NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Metastatic spinal cord compression

Date of Quality Standards Advisory Committee post-consultation meeting:
20 November 2013

2 Introduction

The draft quality standard for Metastatic spinal cord compression was made available on the NICE website for a 4-week public consultation period between 11 September and 9th October 2013. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 16 organisations, which included service providers, national organisations, professional bodies and others.

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

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

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

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

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

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

1. For draft quality statement 1: Is it possible to define ‘at high risk of developing bone metastases’?

2. For draft quality statement 2: Is it possible to define ‘at high risk of developing bone metastases’?

3. For draft quality statement 6: Would it be more appropriate to refer to a management plan for people with MSCC rather than a discharge plan for people with MSCC who are admitted to hospital?

4 General comments

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

- Concerns were raised about the lack of reference to spinal stability.
- Concerns were raised about the lack of reference to ‘paraplegia care’.
- The inclusion of primary care in care pathways was highlighted as important. Stakeholders were particularly concerned about the availability of the MSCC co-ordinator to facilitate access to MRI scanning by GPs.
- Stakeholders suggested that the quality standard should be amended to include more emphasis on people with MSCC and their families and care and compassion.
- Suggestions were made for specialist allied health professionals to be included in the definition of senior clinical advisers.

Consultation comments on data collection

- Stakeholders suggested that if the outcomes are clearly defined and the resources are available then it will be possible to collect the data for the proposed quality measures.
- Stakeholders suggested that the quality standard did not include enough detail on outcome measures. It was suggested that this meant there was not a clear measure of what defines quality in the diagnosis and management of MSCC.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People at risk of developing metastatic spinal cord compression (MSCC) are given information that describes the signs and symptoms of MSCC and what to do if they develop signs and symptoms.

Consultation comments

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

- Stakeholders suggested that healthcare professionals should also be given information about how to identify the symptoms and signs of MSCC.
- Stakeholders suggested that for the process measure it may be more appropriate to measure retrospectively. For example:

  Numerator: the number of patients who have had an MSCC 'early warning' discussion and received an information booklet.
  Denominator: the number of suspected/proven MSCC cases.

- Definitions
  - The definition of information that describes the signs and symptoms of MSCC should be expanded to include other formats such as audio, video and Easyread.
  - As part of the definition of the signs and symptoms of MSCC stakeholders suggested that it would be beneficial to remind the reader that 23% of patients present with MSCC as the first sign of cancer.
  - It was suggested that 'Band like' pain should be included in the description of signs and symptoms as this is a common descriptor of pain for patients with MSCC.

Consultation question 1: Is it possible to define 'at high risk of developing bone metastases'?

Stakeholders made the following comments in relation to consultation question 1:

- Patients at high risk are those with known cancer of the lung, breast, prostate, kidney, GIT and thyroid.
- There is no nationally or internationally agreed definition of 'at high risk of developing MSCC'.
- The following is recognised as high risk:
  - any patient who has had prior MSCC
  - any patient with known bony metastases at any site from any primary site
  - known cancer awaiting investigation for suspicious spinal pain
  - tumour site-specific recommendations
  - prostate: hormone resistant prostate cancer
  - renal: metastatic renal cell cancer
  - lung: any metastatic lung cancer
  - breast: any metastatic breast cancer
  - myeloma: any myeloma
- Yes, tumour site, grade and stage at presentation.

5.2 Draft statement 2

People at risk of developing metastatic spinal cord compression (MSCC), who present with either spinal pain or neurological symptoms or signs, have their diagnostic investigations coordinated by an MSCC coordinator.

Consultation comments

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

- A query was raised about stating 'symptoms and signs' as it was suggested that signs come before symptoms and that the statement should therefore refer to 'signs and symptoms'.

- Concerns were raised about how the data for the process measure denominator will be collected as many people will be managed by an MSCC service.

Consultation question 2: Is it possible to define 'at high risk of developing bone metastases'?

Stakeholders made the following comments in relation to consultation question 2:

- See answers in section 5.1 under consultation question 1.

5.3 Draft statement 3

People with suspected metastatic spinal cord compression (MSCC), who present with neurological symptoms or signs, have an MRI of the whole spine, and a definitive treatment plan developed if there is a confirmed diagnosis of MSCC, within 24 hours of the suspected diagnosis.

