National Institute for Health and Clinical Excellence

Metastatic spinal cord compression – stakeholder consultation table

9 May–6 June 2006

Stakeholder	**No.**	**Section number**	**Comments** Please insert each new comment in a new row.	**Developer's response** Please respond to each comment
National Collaborating Centre for Acute Care			This organisation was approached but did not respond.	
Addenbrookes NHS Trust		General	The scope is reasonable. Very much support the desire to broaden the scope to include not only best clinical management but equally importantly standards for provision of the service.	Thank you for your comment.
Association for Continence Advice			This organisation was approached but did not respond.	
Association for Palliative Medicine of Great Britain and Ireland			This organisation was approached but did not respond.	
Barnsley Primary Care Trust			This organisation was approached but did not respond.	
Bedfordshire & Hertfordshire NHS Strategic Health Authority	1	4.1.1	Guidance is for adults, will the document give reference and recommendation to the children and young adults with malignant SCC, as they are often seen within adult services.	Thank you for your comment. Numerically, children form a small proportion of a much larger problem of all major adult cancers: breast, bronchus, prostate etc. It will not be possible to include the detailed management of children within the guideline but we will consider including a brief paragraph. It should also be noted that the Royal College of Paediatrics and Child Health agree with our proposal not to include children in this guideline.
Bedfordshire & Hertfordshire NHS Strategic Health Authority	2	4.3.f	There are issues around how we educate patients to the risks of SCC. It is important that we encourage a collaborative approach from national organisations to the production of patient Information i.e. Cancerbackup and Macmillan. Will this be included.	Thank you for your comment. We agree, but cannot make recommendations for organisations outside the NHS.
Bedfordshire &	3	4.3	Will the guidance address the huge education needs of all health care	Thank you for your comment. We cannot

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Hertfordshire NHS Strategic Health Authority			professionals	specifically advise on education. This would be considered by the implementation team at NICE.
Bedfordshire & Hertfordshire NHS Strategic Health Authority	4	4.3	Will the work force issues be addressed	Thank you for your comment. This is within the remit of this guidance.
Bedfordshire & Hertfordshire NHS Strategic Health Authority	5	4.3	Will the guidance define the management of patients from metastatic fractures through to SCC	Thank you for your comment. The guidance will consider early diagnosis.
Bedfordshire & Hertfordshire NHS Strategic Health Authority	6	General	Will any resources follow?	Allocation of resources to support implementation of the guideline is not within the remit of the GDG or NCC-C.
Brain and Spine Foundation			This organisation was approached but did not respond.	
Breast Cancer Care	1	4.3.f	From our experience in talking to patients with bone metastase we know there is a need for improved education of patients about the possibility of spinal cord compression (SCC). Anyone with spinal metastases should be aware of the possible signs and symptoms and the need to seek immediate medical advice if they think these symptoms are developing. This is not something that patients always understand as they are often given general unspecific advice which suggests that if symptoms persist over 'a period of time' they should speak to their doctor. Where as people with any signs and symptoms of SCC must seek medical advice immediately. Survival time of patients with bone metastases can be seriously reduced following SCC primarily due to lack of mobility, so quick diagnosis and treatment that will reduce the likelihood and period of immobility is important. At time of diagnosis, patients are given a leaflet detailing the bisphosphonate treatment they will be starting and it would be helpful to also give them information about SCC at this time. Information can also be helpful in aiding the patient to be specific in describing their concerns to their GP/doctor who may not be considering spinal cord compression.	Thank you for your very helpful comments which we will forward to the GDG.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
			Information about who to contact during normal working hours and out of hours, as well as guidance on what to do if patients suspect SCC should also be made available. Breast Cancer Care also believes it is important to raise health professionals' awareness around spinal cord compression. Particularly primary care professionals, as patients may approach their GP with concerns.	
Breast Cancer Care	2	General	Patients at a high risk of spinal cord compression should be considered for orthopedic referral. However, evidence (which evidence? We might be asked for this – ask [X] if it came from her for a ref) suggests up to one third of patients who would benefit from orthopedic referral are not referred. Patients have also told us that there needs to be more information about: - Which patients are considered at high risk; - Activities that may need to be avoided and/or those that may be beneficial to prevent SCC; - Any treatments that may be beneficial; - Whether the risk of SCC is assessed when staging scans are done; and - What evaluation of patients with suspected SCC includes and how this may facilitate remedial action or monitoring. Vertebroplasty to strengthen the vertebrae is a NICE approved technique and should be widely available but our experience from talking to patients at Breast Cancer Care suggests this is not a routinely performed operation. Many patients and health professionals not aware of the	Thank you for your comments. The scope has now been revised to include identification of patients at risk. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis. The scope has now been revised to include identification of patients at risk. Specific treatment modalities will form a large part of the development work of the GDG. This will include medical therapies and minimal intervention. The GDG will consider patient information needs and awareness for this population of patients.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
			possibility of this treatment. We note that NICE's forthcoming guidance on Percutaneous cementoplasty for palliative treatment of bone malignancies due to be published in June 2006 is expected to support the use of cementoplasty in cancer patients for whom other treatment has failed and states the procedure aims to reduce pain but also stabilise bones. We believe this is relevant to spine stability and spinal cord compression.	Thank you. We will include cross-reference to any other relevant NICE guidance.
