identified. The recommendation that surgery should be performed in specialist centres is supported by evidence that adequate surgical margins are more likely when initial surgery for STS is performed in a specialist treatment centre. There was consistent evidence, from four observational studies that local recurrence of sarcoma is less likely when the initial surgery is performed at a specialist treatment centre. In terms of overall survival, the studies which adjusted for case mix reported that people with STS treated at specialist centres have better overall survival than those treated elsewhere. Comparisons that were unadjusted for case mix, however, did not report a survival advantage for those treated at	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.		

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
specialist centres.			
CSG:S – 17 Are outcomes better for people with suspected abdominal or pelvic STS treated in specialist sarcoma units than for those treated in non-specialist units?			
Two studies including a comparison of patterns of care and outcome in people with retroperitoneal STS (RPSTS) were identified. Due to limited direct evidence, institutional case series reporting outcomes in people with RPSTS were also included. One study observed better overall 5 year survival in patients treated at a specialist tertiary referral centre compared to those treated elsewhere. In 25 institutional case series of people with RPSTS published since 1990, hospitals admitted between 2 and 42 patients for treatment per year on average. The difficulties associated with the treatment of this group of patients were a consistent theme. Patients tended to present with large tumours, (median size ranged from 10 to 18cm) which were predominantly high grade. Due to the rarity of retroperitoneal sarcoma, case series even from large institutions often span decades to	No studies identified.	No clinical feedback provided.	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
capture sufficient numbers for statistical analysis. It is difficult to interpret historical improvements and institutional differences in patient outcomes due to changes in patient management practices and technologies over this time.			
CSG:S – 18 When is shared management, between site specific and specialist sarcoma MDTs, appropriate for people with STS?			
No studies specifically addressing shared management and outcomes in people with sarcoma were found. Expert opinion suggests that shared management would be appropriate for people with gynaecological, head and neck, skin, chest wall or CNS sarcomas; also for children with adult-type STS and for people with GIST. Evidence about patterns of care and outcomes for people with gynaecological, head and neck, upper GI, and colorectal cancers, and for children and young adults with cancer is reviewed in the NICE improving outcomes service guidance series. This evidence was not reappraised for this review but is summarised in the guidance.	No studies identified.	No clinical feedback provided.	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
There is evidence throughout the NICE improving outcomes guidance series that management by an appropriate site specific specialist MDT is associated with improved patient outcomes. This is consistent with the recommendation that site (or age) specific MDTs should take primary responsibility for the management of people with sarcoma at certain anatomic sites.			
CSG:S – 19 What is the role for PET in the management of people with sarcoma?			
Evidence included: 3 guidelines, 15 case series, 2 systematic reviews and 2 reviews. Two systematic reviews of good quality considered the use of PET in people with, or suspected of having, sarcoma. One review covered PET for the detection, grading and therapy response of both study soft tissue and bone sarcomas and the other considered PET for the detection and grading of STS only. Sixteen observational studies of variable quality, not included in the systematic reviews, were also appraised. Two systematic reviews found	In total, 18 studies were identified which evaluated the role of PET in management of sarcoma: <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 (Walter et al., 2012). Bone imaging was found not to provide an added diagnostic value over (18)F-FDG-PET/CT. <u>*Staging*</u> Nine studies assessed the use of FDG-	Clinical feedback highlighted that PET imaging in patient assessment pre-operatively and at the time of recurrence is increasingly being used.	New evidence is unlikely to enable a specific recommendation on the use of PET for sarcoma to be made: 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. 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

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
insufficient evidence to support the routine use of FDG-PET in the diagnosis of suspected sarcoma. FDG-PET has the potential to discriminate between high grade sarcomas and low grade sarcomas or benign tumours, but may not offer adequate discrimination between low-grade sarcomas and benign tumours. FDG-PET appears to have relatively high specificity in the diagnosis of local recurrence but has limited sensitivity. It may have a role in ruling in a diagnosis of local recurrence.	PET/CT for staging of sarcoma. *Bone and soft tissue sarcoma* One study evaluated the impact of FDG-PET/CT on initial staging, restaging, and evaluating treatment response in bone and soft tissue sarcomas (Piperkova et al., 2009). 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 (Fuglo et al., 2012, Faizi et al., 2012, Tateishi et al., 2006, Tateishi et al., 2007). *Rhabdomyosarcoma* FDG-PET/CT for staging of rhabdomyosarcoma was investigated in four studies (Federico et al., 2013, Ricard et al., 2011, Tateishi et al., 2009, Eugene et al., 2012). Generally sensitivity was high, but specificity was only reported in one abstract whilst not		using FDG-PET/CT. Studies were generally very small and retrospective in nature. Furthermore, no study specifically focused on the role of FDG-PET/CT in discriminating between low-grade sarcomas and benign tumours. 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.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
	all the studies included a reference standard which may have resulted in inflated estimates of diagnostic test accuracy. *Ewing sarcoma* One study was compared PET/CT with PET alone in the staging and restaging of patients with Ewing tumour (Gerth et al., 2007). PET/CT was found to be significantly more accurate than PET alone for the detection and localisation of lesions in patients with Ewing tumour. *Treatment evaluation* 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 (Gong et al., 2013). 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		