Consultation comments

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

- It was suggested that the statement should specify that the treatment plan is developed with agreement of senior clinical advisers rather than this being specified in the rationale only.
- Definitions
  - Stakeholders suggested that 'pain specialists' be added to the definition of senior clinical advisers.
  - Stakeholders suggested that under the definition of treatment plan the following should be added: the likely response to treatments for spinal metastases and prevention of MSCC.
- Concerns were raised that the statement does not address the issue of when treatment commences. It was felt that a treatment plan might be developed within the specified timescale but that this may not lead to prompt commencement of treatment.

- Concerns were raised about time to surgical intervention not being explicitly stated.
- Stakeholders suggested that the issue of spinal stability should be included within this section.
- Stakeholders suggested that for the outcome measures to be meaningful pre-intervention neurological status and measures of cancer status need to be mandated as stratifying variables.

5.4 Draft statement 4

People with suspected metastatic spinal cord compression (MSCC), who do not present with neurological symptoms or signs, have an MRI of the whole spine, and a definitive treatment plan developed if there is a confirmed diagnosis of MSCC, within 1 week of the suspected diagnosis.

Consultation comments

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

- Concerns were raised about how this statement may be interpreted. It was felt that it may suggest that when MSCC is diagnosed it is acceptable that the treatment plan is developed within 1 week rather than more urgently. For example, if the MRI scan is completed within 24 hours and the results confirm a diagnosis of MSCC the treatment plan may only developed 6 days later.
- Concerns were raised about time to surgical intervention not being explicitly stated.
- Stakeholders suggested that this population should receive an MRI scan within 24 hours and a treatment plan should be developed as a matter of urgency.
- Concerns were raised about variation in the interpretation of neurological symptoms.
- Stakeholders highlighted that it is not possible to clinically suspect MSCC without neurological symptoms or signs.
- Stakeholders advised that ‘suspected MSCC’ is not the appropriate term to use and proposed the alternative of ‘suspected vertebral body metastasis’.

5.5 Draft statement 5

People with metastatic spinal cord compression (MSCC) have their care pathway coordinated by an MSCC coordinator.

Consultation comments

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

- Concerns were raised about how the data for the process measure denominator will be collected as many people will be managed by an MSCC service.
- Stakeholders suggested that the statement should be expanded to include reference to ensuring that physical and psychological needs are addressed.

5.6 Draft statement 6

People with metastatic spinal cord compression (MSCC) have a discharge plan that includes an assessment of ongoing care and rehabilitation needs.

Consultation comments

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

- Stakeholders suggested that the statement should make reference to the other issues covered in the Supportive care and rehabilitation section of the clinical guideline e.g. management of pressure ulcers, bladder and bowel continence etc.
- Stakeholders suggested that the statement should include reference to using an MDT approach.
- There was a suggestion that the rationale should state that MSCC is closely associated with the end-of-life through its highest incidence in the late stages of advanced malignancy rather than stating that MSCC is life-limiting. It was also suggested that the statement needs to focus more on the person's needs as a whole rather than just the needs related to MSCC.

Consultation question 3: Would it be more appropriate to refer to a management plan for people with MSCC rather than a discharge plan for people with MSCC who are admitted to hospital?

Stakeholders made the following comments in relation to consultation question 3:

- Patients have a care plan including a discharge plan following a hospital inpatient episode.
- All patients with MSCC should have a care plan.
- ‘Plans for onward care following an episode of MSCC’ or similar would address the needs of the whole patient.
- A management plan seems more appropriate as this will presumably be an ongoing plan rather than just relating to those who have had a hospital admission and are in the process of being discharged or have recently been discharged from hospital.
- Patients with MSCC who are admitted to hospital require both, a management plan should include rehabilitation and a discharge plan.

6 Suggestions for additional statements

There were no suggestions made for additional statements.

