

# Metastatic spinal cord compression in adults

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This standard is based on CG75.

This standard should be read in conjunction with QS12, QS15, QS17, QS54 and QS124.

# Introduction

This quality standard covers the early detection, diagnosis and management of metastatic spinal cord compression (MSCC) in adults (18 years and older). For more information, see the <u>topic</u> <u>overview</u>.

# Why this quality standard is needed

MSCC is compression of the spinal cord and/or cauda equina by pathological vertebral collapse and/or direct tumour expansion, which may cause partial or complete loss of neurological function. MSCC is a complication of cancer and is usually considered an oncological emergency. Outcomes can be optimised using simple and rapid referral pathways, early recognition, rapid diagnosis through prompt imaging, and appropriate management, all of which aim to prevent often avoidable paralysis.

Adults with breast, lung and/or prostate cancer account for more than 50% of MSCC diagnoses. MSCC can also be caused by other tumours and haematological malignancies. Research has shown that 77% of people diagnosed with MSCC have an established diagnosis of cancer and 23% of people present with MSCC as the first presentation of their malignancy<sup>[1]</sup>.

The incidence of MSCC in England is unknown because cases are not systematically recorded. However, post-mortem evidence indicates that it is present in 5–10% of people with advanced cancer. MSCC is estimated to affect approximately 3000 people annually in England<sup>[2]</sup>. The average age at the time of diagnosis is 65. It is important that care is delivered on an individualised basis and is not influenced by the age of the person.

# How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 2 outcomes frameworks published by the Department of Health:

- <u>NHS Outcomes Framework 2014–15</u>
- Improving outcomes and supporting transparency: a public health outcomes framework for England 2013–2016, Part 1 and Part 1A.

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

#### Table 1 NHS Outcomes Framework 2014–15

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	Overarching indicator 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare i Adults 1b Life expectancy at 75 i Males ii Females Improvement areas 1.4 Under 75 mortality rate from cancer* i One-and ii Five-year survival from all cancers iii One-and iv Five-year survival from breast, lung and colorectal cancer

4 Ensuring that people have a positive	Overarching indicator
experience of care	4a Patient experience of primary care
	i GP services
	4b Patient experience of hospital care
	Improvement areas
	Improving people's experience of outpatient care
	4.1 Patient experience of outpatient services
	Improving hospitals' responsiveness to personal needs
	4.2 Responsiveness to in-patients' personal needs
	Improving the experience of care for people at the end of their lives
	4.6 Bereaved carers' views on the quality of care in the last 3 months of life
	Improving people's experience of integrated care
	4.9 People's experience of integrated care
5 Treating and caring for people in a safe	Overarching indicator
environment and protect them from avoidable harm	5c Hospital deaths attributable to problems in care
	Improvement areas
	Reducing the incidence of avoidable harm
	5.1 Deaths from venous thromboembolism (VTE) related events
	5.3 Proportion of patients with category 2, 3 and 4 pressure ulcers

Alignment across the health and social care system

\* Indicator shared with Public Health Outcomes Framework (PHOF)

\*\*\* Indicator shared with Adult Social Care Outcomes Framework

Domain	Objectives and indicators
4 Healthcare public health and preventing premature mortality	ObjectiveReduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communitiesIndicators4.5 Under 75 mortality rate from cancer

#### Table 2 Public health outcomes framework for England, 2013–2016

#### Coordinated services

The quality standard for MSCC specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole MSCC care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to adults with MSCC.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the <u>library of NICE quality standards</u> when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality MSCC service are listed in <u>Related quality standards</u>.

#### Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in assessing, caring for and treating adults with MSCC should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

#### Role of families and carers

Quality standards recognise the important role families and carers have in supporting adults with MSCC. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

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<sup>[1]</sup>Levack P, Graham J, Collie D et al. (2001) A prospective audit of the diagnosis, management and outcome of malignant spinal cord compression. Clinical Resource and Audit Group (CRAG) 97/08

<sup>[2]</sup>National Spinal Task Force (2013) <u>Commissioning spinal services – getting the service back on</u> <u>track</u>

# List of quality statements

<u>Statement 1.</u> Adults at high risk of developing metastatic spinal cord compression (MSCC), and their families or carers (as appropriate), are given information that describes the symptoms of MSCC and what to do if they develop symptoms.