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
	determine whether changes in tumour FDG uptake predict histopathologic treatment responses in high-grade soft tissue sarcoma after the initial cycle of neoadjuvant chemotherapy (Benz et al., 2009). 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. *Follow-up* 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. Niccoli-Asabella et al., 2013) 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 (Alford et al., 2012). Sensitivity of FDG-PET		

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
	imaging was 100% but specificity was not reported. <u>*Detection of recurrence*</u> Three studies assessed the role of FDG-PET/CT in the detection of recurrence of uterine sarcoma (Kao et al., 2011, Sharma et al., 2012, Park et al., 2008). 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.		
CSG:S – 20 Is there any evidence to support the role of a key worker for people with sarcoma?			
No evidence about key workers for people with sarcoma was identified. Evidence about key workers for people with cancer is reviewed in the NICE guidance on *Improving Supportive and Palliative Care in Adults with Cancer*. This evidence was not reappraised for this guidance. Extrapolation from the evidence presented in the NICE guidance on *Improving Supportive and* Palliative *Care in Adults with Cancer* supports	No studies identified.	No clinical feedback provided.	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
the recommendation for key workers for people with sarcoma.			
CSG:S – 21 Do limb prostheses, as currently prescribed, suit patients' needs? (as measured by outcomes including function, quality of life and complications)			
Evidence included: 2 cross-sectional studies, 12 case series and 2 observational studies. Five of the studies identified used a cross sectional survey design. Eleven papers were based on surveys of patients drawn from the records of single institutions (case series). The identified evidence suggests that a significant proportion of limb prosthetic users are not satisfied with their prosthesis, suggesting that the prosthesis do not meet the needs of these people.	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 (Henderson et al., 2010). From an assessment of the abstract, however, no information on prosthetic usefulness (such as range of motion) and satisfaction with daily use was reported.	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations: In summary, a small retrospective review reported 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.
CSG:S – 22 Are current limb fitting services providing an adequate service?			
The evidence for the above question (CSG:S – 21) was used for this question. The evidence suggested at least some inadequacies in limb fitting services. A report by the Audit Commission (2000) found that approximately 25% of people fitted with prosthetic limbs found them unusable for reasons of discomfort,	No studies identified.	No clinical feedback provided.	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
pain, poor fit and appearance.			
CSG:S – 23 Does specialist rehabilitation (physiotherapy and occupational therapy) improve outcomes for people with sarcoma?			
Evidence included: 2 reviews, 1 case report, 1 case series, 1 cross-sectional study and 2 expert opinions. Sarcoma-specific evidence was limited to unsystematic reviews and case reports of the rehabilitation process. No studies of the effectiveness of rehabilitation for people with sarcoma, or of specialist sarcoma physiotherapists, were found. There was limited evidence in support of the recommendation that a specialist sarcoma physiotherapist should be included as a member of the extended sarcoma MDT.	No studies identified.	No clinical feedback provided.	No relevant evidence identified.
CSG:S – 24 Do palliative care specialists with an interest in sarcomas enhance quality of life for people with sarcoma?			
No evidence about the palliative care of people with sarcomas was identified. NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* reviewed evidence for the configuration of palliative care services, and is likely to be applicable to people with sarcoma. Evidence from systematic reviews	No studies identified.	The GDG highlighted that a research project funded by Sarcoma UK is being completed at present at the Royal Marsden Hospital. This is looking at the quality-of-life of metastatic patients on a terminal pathway. It is anticipated from early analysis that there may be an	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
supports the effectiveness of specialist palliative care teams for the control of pain and symptoms of people with cancer. People cared for by specialist teams were more satisfied than those cared for elsewhere. Evidence from systematic reviews suggests that specialist palliative care delivered at a patient's home or in a hospice can be as effective as conventional hospital-based care in the control of pain and symptoms and in terms of patient satisfaction. There was insufficient evidence to recommend the ideal structure of a specialist palliative care team but patient outcomes tended to be better with specialist palliative care teams made up of multidisciplinary trained staff.		unexpectedly high QoL until late in that pathway, suggesting that patients benefit from effective supportive and palliative care for long beyond 2nd-line and 3rd-line therapy. This is due to publish in early 2014.	
CSG:S – 25 For how long should people with sarcoma be followed up and by what method?			
There was a lack of research evaluating follow up strategies for people with STS. Most of the studies identified were reports of follow up routines for people with extremity STS. Applicability of the evidence to the UK setting was questionable. The following literature was included: 2	The impact of frequency of surveillance imaging on disease-specific survival in patients with extremity soft tissue sarcoma was evaluated in one study (Chou et al., 2012). More frequent follow-up was associated with improved survival in high-risk relapsing patients with extremity soft tissue sarcoma.	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations: In summary, the identified new evidence was heterogeneous and evaluated different aspects of follow-up. There is insufficient conclusive new evidence on timing