Appendix 1: Quality standard consultation comments table

Comment ID	Stakeholder	Statement no.	Comment
1	Royal College of Nursing	General	It would be desirable to develop this quality standard. The aims of this draft are admirable. We do however have some concerns about the bureaucratic approach to this, and how much this standard will be adhered to in clinical practice. We would like to see more reference to relevant evidence of good practice, and use of such words as "patient and their family" and "care and compassion" in the text.
2	The Royal College of Radiologists	General	The RCR is concerned about the lack of reference to spinal stability in this Quality Standard (for example, clear advice on the use of (eg) ASPEN collar). Moving and handling to maintain spinal integrity at the diagnostic stage are essential for optimal patient management. The RCR is concerned that inappropriate immobility can grossly impair quality of life and suggests that the MSCC coordinator should be tasked with confirming spinal stability within 24 hours of diagnosis.
3	South Wales Cancer Network	General	Page 17: Senior clinical advisors – This statement should include specialist AHPs.
4	University Hospitals Coventry and Warwickshire NHS Trust	General	The MSCC coordinator can fulfil other roles in the Acute oncology team and can be (partially) covered by the acute oncology nurses, in conjunction with the Consultant Oncologist on call.
5	RCGP	General	Please ensure care pathways include Primary Care, especially the availability of MSCC Care Coordinator contacts to facilitate the direct access of MRI scanning by GPs. All patients with known spinal mets should have their MSCC Care Coordinator details included in hospital communications, and where appropriate copied to the patient.
6	South Wales Cancer Network	Introduction	Second paragraph, last sentence, 'MSCC is a complication of cancer and is usually an oncological emergency', would read better as 'MSCC is a complication of cancer and is deemed an oncological emergency'.

Comment ID	Stakeholder	Statement no.	Comment
7	The Royal College of Radiologists	Introduction	The RCR welcomes the fact that the Quality Standard addresses the timely investigation and treatment for patients with metastatic spinal cord compression (MSCC) and that it reinforces existing guidance and good practice.
8	Ferring Pharmaceuticals	Questions about the Quality Standard. Question 1	While there is a large amount of emphasis on systems and processes, Ferring feel that this quality standard does not contain enough detail on outcomes. While some outcomes are mentioned, e.g. rates of paraplegia and rates of mortality, there is no clear definition as to how you intend to determine whether a good or a bad outcome has been achieved. In other words there does not appear to be a clear measure of what defines quality in the diagnosis and management of MSCC.
9	Society of British Neurological Surgeons (SBNS)	Questions about the Quality Standard. Question 1	We think the Standard has covered the important aspects
10	Ferring Pharmaceuticals	Questions about the Quality Standard. Question 2	If the outcomes are clearly defined then it should be possible to collect the data for the proposed quality measures.
11	Society of British Neurological Surgeons (SBNS)	Questions about the Quality Standard. Question 2	It is possible to collect data to audit standards given the resources to do so
12	The Christie NHS Foundation Trust	Questions about the Quality Standard. Question 2	Yes

<table>
<tr><th>Comment ID</th><th>Stakeholder</th><th>Statement no.</th><th>Comment</th></tr>
<tr><td>13</td><td>Medtronic UK</td><td>Questions about the Quality Standard. Question 2</td><td>
Key need to recommend outcome measures and respective tools that can offer sufficient sensitivity and specificity to capture the impact of surgical interventions offered to MSCC patients e.g. vertebral augmentation (as per CG 75).

Table 1: Summary of outcomes measures for cancer patients with VCFs
<table>
<tr><td>Type of instrument</td><td>Cancer VCFs</td><td>Key rational</td></tr>
<tr><td>Symptom scale</td><td>VAS pain</td><td>Sensitivity
Unlike NRS it can be reported as mean percentage change from baseline.
More appropriate and more often used in single-arm prospective studies of Vertebral Augmentation.</td></tr>
<tr><td>Generic HRQoL and utility derivation measures</td><td>SF-12
EQ-5D</td><td>SF-12 is derived from SF-36 for use in real-life observational studies. The SF-36 is the most appropriate generic health status questionnaire for use in people with spinal disorders.
A single preference-based score can be more easily derived from the EQ-5D than from SF-12.</td></tr>
<tr><td>Functional performance status</td><td>Modified Barthel Index (observer-assessed) – (Appendix 1 - Table 3)