Breast Cancer Care	3	4.3.a, b	Once spinal cord compression is suspected there must be fast referral back to secondary and tertiary care for assessment and treatment and it needs to be treated as an emergency situation. People who develop spinal cord compression will then be cared for in a variety of settings (general ward, oncology wards, community, neuro units, hospices) and usually require intensive long term nursing. As a result, any measures to improve prevention and treatment which aim to maintain a person's mobility and independence would be cost effective.	Thank you for your comment.
Breast Cancer Care	4	4.2.a	The reference to rehabilitation and supportive care needs to be broad enough to consider psychological care but also practical and financial support. People affected by SCC can be in hospital for periods of time as well as suffer limited mobility and function and so issues such as lost finances and child care can be hugely pertinent but all too often neglected.	Thank you for your comment. We will discuss with the GDG.
Brighton & Sussex University Hospitals Trust			This organisation was approached but did not respond.	
British Association Of Spine Surgeons	1	4.2.a	Primary care - providing educational material so that G.P.'s are aware of the risk of spinal metastases amongst their cancer patients, know the common clinical presentations and the importance of prompt referral for diagnosis and treatment.	Thank you for your comment. We will discuss with the GDG.
British Association Of Spine Surgeons	2	4.2	The arrangements for rapid diagnosis – provision of radiographs,	Thank you for your comment. We will be discussing service provision with the GDG.
British Association Of Spine Surgeons	3	General	MRI and CT scanning - implications for after hours service provision.	The current level of MRI and CT provision will be examined and we hope that implementation of the guideline will help drive service provision and improve access.
British Association Of	4	4.3.b	Treatment of:	Thank you for your comment. The scope has

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Spine Surgeons			a).spinal metastases before vertebral collapse. b).spinal mets with bone pain from infiltration or pain due to pathological fracture (The place of bisphosphonates, DXT, chemotherapy, vertebroplasty, kyphoplasty and surgical excision and stabilisation should be considered. c). Spinal metastases with cord compression: cord compressed by tumour within the canal and by mechanical effects of vertebral collapse (Different treatments may be appropriate for these different situations). The care of the patient with impaired sensation and motor paresis/paralysis. The role of surgery - Surgical approaches - anterior, vs posterior vs. combined approach (front and back)	now been revised. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis. It is anticipated that different clinical scenarios will be considered by the GDG and an algorithm to describe patient management will be considered.
British Association Of Spine Surgeons	5	4.3.b	Timing of radiotherapy - pre-op or post-op.	Thank you for your comment.
British Association Of Spine Surgeons	6	4.3.b	Recommendations regarding the use of the scoring systems of Tomita and Tokuhashi for improving patient selection for different forms of treatment.	Thank you for your comment. We agree.
British Association Of Spine Surgeons	7	4.3.b	Formation of a team within a hospital, e.g. Oncologists/Spinal Surgeons/Radiologists/ where necessary ITU consultants and abdominal or vascular surgeons (the latter for possible help with surgical approaches) - could be useful in planning the management of these cases.	Thank you for your comment. The GDG will be considering the whole patient pathway and will be making appropriate recommendations on service provision.
British Association Of Spine Surgeons	8	4.3 b,c,d,e,f	Fragmentation of care occurs when often the patient is left on a general orthopaedic or spinal / neurosurgical ward, whereas the patient would best be managed by oncologists and intensivists with only a short stay with spinal surgeons for the immediate peri-operative care.	Thank you for your comment. We will consider the whole pathway of care in the guideline.
British Association Of Spine Surgeons	9	4.3.b	Aftercare and rehabilitation - For transthoracic approaches these patients may require: ICU support and short periods of post-operative ventilation – There is a	Thank you for your comment. The GDG will be discussing all aspects of service provision for these patients.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
			reluctance to admit cancer patients to intensive care units so guidelines for ICU staff should be covered.	