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
guidelines, 3 review articles, 6 case series, 4 cross-sectional studies and 1 systematic review. The lack of studies comparing follow-up strategies for people with sarcoma, in terms of health outcomes, supports the recommendation for research into appropriate follow-up protocols for each tumour type and location.	The efficacy of a follow-up regime for patients with sarcoma of the extremities was evaluated in one study (Cool et al., 2005). However, no detail about the follow-up policy was specified in the abstract. 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% relpases occurred within 1 year and 84% within 3 years; n = 19) (Plumb et al., 2013). One study was identified which compared patients with GIST who developed recurrence before 5 years and patients who developed recurrence 5 years after the primary tumour's excision (Nannini et al., 2012). The study was unable to conclude an optimum duration of follow-up for radically excised patients with GIST.		and protocols for follow-up for different sarcoma types which would facilitate a more specific recommendation on follow-up protocols to be made.
CSG:S – 26 What is the impact of follow up of people with sarcoma on their survival and disease recurrence?			
The studies identified for the question above were used for this question (therefore, the following literature was	The results of a retrospective review indicated that long-term follow-up soft tissue sarcoma may potentially enable	No clinical feedback provided.	New evidence is unlikely to impact on guideline recommendations:

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
included: 2 guidelines, 3 review articles, 6 case series, 4 cross-sectional studies and 1 systematic review). None of the studies compared the outcomes survival or disease recurrence in patients followed-up using different strategies. There was insufficient evidence to estimate the effect of follow up on survival and disease recurrence in people with sarcoma.	disease control if relapse occurs (Nakamura et al., 2013). A small retrospective chart review was identified which evaluated whether regular follow-up improves overall survival of children with recurrent sarcomas (Postovsky et al., 2008). The study concluded that regular follow-up with imaging studies 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.		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.
CSG:S – 27 Does surveillance improve outcomes for people predisposed to sarcoma?			
The following literature was included: 1 cohort and case control study, 4 case series and 1 guideline. No studies compared outcomes in people at risk of sarcoma who were actively monitored with those who did not receive surveillance. Several studies discussed the surveillance of groups predisposed to sarcoma and were included as evidence. These studies do not represent an exhaustive list of the genetic syndromes or other risk factors predisposing to sarcoma.	No studies identified.	No clinical feedback provided.	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
There is good evidence that certain groups face an increased risk of developing sarcoma but the lack of relevant studies means it is not possible to say whether surveillance will improve their outcomes. Several authors have concluded that the increased risk of sarcoma in itself is sufficient to justify the surveillance of these people.			
CSG:S – 28 Do clinical trials improve outcomes in people with sarcoma?			
The following literature was included: 1 cohort study, 3 case series and a systematic review. There is some evidence that inclusion in a clinical trial is associated with better outcome in people with bone sarcoma. It is difficult to say whether inclusion in the trial itself improves outcomes (by strict adherence to treatment protocols for example), or whether the centres that enrol patients in trials are also those that provide better care. It is also possible that trial entry criteria may exclude those patients with poor prognosis.	No studies identified.	No clinical feedback provided.	No relevant evidence identified.

Conclusions from guideline (published 2006)	Is there any new evidence/intelligence identified during this 8-year surveillance review (2014) that may change this conclusion?	Clinical feedback from the GDG	Conclusion of this 8-year surveillance review (2014)
CSG:S – 29 Is the outcome for people with sarcoma improved by the use of national cancer datasets and disease-based cancer registries?			
The following literature was included: 2 reviews, 1 cohort study and 3 observational studies. There was little direct evidence to answer this question. The Scandinavian Sarcoma Group register provides an example of the benefits of a national disease based register of soft tissue and bone tumours. It allows evolving treatment patterns and patient outcomes to be monitored and enables regular audit of patient management against recommendations. A review of the epidemiology of sarcoma underlined the usefulness of national cancer registries. In addition, observational evidence suggests diagnostic accuracy may be improved by the central pathology review that follows the submission of a case to a sarcoma specific registry.	One study was identified which aimed to determine patient outcomes after different surgical approaches for gastrointestinal sarcomas, including gastrointestinal stromal tumors (GIST), utilising a large prospective cancer registry from 1991 to 2002 (Perez et al., 2007). The results indicated that therapies such as surgical resection and treatment with imatinib are likely to be of benefit in this population.	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.	New evidence is consistent with guideline recommendations: 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. As such, this study does not change the direction of the current recommendation which states that cancer registries should act as a data repository for an agreed dataset.