Karnofsky performance status – patient reported – (Appendix 1 - Table 4)</td><td>Assesses target treatment concepts historically omitted: disability related to physical functioning
MBI has established prognostic value of patients' functional independence in stroke patients
Easy to apply in clinical</td></tr>
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<tr><th>Comment ID</th><th>Stakeholder</th><th>Statement no.</th><th>Comment</th></tr>
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<tr><td></td><td></td><td>practice
MBI permits blinding observer (e.g. telephone interviews)
MBI is negatively correlated with increased spinal deformity in OVCF patients
MBI has reference data for VCF patients</td></tr>
<tr><td>Disease-specific HRQoL sensitive to spine events</td><td>Spine Oncology Study Group Outcomes Questionnaire (SOSGOQ) – (Appendix 1 - Table 2)</td><td>It is the only patient-reported questionnaire available for cancer patients with spine events.
Theoretically, it provides a more comprehensive assessment of intervention specific to this patient population.</td></tr>
</table>

With respect to the outcomes of interest; the aim should be to capture symptom scale, generic HRQoL, functional performance indicator and disease-specific HRQoL

From published literature, it is know that patients with tumors affecting the spine have significant impairment in domains that include physical function, neural function, pain, mental health, and social roles.
Street et al1 have noted the inappropriateness of outcomes measures for this patient population (lack of specificity) and of content validity (use of process measures and gross instrument of function, e.g. ambulatory status, Frankel score). They have also reported the very limited use of patient-reported instruments, which permit a direct measure of the value of care as perceived by the recipient.
The authors have thus developed a patient reported instrument specific for patients with metastatic disease of the spine – the Spine Oncology Study Group Outcomes Questionnaire (SOSGOQ), featured in Table 1 above.
</td></tr>
</table>

Comment ID	Stakeholder	Statement no.	Comment
			1. Street J et al; Introducing a new health-related quality of life outcome tool for metastatic disease of the spine: Spine 2010;35(14):1377–86) Please refer to appendix one (also attached) for more details on the outcome tools recommended above. Currently no specific section exists within the the Cancer Outcomes and Services Data Set for patients with tumours affecting the spine under. It is suggested for all diagnoses not covered by a site specific data set only, the Core Data Set should be completed. The recommended outcome measures could be linked to the Core Data Set – under 'Surgery and other procedures –Core' The recommended outcome measures, above, also support key indicators with the NHS Outcomes Framework – 1. Preventing people from dying prematurely – specific indicator 1.4 for under 75 mortality rate from cancer (PHOF 4.5) 2. Enhancing QoL for people with long term conditions – improve functional ability Improving recovery for people with fragility fractures under 3.5 mobility at 30 and 120 days
14	Society of British Neurological Surgeons (SBNS)	Questions about the individual quality statements. Questions 1 &2.	Patients at high risk are those with known cancer of Lung, Breast, Prostate, Kidney, GIT and Thyroid.
15	Leeds Teaching Hospitals NHS Trust	Questions about the individual quality statements. Questions 1 &2.	The denominator 'number of people at risk of developing MSCC' is currently undefined.
16	Leeds Teaching Hospitals NHS Trust	Questions about the individual quality statements. Questions 1 &2.	There is no nationally or internationally agreed definition of 'at high risk of developing MSCC'

Comment ID	Stakeholder	Statement no.	Comment
17	Leeds Teaching Hospitals NHS Trust	Questions about the individual quality statements. Questions 1 &2.	The West Yorkshire Strategic Cancer Network (formally the YCN) recognise the following as high risk: Any patient who has had prior MSCC Any patient with known bony metastases at any site from any primary site Known cancer awaiting investigation for suspicious spinal pain Tumour site-specific recommendations Prostate: Hormone resistant prostate cancer Renal:Metastatic renal cell cancer Lung: Any metastatic lung cancer Breast: Any metastatic breast cancer Myeloma: Any myeloma
18	The Christie NHS Foundation Trust	Questions about the individual quality statements. Questions 1 &2.	Yes, tumour site, grade and stage at presentation.
19	The Christie NHS Foundation Trust	Questions about the individual quality statements. Questions 1 &2.	Question 2 is the same as question 1? Should this question read “Is it possible to define ‘at high risk of developing bone metastases’”?
20	Society of British Neurological Surgeons (SBNS)	Questions about the individual quality statements. Question 3	Patients have a Care Plan including a Discharge plan following a hospital inpatient episode
21	Society of British Neurological Surgeons (SBNS)	Questions about the individual quality statements. Question 3	All patients with MSCC should have a Care Plan
22	Leeds Teaching Hospitals NHS Trust	Questions about the individual quality statements. Question 3	‘Plans for onward care following an episode of MSCC’ or similar would address the needs of the whole patient.