British Association Of Spine Surgeons	10	4.3.e	Post-op. rehabilitation and the role of spinal injuries units (they are also stakeholders and current spinal injuries overburden the services and prevent access for cancer sufferers).	Thank you for your comment. We will address this during development of the guidance.
British Association Of Spine Surgeons	11	4.3.e	Palliative care - involvement of social services and Hospices – crucial to overall well-being of patient and pain management.	Thank you for your comment. We will address aspects of palliative care specific for this group of patients, but cannot make recommendations for agencies outside the NHS.
British Lymphology Society		General	BLS has no comment as yet on this much needed document.	Thank you.
British National Formulary (BNF)			This organisation was approached but did not respond.	
British Society of Rehabilitation Medicine	l	General	Agree with scope and steps in pathway. Communication, informed consent also included? And Guidance on breaking bad news… Recommendations for further research included?	Thank you for your comment. These issues are already covered by NICE guidance on supportive and palliative care. We expect audit and research recommendations to be included in the final guideline.
British Society of Rehabilitation Medicine	2	General	Assume will include recommendations for social services including provision of equipment, needs assessments and timely discharge from hospital. Should also include wheelchair services Assume will make recommendations for rehabilitation process as well as components of it… Assume will address mobility, activity / function , bladder and bowel management, education, discharge planning, pain management, individual and family psychosocial support	Thank you for your comment. We cannot make recommendations for agencies outside the NHS. However, the guideline will include cross reference to appropriate published NSFs e.g. long term conditions. The GDG will consider the whole patient pathway and it is anticipated we will make recommendations on access and availability of services and equipment.
British Society of Rehabilitation Medicine	3	General	Related Guidance to include pressure ulcer?	Thank you for your comment. NICE has already published the clinical guideline 'Pressure ulcers: The management of pressure ulcers in primary and secondary care', issued September 2005. Reference CG029.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
British Society of Skeletal Radiologists			This organisation was approached but did not respond.	
Cancer Research UK			This organisation was approached but did not respond.	
CASPE			This organisation was approached but did not respond.	
National Collaborating Centre for Chronic Conditions			This organisation was approached but did not respond.	
College of Occupational Therapists			This organisation was approached but did not respond.	
Coloplast Limited			This organisation was approached but did not respond.	
Commission for Social Care Inspection			This organisation was approached but did not respond.	
Company			This organisation was approached but did not respond.	
Connecting for Health			This organisation was approached but did not respond.	
Continence Foundation			This organisation was approached but did not respond.	
Conwy & Denbighshire NHS Trust			This organisation was approached but did not respond.	
Department of Health	1	General	Thank you for the opportunity to comment on the draft scope for the above guideline. The Department of Health is content with the scope as drafted and has no further comments.	Thank you.
General Chiropractic Council	1	3.b,c	Many patients consult chiropractors, osteopaths and physiotherapists for back pain or nerve root symptoms n the independent sector for early in their episodes. These practitioners have considerable scope to provide earlier detection and this should be considered in any guideline.	Thank you for your comment. The scope has now been revised. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis. However we cannot make specific recommendations for professionals working outside the NHS.
General Chiropractic Council	2	4.1.1.a	By the time spinal cord and nerve root compression are suspected AND diagnosed, an adverse amount of time can have passed. Suggest	Thank you for your comment. We agree and the scope has now been revised. The

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
			suspected alone is sufficient.	guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis.
General Chiropractic Council	3	4.2.a	Suggest including musculoskeletal practice in the independent primary care sector.	Thank you for your comment. The GDG will be asked to consider your suggestion. However we cannot make specific recommendations for professionals working outside the NHS.
General Chiropractic Council	4	4.3.a	Suggest that this includes criteria for investigations.	Thank you for your comment. Although this is something that we are likely to address, the scope does not require that level of detail.
Great Ormond Street Hospital for Children NHS Trust			This organisation was approached but did not respond.	
Health and Safety Executive			This organisation was approached but did not respond.	
Healthcare Commission			This organisation was approached but did not respond.	
Heart of England NHS Foundation Trust			This organisation was approached but did not respond.	
Help the Hospices			This organisation was approached but did not respond.	
Hove Polyclinic			This organisation was approached but did not respond.	
International Myeloma Foundation (UK)			This organisation was approached but did not respond.	