<u>Statement 2.</u> Adults with spinal pain suggestive of spinal metastases, but with no neurological symptoms or signs, have an MRI of the whole spine and any necessary treatment plan agreed within 1 week of the suspected diagnosis.

<u>Statement 3.</u> Adults with suspected MSCC who present with neurological symptoms or signs have an MRI of the whole spine and any necessary treatment plan agreed within 24 hours of the suspected diagnosis.

<u>Statement 4.</u> Adults with suspected MSCC who present with neurological symptoms or signs have their diagnostic investigations coordinated by an MSCC coordinator.

<u>Statement 5.</u> Adults with MSCC have their ongoing care coordinated by an MSCC coordinator.

<u>Statement 6.</u> Adults with MSCC, who present with neurological symptoms or signs, start definitive treatment (if appropriate) within 24 hours of the confirmed diagnosis.

<u>Statement 7.</u> Adults with MSCC have a management plan that includes an assessment of ongoing care and rehabilitation needs.

# Quality statement 1: Information about recognising the symptoms of metastatic spinal cord compression

### Quality statement

Adults at high risk of developing metastatic spinal cord compression (MSCC), and their families or carers (as appropriate), are given information that describes the symptoms of MSCC and what to do if they develop symptoms.

# Rationale

It is important that adults at high risk of developing MSCC, and their families or carers (as appropriate), receive information about how to recognise the symptoms of MSCC so they can seek help to ensure prompt diagnosis and treatment. If people have information they are empowered to manage their condition, which can lead to early detection and improved outcomes. Healthcare professionals should carefully consider the timing of giving information, because adults with cancer receive a wide variety of supporting information about the disease. It is important to communicate information about MSCC clearly, and to emphasise the importance of being aware of the symptoms.

### Quality measures

#### Structure

Evidence of local arrangements and written clinical protocols to ensure that adults at high risk of developing MSCC, and their families or carers (as appropriate), are given information that describes the symptoms of MSCC and what to do if they develop symptoms.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-1E-105y (Network Information on Early Detection of MSCC) and 11-3Y-311 (Patient Information on Early Detection of MSCC) <u>Manual for cancer services</u>: <u>acute oncology – including metatastic spinal cord</u> <u>compression measures</u> (2011).

#### Process

Proportion of adults identified as at high risk of developing MSCC, or their families or carers, who receive information that describes the symptoms of MSCC and what to do if they develop symptoms.

Numerator – the number of adults in the denominator or their family member or carer who receive information when they are identified as at risk that describes the symptoms of MSCC and what to do if they develop symptoms.

Denominator - the number of adults identified as at high risk of developing MSCC.

*Data source*: Local data collection. NICE <u>audit support</u> for <u>Metastatic spinal cord compression</u> (NICE clinical guideline 75).

# What the quality statement means for service providers, healthcare professionals and commissioners

Service providers ensure that patient information about the symptoms of MSCC is available, and that healthcare professionals are trained to understand and explain the information and to give it to adults at high risk of developing MSCC, and their families or carers (as appropriate).

Healthcare professionals in both primary and secondary care ensure that they understand and can explain the patient information about the symptoms of MSCC, and that they give this information to adults at high risk of developing MSCC, and their families or carers (as appropriate).

**Commissioners** ensure that they commission services that provide patient information about the symptoms of MSCC, and that they train healthcare professionals to understand and explain the information and give it to adults at high risk of developing MSCC, and their families or carers (as appropriate).

### What the quality statement means for patients, service users and carers

Adults at high risk of MSCC, and their families or carers (as appropriate), are given information that describes the symptoms to look out for, and advice on what to do if they notice any symptoms of MSCC developing.

#### Source guidance

• Metastatic spinal cord compression (NICE clinical guideline 75), <u>recommendation 1.3.1.1</u> (key priority for implementation).