Comment ID	Stakeholder	Statement no.	Comment
23	NHS Direct	Questions about the individual quality statements. Question 3	A management plan seems more appropriate as this will presumably be an ongoing plan rather than just relating to those who have had a hospital admission and are in the process of being discharged or have recently been discharged from hospital.
24	The Christie NHS Foundation Trust	Questions about the individual quality statements. Question 3	Patients with MSCC who are admitted to hospital require both, a management plan should include rehabilitation and a discharge plan.
25	Ferring Pharmaceuticals	Questions about the individual quality statements.	Ferring do not believe that we are in an appropriate position to comment on these questions.
26	Society of British Neurological Surgeons (SBNS)	Statement 1	Indicate that patients should be given written or Audio (or equivalent) information which is easily understood describing the signs and symptoms of MSCC etc
27	The Royal College of Radiologists	Statement 1	The RCR feels that patient education and empowerment are essential to improve early diagnosis and functional outcome. Ensuring distribution of relevant written information to "at risk" groups - ie those with proven bone metastases and documenting in clinical notes and communicating with GP - is the most effective way of doing this, in tandem with a robust care pathway to action patient/carer / GP concerns via the acute oncology service.
28	Leeds Teaching Hospitals NHS Trust	Statement 1	Practically it may be more appropriate to record the number of patient's who present with suspected MSCC/proven MSCC who have had an MSCC 'early warning' discussion and information booklet previously as the numerator and the number of suspected/proven MSCC cases as denominator.
29	Royal College of Nursing	Statement 1	The information to be provided to patients and their carers as stated in Statement 1 needs to be accessible i.e. in a format that they can understand. The information may need to be broader than just a printed educational leaflet and perhaps be in the form of a video clip or Easyread.

Comment ID	Stakeholder	Statement no.	Comment
30	The Christie NHS Foundation Trust	Statement 1	1.3.2.1 – It would be beneficial to remind the reader that 23% of patients present with MSCC as the first sign of cancer. 'Band like' pain should be included in the description of signs symptoms as this is a common descriptor of pain for patients with MSCC. Bullet point 3, 'severe unremitting spinal pain' could occur in any area, not just in the lower spine. Bullet point 4, 'spinal pain aggravated by straining, and also by moving often indicates spinal instability and is a key sign of this.
31	The College of Occupational Therapists	Statement 1	An appendix of examples of educational information provided to patients regarding MSCC would be useful as these appear to range from "Alert Cards" to individual services' educational leaflets.
32	Society of British Neurological Surgeons (SBNS)	Statement 2	The MSCC Co-ordinator needs to have the skills and experience and the time to deliver this role. The cover out of hours and weekends has to be arranged to deliver the same standard.
33	Society of British Neurological Surgeons (SBNS)	Statement 2	The infrastructure to have MRI scans performed for MSCC patients Including DGH and GP access should be enhanced to facilitate the role of the busy MSCC Co-ordinator.
34	South Wales Cancer Network	Statement 2	Page 12: Can we question why the guidelines read 'symptoms and signs', would this read better as 'signs and symptoms' as signs appear before symptoms.
35	Leeds Teaching Hospitals NHS Trust	Statement 2	The process metrics may be compromised as most many/most MSCC will eventually be managed via an MSCC service. It will be impossible to collect metrics on the presentation described in the proposed denominator.
36	Leeds Teaching Hospitals NHS Trust	Statement 2	A better metric may be to measure the proportion of patients with eventual MSCC on MRI who access treatment via the MSCC coordinator. Separate data should be collated on those with and without neurology.
37	Leeds Teaching Hospitals NHS Trust	Statement 2	Compliance will be <100% as ~20% of MSCC presentations are first presentations of cancer and are outside the CG75 guideline remit (known adult cancers).