James Cook University Hospital		General	I would like to make a few suggestions regarding the scope of the guidelines. 1, The title suggests metastatic cord compression but of course the optimum time for intervention in many cases is in pathological fracture prior to the development of actual neurological deficit. I think the guidelines should include the management of spinal metastasis with pathological deformation and incipient cord compression. 2. The guidelines should address the question of tissue diagnosis. In some areas blind treatment is utilised for secondaries of unknown origin which I	Thank you for your comments. The scope has now been revised to include identification of patients at risk. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis Specific treatment modalities will form a large part of the development work of the GDG.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
			believe is not satisfactory. 3, Clearly the guidelines will need to address indications and timing of a referral for surgical opinion. 4. We should consider whether guidelines can be provided as to who is competent to provide a surgical opinion for spinal metastasis. Not all surgeons involved in spinal surgery are able to undertake all the procedures that may be necessary for the management of metastatic disease., Under these circumstances they might not be able to recommend appropriate treatment. 5, I believe that the Committee should be considering guidelines on the surgical approach to the disease and provision of instrumentation, 6. The guidelines should consider the use of adjuvant therapies, of course including radiotherapy and chemotherapy bitt also if surgical intervention is to be considered, procedures such as embolisation. 7. One area in which spinal surgery can assist considerably is in the management of the unstable metastatic disease for pain but without neurological compression. 8. The role of prediction is important and the committee may like to consider assessment tools such as the Tokuhashi score or Tomita score. 9. Finally it is clear that the surgical management of metastatic spinal disease is only an incident in the ongoing oncological management. However, surgical indications and techniques can only be improved by the assessment of outcome and the committee may like to consider whether guidelines should be put in place concerning the formation of a multi-disciplinary team including oncologists and spinal surgeons and particularly to consider whether more follow-up in the spinal surgical• side would be of value.	This will include medical therapies and minimal intervention. We agree. Service recommendations will be made in the guidance. Service recommendations will be made in the guidance. The GDG will be considering medical therapies and this has now been included in the scope. Management of pain is within the remit of this guideline. Utility of scoring system may be examined. Yes, we agree. The GDG will discuss these points.
Johnson & Johnson Medical	1	General	We are happy with the scope and its proposed remit. As written, we have no additions to make.	Thank you.
Leukaemia Research			This organisation was approached but did not respond.	

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Fund				
Marie Curie Cancer Care	1	1 Title	'Patients' should read 'Adults'	Thank you for your comment. We agree and have changed the scope.
Marie Curie Cancer Care	2	4.1.1.b	This second group of patients who will be covered "…with direct infiltration from primary (ie non CNS) tumours" is not correctly described by the title of '**Metastatic**' Spinal cord compression. Would 'malignant' be a more appropriate term?	Thank you for your comment. We agree that the term metastatic does not truly cover this group of patients whom we wish to include in the scope. Malignant is more misleading because the remit is for metastases. We are including myeloma but are not including primary malignant tumours of CNS or bone.
Marie Curie Cancer Care	3	4.1.2 d	Should simply read 'Children'	Thank you for your comment. We agree and will change the scope.
Marie Curie Cancer Care	4	4.2.e	'Palliative Care Services' should be placed as point **'d**'. Almost all these patients will be cared for, at least in part, by palliative care services. The whole point should read "Palliative Care Services in primary, secondary and tertiary care settings".	Thank you for your comment. We disagree. This is a concern we wish to address with the aim to review access to these services.
Marie Curie Cancer Care	5	4.2.d	This point should be placed last. Clinical experience shows that very few patients with spinal cord compression caused by metastatic disease will be accepted by specialist rehabilitation centres.	Thank you for your comment. We disagree. This is a concern we wish to address with the aim to review access to these services.
Marie Curie Cancer Care	6	4.3	This list could be ordered consecutively to reflect the usual clinical 'pathway' of the patient.	Thank you for your comment. We have amended the list in the scope.
Marie Curie Cancer Care	7	4.3.c	This point could better read "All aspects of rehabilitation and supportive care". These services will be required, but overlap significantly with point **4.3.e** (see below). Once a patient develops metastatic disease at any site, a referral to palliative care services should be mandatory.	Thank you for your comment. We disagree and have not changed the scope.
Marie Curie Cancer Care	8	4.3.d	This should be placed at the end of the section as **'f)'**. It would be unusual for a person with malignant cord compression to require follow up which can be separated from the general palliative and/or oncological follow up he should already be receiving. (See comments **4.3.c** and **4.3.e**)	Thank you for your comment. We agree and have changed the scope accordingly.