Comment ID	Stakeholder	Statement no.	Comment
38	The Christie NHS Foundation Trust	Statement 2	Regarding 'giving information to patients', it would also be beneficial to mention that Healthcare professionals, especially non-oncology professionals should also be given information regarding the signs and symptoms, i.e. red flags for serious spinal pathology. The Red Flag cards produced in Manchester are used nationwide for this purpose. Its wider distribution should be encouraged.
39	South Wales Cancer Network	Statement 2	Page 12: Do we need to define who could carry out the role of an MSCC coordinator? As a guide we could include a list of possible health care professionals.
40	The Royal College of Radiologists	Statement 2	The RCR feels the role of MSCC coordinator is unclear. Is this someone based in the spinal unit or a member of the acute oncology team? The RCR suggests it would be useful to clarify who the MSCC Coordinator should be and acceptable local solutions.
41	Society of British Neurological Surgeons (SBNS)	Statement 3	Amend to indicate that a treatment plan is developed after discussion between relevant Senior Clinicians including Oncologist, Neurosurgeon/Spinal Surgeon
42	The Society and College of Radiographers	Statement 3	People with suspected metastatic spinal cord compression (MSCC), who present with neurological symptoms or signs, have an MRI of the whole spine, and a definitive treatment plan developed if there is a confirmed diagnosis of MSCC, within 24 hours of the suspected diagnosis. The quality measures would appear to indicate one assessment whether or not an MRI had been undertaken, and another whether or not a treatment plan had been developed, but there does not appear to be a quality assessment of how soon treatment commences. For example a positive MRI might lead to the senior clinical advisers creating a definitive treatment plan, but whether the plan is to start radiotherapy the next day, as opposed to planning and starting treatment the same day. These two scenarios would appear the same when the quality measures were compared, but the outcomes for the patients may be very different i.e. The outcome should be related to when treatment was commenced, not when a treatment plan was decided.

Comment ID	Stakeholder	Statement no.	Comment
43	The Royal College of Radiologists	Statement 3	The RCR notes that this has largely been implemented nationally as reflected in the RCR's audit of radiotherapy in the treatment of MSCC in 2012. By implication, all hospitals should have access to out-of-hours MRI to fulfil this target and contingency plans for safe patient transfer to another site for timely MR. (See also comments below on MRI access)
44	The Royal College of Radiologists	Statement 3	The RCR notes that MRI is pivotal, but many departments are hard pressed. In some acute hospitals the provision of MRI out of hours or on weekends still needs to be addressed. Issues of imaging provision and capacity are more of a concern for those charged with implementation of guidance. The RCR feels that publication of a Quality Standard should concentrate attention on areas presently deficient.
45	Johnson & Johnson Medical	Statement 3	Treatment plans for patients with MSCC should be agreed in line with evidence based recommendations from NICE guidance.
46	Johnson & Johnson Medical	Statement 3	Time to surgical intervention is not explicitly stated within this quality standard. Inclusion of a benchmark to drive improvement in the timeliness of surgery could be of benefit to patients for whom surgical intervention is indicated.
47	The Christie NHS Foundation Trust	Statement 3	In this section a sentence regarding the fact that 'spinal stability should be assumed until proven otherwise' and that patients should be on flat bed rest and log rolled until the MRI scan results are available and discussion regarding spinal stability has taken place and been documented. This information is not contained anywhere within the Quality Standards!
48	Leeds Teaching Hospitals NHS Trust	Statement 3	This is not a whole process measure as it simply examines diagnostics and assessment, not time to definitive therapy. Delay once the diagnosis is known may be just as critical.
49	Leeds Teaching Hospitals NHS Trust	Statement 3	Rates of paraplegia at 3 months and mortality at 30 days are not measures of service quality (they are part of a composite metric). Both are indicative of the status of the patient at presentation, the relative impact of intervention and the natural history of advanced metastatic malignancy. For these measures to be meaningful pre-intervention neurological status and measures of cancer status need to be mandated as stratifying variables.

Comment ID	Stakeholder	Statement no.	Comment
50	Royal College of Nursing	Statement 3	Most of the patients will arrive in hospital with severe pain, therefore consider adding 'pain specialists' to the section below: Senior clinical advisers Include clinical oncologists, spinal surgeons and radiologists with experience and expertise in treating patients with MSCC.
51	Royal College of Nursing	Statement 3	It might also be worth emphasizing that all the specialists, not just the co-ordinator, should be available 24 hours/7 days a week because this is undoubtedly where the delays occur, particularly in smaller centres.
52	South Wales Cancer Network	Statement 3	Page 17: Treatment plan, the guidelines currently state 'A definitive treatment plan for people with MSCC should be agreed by senior clinical advisors and should be documented'. Should we state '.....with support from the MDT'.
53	Medtronic UK	Statement 3	Please consider the addition of the following bullet point under the treatment plan section: 'the likely response to treatments for spinal metastases & prevention of MSCC; e.g. vertebral body collapse
54	Johnson & Johnson Medical	Statement 4	Treatment plans for patients with MSCC should be agreed in line with evidence based recommendations from NICE guidance.
55	Johnson & Johnson Medical	Statement 4	Time to surgical intervention is not explicitly stated within this quality standard. Inclusion of a benchmark to drive improvement in the timeliness of surgery could be of benefit to patients for whom surgical intervention is indicated.
56	The Christie NHS Foundation Trust	Statement 4	Comment about quality statement 4 – We have concerns that this statement may be interpreted that having a treatment plan within 1 week of the suspected diagnosis is acceptable, where there is actual MSCC.
57	The Royal College of Radiologists	Statement 4	The RCR suggests that MR should be reported within 24 hours and the result conveyed urgently to the clinical team and the action plan confirmed.

Comment ID	Stakeholder	Statement no.	Comment
58	The Royal College of Radiologists	Statement 4	The RCR notes that MRI is pivotal, but many departments are hard pressed. In some acute hospitals the provision of MRI out of hours or on weekends still needs to be addressed. Issues of imaging provision and capacity are more of a concern for those charged with implementation of guidance. The RCR feels that publication of a Quality Standard should concentrate attention on areas presently deficient.
59	The Christie NHS Foundation Trust	Statement 4	Comment about quality statement 4 – We have concerns that this statement may be interpreted that having a treatment plan within 1 week of the suspected diagnosis is acceptable, where there is actual MSCC. It is not always clear cut, patients with neurological symptoms may turn out not to have MSCC on MR scan, conversely, patients with no clear neurological symptoms but with severe spinal pain may have MSCC confirmed by MR scan. In addition, the interpretation of neurological symptoms vary hugely, some clinicians would not consider referred pain as neurological symptoms, only when there is definite muscle weakness and loss of mobility would this be classified as neurological symptoms.
60	Leeds Teaching Hospitals NHS Trust	Statement 4	It is not possible to clinically suspect MSCC without neurological symptoms or signs. One can identify that spinal pain is of concern/has worrying characteristics for being metastatic in nature but the compressive characteristics can only be inferred through defined symptoms and signs.
61	Leeds Teaching Hospitals NHS Trust	Statement 4	It is not suspected MSCC, but a suspected vertebral body metastasis. This is an important clarification for the process denominator metric.
62	Royal College of Nursing	Statement 4	Most of the patients will arrive in hospital with severe pain, therefore consider adding 'pain specialists' to the section below: Senior clinical advisers Include clinical oncologists, spinal surgeons and radiologists with experience and expertise in treating patients with MSCC.
63	Medtronic UK	Statement 4	Please consider the addition of the following bullet point under the treatment plan section: ‘the likely response to treatments for spinal metastases & prevention of MSCC; e.g. vertebral body collapse