Marie Curie Cancer Care		4.3.e	The phrasing of this point in the draft suggests that palliative care is a minor aspect of the care required by a person with metastatic cord. For me this reflects a major misunderstanding of the disease trajectory of people with MALIGNANT spinal cord compression. They will almost all have other sites of metastatic disease and will be requiring palliative care services for the management of the WHOLE person. It will often be difficult to separate out the physical and psychological symptoms directly referable to the cord	Thank your for your comment. It is not our intention to minimise the role of palliative care. But we will need to concentrate on those aspects that are specific for patients with metastatic spinal cord compression in addition to other general aspects and needs.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
			compression from those which more generally reflect the fact that the patient has advancing metastatic disease.	
Medicines and Healthcare Products Regulatory Agency (MHRA)			This organisation was approached but did not respond.	
Mental Health Act Commission			This organisation was approached but did not respond.	
National Collaborating Centre for Mental Health 2			This organisation was approached but did not respond.	
Midlands Centre for Spinal Injuries			This organisation was approached but did not respond.	
National Council for Palliative Care	1	1	'Patients' should read 'Adults'	Thank you for your comment. We agree and have changed the scope.
National Council for Palliative Care	2	4.1.1.b	This second group of patients who will be covered: with direct infiltration from primary, non CNS tumours is not correctly described by the title 'metastatic spinal cord compression'.	Thank you for your comment. We agree that the term metastatic does not truly cover this group of patients whom we wish to include in the scope but the remit is for metastases. However, malignant is more misleading because we are including myeloma but not including primary malignant tumours of CNS or bone.
National Council for Palliative Care	3	4.1.2.d	Currently reads 'children with malignant tumours' could read more precisely just 'children'.	Thank you for your comment. We agree and will change the scope.
National Council for Palliative Care	4	4.2.e	'Palliative care services' should be placed as point (d). Almost all of these patients will be cared for, at least in part, by palliative care services. The whole point should read 'palliative care services in primary, secondary and tertiary care settings'.	Thank you for your comment. We disagree. This is a concern we wish to address with the aim to review access to these services.
National Council for Palliative Care	5	4.2.d	This point should be placed last. Very few patients with metastatic cord compression will be accepted by specialist rehabilitation centres.	Thank you for your comment. We disagree. This is a concern we wish to address with the aim to review access to these services.
National Council for Palliative Care	6	4.3.c	This point might better read 'all aspects of rehabilitation and supportive care'.	Thank you for your comment. We disagree and have not changed the scope.
National Council for Palliative Care	7	4.3.d	This should be placed at the end of the section as point (f).	Thank you for your comment. We agree and have changed the scope accordingly.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
National Council for Palliative Care	8	4.3.e	This point presumes aspects of the person can be separated out as needing palliative care whereas in fact a person with spinal cord compression is likely to have other palliative care needs. Perhaps it would better read palliative care input as determined by the person's and family's needs.	Thank your for your comment. It is not our intention to minimise the role of palliative care. But we will need to concentrate on those aspects that are specific for patients with metastatic spinal cord compression in addition to other general aspects and needs.
National Patient Safety Agency			This organisation was approached but did not respond.	
National Public Health Service - Wales			This organisation was approached but did not respond.	
National Treatment Agency for Substance Misuse			This organisation was approached but did not respond.	
NCC for Cancer			This organisation was approached but did not respond.	
NHS Health and Social Care Information Centre			This organisation was approached but did not respond.	
NHS Plus			This organisation was approached but did not respond.	
NHS Quality Improvement Scotland			This organisation was approached but did not respond.	
North Trent Cancer network			This organisation was approached but did not respond.	
Northwest London Hospitals NHS Trust			This organisation was approached but did not respond.	
Novartis Pharmaceuticals UK Ltd	1	4.3	In the section discussing the treatments that will be reviewed, we note that bisphosphonate therapy is not included. Although bisphosphonate therapy does not have a role in the acute management of spinal cord compression, there is considerable evidence that the use of bisphosphonates in metastatic cancer with bony involvement prevents the incidence of skeletal related events including spinal cord compression.	Thank you for your comment. Identification of patients at risk will now be included in the scope. The GDG will also be considering all medical therapies and the scope has been changed to reflect this.
National Collaborating Centre for Nursing and Supportive Care			This organisation was approached but did not respond.	
Patient and Public	1	General	We think this scope sets out a clear strategy for a clinical guideline on	Thank you.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Involvement Programme for NICE			metastatic spinal cord compression. We welcome the focus on rehabilitation and support needs, specific elements of palliative care, and on communication and information resources for patients, carers and family members.	
Patient and Public Involvement Programme for NICE	2	4.1.2.d	We understand that the guideline is about adults. It would be helpful if an age range could be given, to clarify any boundary between services for children, young adults and adults.	Thank you for your comment. It is very difficult to define the cut off between adults and children, hence we do not intend to be prescriptive in this guideline.
PERIGON (formerly The NHS Modernisation Agency)			This organisation was approached but did not respond.	
National Collaborating Centre for Primary Care			This organisation was approached but did not respond.	
Prostate Cancer Charity, The	1	General	It seems appropriate that children are excluded from this guideline as their needs and management are so very different from the care an adult might receive. It seems likely that the body of evidence and knowledge are derived from adult experience anyway, as the incidence in adults must be much more common.	Thank you, we agree.
Prostate Cancer Charity, The	2	General 4.1.1.	We wonder if the groups that will be covered should also include some patients who are earlier in their cancer journey – those known to have cancer but who do not have a spinal cord compression? The SCOPE seems to assume that some form of information, support and advice for patients who could possibly be identified early as 'at an increased risk of experiencing spinal cord compression', is clinically useless. Is this known to be so? There may be some evidence on how patients with cancer feel when they 'progress' to a spinal cord compression and then discover that this is a recognised possibly sequelae of the cancer they had – and no one had warned them of the possibility.	Thank you for your comment. The scope has now been revised. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis. Thank you. The scope does not make that assumption. This will be discussed by the GDG.
Prostate Cancer	3	General	In light of this please consider adding a new group to 4.1.1: "Adult patients	Thank you for your comment. The scope has

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Charity, The			at particular risk of developing metastatic spinal cold compression as a result of a pre-existing cancer diagnosis". Failing that, consider modifying 4.1.1. (a) to 'Adults ***at risk of*****,** or with suspected and diagnosed spinal cord and nerve root compression due to ***potential or diagnosed*** metastatic disease.	now been revised. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis.
Prostate Cancer Charity, The	4	General	As the results of spinal cord compression can be catastrophic, (3b refers) the Guidelines may be able to seize some advantage of time for a subset of patients (and the health professionals who look after them) by choosing as a start point any potential for early identification and perhaps some kind of monitoring or evaluation of 'patients at risk'. By searching for and evaluating the evidence for early warning, the clinical guideline may be able to help the patients to an appropriate presentation to the Primary Health Care Team at the earliest possible time. We appreciate there may not be any such evidence of early warning but most patients would support all attempts to improve the management of metastatic spinal cord compression by taking every opportunity to pre-empt the worst consequences.	Thank you for your comment. The scope has now been revised. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis. The GDG will also look at early diagnosis and pre-emptive treatment.
Regional Public Health Group - London			This organisation was approached but did not respond.	
Robert Jones & Agnes Hunt Orthopaedic & District Hospital NHS Trust			This organisation was approached but did not respond.	
Royal College of General Practitioners			This organisation was approached but did not respond.	
Royal College of Nursing	1	General	We welcome the opportunity to comment on this document.	Thank you.
Royal College of Nursing	2	3.a	All incidences of MSCC both impending and actual need to be recorded in every Trust. Currently accurate coding is not recorded.	Thank you for your comment. We agree and will discuss with the GDG.
Royal College of Nursing	3	4.2.a	NICE needs to consider how to raise the multidisciplinary awareness of recognising early symptoms of spinal cord compression especially in primary care. Development of a simple checklist should be considered.	Thank you for your comment. This is outside the remit of this guideline, but we will cross refer to the NSF for long term conditions where appropriate.
Royal College of	4	4.2.b	Is there a role for chemotherapy in the management of patients with spinal	Thank you for your comment. The GDG will

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Nursing			cord compression?	be considering medical therapies and this has now been included in the scope.
Royal College of Nursing	5	4.3.a	NICE needs to consider access to appropriate investigations both in and outside core hours. MRI access for all Trusts needs to be considered. Most areas do not have access to MRI scanning or expert clinical assessment within their locality within hours and out of hours.	Thank you for your comments. We will consider service provision and appropriate levels of access. Yes, we agree.
Royal College of Nursing	6	4.3.a	NICE will need to consider which radiological investigation will be crucial prior to referral to different treatment pathways. If patients are to be transferred some distance for their radiological investigations such as MRI then assessment for fitness to travel, mode of transport and overnight stay facilities needs to be considered.	Thank you for your comment. Yes, we agree.
Royal College of Nursing	7	4.3.b	If patients are moved between centres for treatment, surgery etc, then repatriation arrangement/issues needs to be clarified.	Thank you for your comment.
Royal College of Nursing	8	4.3.b	Would the use of prognostic indicators be considered when considering appropriateness for spinal surgery?	Thank you for your comment. We agree.
Royal College of Nursing	9	4.3.c	NICE will need to consider which healthcare setting should provide rehabilitation. Currently there are too few rehabilitation beds or specialist palliative care beds in most areas.	Thank you for your comment. We agree.