Comment ID	Stakeholder	Statement no.	Comment
64	British Society Interventional Radiology	Statement 5	P22. The first sentence under the title Rationale should read radiology rather than radiography.
65	Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	Statement 5	Suggest addition to statement in line with Quality Standard QS138, statement 10 People with metastatic spinal cord compression (MSCC) have their care pathway coordinated by an MSCC coordinator to ensure their physical and psychological needs are addressed.
66	South Wales Cancer Network	Statement 5	Page 22: Rationale paragraph – first sentence to include AHPs in the specialities.
67	Leeds Teaching Hospitals NHS Trust	Statement 5	The process metric will be the same as for Quality Measure 2, as discussed above.
68	Leeds Teaching Hospitals NHS Trust	Statement 5	Important clarification needs to be provided on line 18 page 23: Care plan confirms that the MSCC coordinator role includes responsibility for nursing care also. Is this intended?
69	The Royal College of Radiologists	Statement 5	The RCR suggests that further clarification is needed on the role and responsibilities of the MSCC coordinator. This is potentially an expensive role as it is a "stand alone service". The Quality Standard should define how this coordinator fits into the acute oncology team and acceptable ways of ensuring 24-hour cover. The RCR's audit data showed that while the MSCC coordinator was often in place, they were only involved in patient management in a minority of cases.

Comment ID	Stakeholder	Statement no.	Comment
70	Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	Statement 6	1. Strongly recommend that this statement makes specific reference to the sections in the original clinical guidance that cover 'paraplegia care' i.e. making sure that bladder and bowel function is assessed, pain addressed, loss of sensation recognised, loss of dexterity and mobility, including bed mobility evaluated, together with institution of pressure sore prevention. All of these aspects are well covered in the MSCC clinical guidance and there are several relevant NICE clinical guidance documents that provided further, directly applicable, elements for this care: pressure sore management, neurological bladder dysfunction, incontinence – both bladder and bowel, neuropathic pain. 2. This should not be about a 'discharge plan' but about instituting a 'management plan' from the outset, or initial presentation, and certainly on admission, of any degree of neurological loss of function. Without this approach, patients are vulnerable to preventable complications of the consequences of neurological loss (and the additional cost of the care involved). Without this approach from the start, with subsequent reassessment and review, patients are subject to unnecessary additional physical, if not psychological, problems. 3. Suggested re-wording for this quality statement: People with metastatic spinal cord compression (MCSS) have a management plan for supportive care and rehabilitation that includes assessment and implementation of relevant protocols for pain management, pressure sore prevention, loss of bladder and bowel function, mobility and dexterity. Background comment: These quality standards make no specific reference to instituting 'paraplegia care', for want of a better phrase, which is actually well detailed in sections 1.6.2, page 19 of the guidance itself AND the reference to rehabilitation in statement 6 is vague. In contrast, this is part of the section on 'rehabilitation and supportive care - 1.5.1 which should 'start on admission'.
71	Leeds Teaching Hospitals NHS Trust	Statement 6	Not all patients are hospitalised/managed as inpatients.
72	South Wales Cancer Network	Statement 6	Page 25: We feel that this statement should include an MDT approach throughout.

Comment ID	Stakeholder	Statement no.	Comment
73	The Royal College of Radiologists	Statement 6	The RCR feels this is excellent. The prognosis for paraplegic patients is very short, time is precious and facilitating care close to, or at, home is to be commended. Expediting care packages and breaking down bureaucratic barriers to facilitate urgent discharge planning would be a major quality improvement both for patients and for reducing inappropriate acute hospital bed usage.
74	Leeds Teaching Hospitals NHS Trust	Statement 6	Several of the statements in the rationale section are erroneous. MSCC is not life-limiting: It is closely associated with the end-of-life through its highest incidence in the late stages of advanced malignancy. The MSCC in the context of advanced malignancy needs to be managed, with the MSCC event as a marker for advanced disease status. Patient care needs to be focussed on 'whole-patient' need, not just that due to MSCC. This should be considered a flag for 'end-of-life-care-planning' assessment.
75	The Christie NHS Foundation Trust	Statement 6	It should be added that some patients with a better outcome and prognosis may benefit from a short period of in-patient rehabilitation to maximise their functional potential and independence.
76	Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	Statement 6	Evidence of local arrangements and written protocols to ensure that people with MSCC have a management plan that covers an initial and on-going assessment of the supportive care required (including, when relevant, pain control, bladder and bowel management, mobility and dexterity, pressure sore prevention) and rehabilitation needs.
77	The Christie NHS Foundation Trust	Statement 6	Add to this statement: Ensure that people with MSCC are referred to the physiotherapist within 24 hours, and occupational therapist within 48 hours of admission.