Royal College of Nursing	10	4.3.c	Rehabilitation is paramount after any spinal intervention. If education and guidelines are adequate to aid early diagnosis then planned rehabilitation services will be even more important to patient's quality of life following intervention. Currently various physiotherapy practices exist so guidance on rehabilitation is essential.	Thank you for your comment. We agree.
Royal College of Nursing	11	4.3.c	Will there be clear guidelines for physiotherapists and occupational therapists regarding moving and handling?	Thank you for your comment. We cannot say at this stage how much detail on this will be given in the guideline. We will investigate what guidelines exist in this area.
Royal College of Nursing	12	4.3.d	Timely follow up is important so that early signs of possible reoccurrence of cord compression are detected early and treatment implemented.	Thank you for your comment. We agree. Follow up of these patients will be covered in the scope.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Royal College of Nursing	13	4.3.d	Follow up may need to be provided by staff in the community setting as potentially these patients will have difficulty accessing hospital services.	Thank you for your comment. During the development of the guideline we will be considering the entire patient pathway and will link in and cross refer to all relevant NSFs.
Royal College of Nursing	14	4.3.e	Need to consider timely access to equipment in order for the patient to be rehabilitated to their maximum independence.	Thank you for your comment. We agree.
Royal College of Nursing	15	4.3.e	Will the guidelines cover nursing issues such as bowel care, bladder or catheter care and assessment for pressure relieving aids and other equipment needs that is required for rehabilitation in any healthcare setting?	Thank you for your comment. The GDG will be asked to consider these issues.
Royal College of Nursing	16	4.3.f	Information resources potentially need to cover all potential care pathways such as surgery, radiotherapy, rehabilitation.	Thank you for your very helpful comments which we will forward to the GDG.
Royal College of Nursing	17	4.3.f	What information should be made available to patients who have the potential to develop spinal cord compression? At what point should they be given this information and by whom?	Thank you for your very helpful comments which we will forward to the GDG.
Royal College of Nursing	18	General	How will the implementation of the guidance be monitored? Will the guidance be incorporated into the Manual of cancer services standards when it is reviewed?	Thank you for your comment. This is the responsibility of the Department of Health. Hopefully yes. But this is also the responsibility of the Department of Health.
Royal College of Nursing	19	General	The development and implementation of the guideline is important but the condition is quite uncommon, therefore consideration should be given to re-issue of a resume of the guideline annually to maintain awareness especially in primary care.	Thank you for your comment. The need for updating and re-issue of clinical guidelines is regularly reviewed by the NCC-C and NICE.
Royal College of Paediatrics and Child Health	1	General	Metastatic spinal cord compression is rare in children and even more rare as the initial presenting problem. It is therefore appropriate to exclude children from this clinical guideline.	Thank you.
Royal College of Physicians of London			This organisation was approached but did not respond.	
Royal College of Psychiatrists			This organisation was approached but did not respond.	
Royal College of Radiologists		General	1 Education. Specific target groups of professionals.	Thank you for your comments. The scope has now been revised. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
				In relation to many of your other comments given below, specific treatment modalities will form a large part of the development work of the GDG. This will include medical therapies and minimal intervention.
Royal College of Radiologists		General	Programme.	Thank you for your comment. We are unsure how this relates to this section of the scope.
Royal College of Radiologists		General	Key symptoms/signs.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	Neurological examination in 1 minute.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	2 Children – it would be good to include a paragraph on children.	Thank you for your comment. This is not within the scope of the guideline. It will not be possible to include the detailed management of children within the guideline but we will consider including a brief paragraph. It should also be noted that the Royal College of Paediatrics and Child Health agree with our proposal not to include children in this guideline.
Royal College of Radiologists		General	3 Timeliness of diagnosis.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	Will the scope include management of vertebral fracture which as yet has not progressed to spinal cord compression.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	Management of uni and multiple levels.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	Management of patients who present with spinal cord compression (and no previous histology malignancy).	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	4 MRI Access	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	Guidelines on specific MRI examination.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	Timeliness of subsequent surgical action after MRI	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	5 Radiotherapy – optimal volume, dose, fractionation.	Thank you for your comment. This will be discussed by the GDG.

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Royal College of Radiologists		General	Is radiotherapy needed after surgical fixation.	Thank you for your comment. The GDG will be considering medical therapies and this has now been included in the scope.
Royal College of Radiologists		General	Evidence for the use and withdrawal of Dexamethasone.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	Vertebroplasty - ? role.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	Integration of the service - ? clinical nurse specialist.	Thank you for your comment. This will be discussed by the GDG.
Royal College of Radiologists		General	? Designated surgical centres – 24/7 accessibility	Thank you for your comment. Appropriate service recommendations will be included in the final guideline and this will be discussed by the GDG.
Royal United Hospital, Bath NHS Trust			This organisation was approached but did not respond.	
Scottish Intercollegiate Guidelines Network (SIGN)			This organisation was approached but did not respond.	
Sheffield Teaching Hospitals NHS Trust	1	General	Regarding the overall scope of the metastatic spinal cord compression I have the following comment (submission requested by GDG at stakeholder meeting). I believe The GDG should give consideration not only to the management of actual spinal cord compression with established neurological deficit but also to the management of cancer patients with proven spinal metastasis. The scope document may cover this when it refers to 'impending' spinal cord compression, but thought should be given to the exact definition of this before commencing any service review. My experience is that the early management of spinal metastatic disease is often sub-optimal (ie DXT for pathological vertebral fractures). Obviously, the more clinical scenarios which can incorporated in the review the better but I appreciate the need to keep the review manageable.	Thank you for your comment. Thank you very much for your helpful comments, which we will forward to the GDG. The scope has now been revised. The guidance will now address early identification of patients at risk and targeted assessment of certain individuals in the hope of averting paralysis. Specific treatment modalities will form a large part of the development work of the GDG. This will include medical therapies and minimal intervention.
Society and College of Radiographers	1	4.1.a	What is cut off point between adult and children? Is the guideline going to be prescriptive?	Thank you for your comment. It is very difficult to define the cut off between adults

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
				and children, hence we do not intend to be prescriptive in this guideline.
Society and College of Radiographers	2	4.3.a	Clinical Diagnosis – will need input from Radiographer/therapist with regard to workforce issues.	Thank you for your comment. We agree.
Society and College of Radiographers	3	4.3.b	I note that there appears to be no neurosurgery representation	Thank you for your comment. There will be appropriate neurosurgery representation on the GDG, including that of the Chair.
Society and College of Radiographers	4	4.3.d	Consultant Radiographers may well be involved in follow up.	Thank you for your comment. We agree consultant radiographers may well be involved in follow up.
Society of British Neurological Surgeons	1	General	The Society of British Neurological Surgeons (SBNS) was represented By [X] at this scoping meeting. His comments are that this was a useful meeting and the scope of the guidelines reasonable. We would support the view that this is broadened to include ideal service provision.	Thank you for your comment and support.
Staffordshire Moorlans Primary Care Trust			This organisation was approached but did not respond.	
Stockport PCT			This organisation was approached but did not respond.	
The Chartered Society of Physiotherapy	1	4.3.a	To facilitate early clinical diagnosis this will need to happen both in the primary and acute settings, therefore we need to consider the role of GPs and other suitably educated healthcare professionals e.g. Physiotherapists in detection and immediate onward referral. In some settings, particularly considering the new roles for physiotherapists working in extended roles, i.e. undertaking tasks previously performed by doctors, in some cases it may well be a physiotherapist requesting and interpreting the investigations that lead to such a diagnosis being made.	Thank you for your comment. Identification of patients at risk will now be included in the scope. The GDG will consider the role of all healthcare professionals in the diagnosis and treatment of these patients.
The David Lewis Centre			This organisation was approached but did not respond.	
The Royal Society of Medicine			This organisation was approached but did not respond.	
University of Hertfordshire			This organisation was approached but did not respond.	
Walton Centre for Neurology and Neurosurgery NHS			This organisation was approached but did not respond.	

Stakeholder	No.	Section number	Comments Please insert each new comment in a new row.	Developer's response Please respond to each comment
Trust				
Welsh Assembly Government	1	4.1.1	It is not clear why children with metastatic spinal cord lesions should be excluded from these guidelines. The DoH guidance did not specify age restrictions so if practicable within the timeframe of the project children should be included. Otherwise there is probably a need to develop specific guidance for this age group.	Thank you for your comment. Numerically, children form a small proportion of a much larger problem of all major adult cancers: breast, bronchi, prostate etc. It will not be possible to include the detailed management of children within the guideline but we will consider including a brief paragraph. It should also be noted that the Royal College of Paediatrics and Child Health agree with our proposal not to include children in this guideline.
Welsh Scientific Advisory Committee (WSAC)			This organisation was approached but did not respond.	
Wessex Neurological Centre			This organisation was approached but did not respond.	
National Collaborating Centre for Women's and Children's Health			This organisation was approached but did not respond.	