# Definitions of terms used in this quality statement

#### Adults at high risk of MSCC

Adults with cancer who have, or who are at high risk of developing, bone metastases, and adults with cancer who present with spinal pain. [Adapted from <u>NICE clinical guideline 75</u> recommendation 1.3.1.1]

#### Adults at high risk of developing bone metastases

This group includes, but is not limited to, adults with known cancer of the lung, breast or prostate, or myeloma. The risk can be determined by identifying the tumour site, grade and stage at presentation. [Definition developed from expert consensus]

#### Information that describes the symptoms of MSCC

Information may be in the form of, for example, a leaflet, a 'red flag' card, or audio/visual materials. It should list the early warning symptoms of MSCC, together with clear advice on what action to take if any symptoms develop.

NICE has produced <u>information for the public</u> about MSCC. In addition, the <u>full clinical guideline on</u> <u>MSCC</u> includes an example of a patient information leaflet. [Definition developed from the <u>full</u> <u>clinical guideline 75</u> appendix 2 and expert consensus]

#### Symptoms of MSCC

The following symptoms are suggestive of MSCC:

- progressive pain in the spine
- severe unremitting spinal pain
- spinal pain aggravated by straining (for example, when passing stools, when coughing or sneezing, or when moving)
- pain described as 'band like'
- localised spinal tenderness
- nocturnal spinal pain preventing sleep

• neurological symptoms: radicular pain, any limb weakness, difficulty in walking, sensory loss, or bladder or bowel dysfunction.

[Definition developed from <u>NICE clinical guideline 75</u> recommendations 1.3.2.1 and 1.3.2.2 and expert consensus]

# Equality and diversity considerations

All information given about the symptoms of MSCC and what to do if symptoms develop should be accessible to people with additional needs, such as physical, sensory or learning disabilities, and to people who do not speak or read English. Adults at high risk of developing MSCC should have access to an interpreter or advocate if needed.

# Quality statement 2: Imaging and treatment plans for adults with suspected spinal metastases

#### Quality statement

Adults with spinal pain suggestive of spinal metastases, but with no neurological symptoms or signs, have an MRI of the whole spine and any necessary treatment plan agreed within 1 week of the suspected diagnosis.

# Rationale

Adults with spinal pain suggestive of spinal metastases need timely access to imaging that will accurately identify spinal metastases. Whole-spine MRI is central to the diagnosis, staging and planning of treatment. If spinal metastases are suspected, it is essential that investigation, planning and treatment take place before any loss of neurological function occurs. To reduce the risk of avoidable disability for adults with suspected spinal metastases, it is important that an MRI is performed and that treatment is planned by senior clinical advisers, within 1 week of the suspected diagnosis.

#### Quality measures

#### Structure

Evidence of local arrangements and written protocols to ensure that adults with spinal pain suggestive of spinal metastases, but with no neurological symptoms or signs, have an MRI of the whole spine and any necessary treatment plan agreed within 1 week of the suspected diagnosis.

Data source: Local data collection.

#### Process

a) Proportion of adults with spinal pain suggestive of spinal metastases, but with no neurological symptoms or signs, who receive an MRI of the whole spine within 1 week of the suspected diagnosis.

Numerator – the number of adults in the denominator who receive an MRI of the whole spine within 1 week of presenting with spinal pain suggestive of spinal metastases, but with no neurological symptoms or signs.

Denominator – the number of adults who present with spinal pain suggestive of spinal metastases, but with no neurological symptoms or signs.

b) Proportion of adults with spinal metastases confirmed by MRI of the whole spine, but with no neurological symptoms or signs, who have a treatment plan agreed within 1 week of the suspected diagnosis.

Numerator – the number of adults in the denominator who have a treatment plan agreed within 1 week of presenting with spinal pain suggestive of spinal metastases, but with no neurological symptoms or signs.

Denominator – the number of adults with spinal metastases confirmed by MRI of the whole spine, but with no neurological symptoms or signs.

Data source: Local data collection. British Spine Registry Spinal tumour data (2013).

#### Outcome

a) Proportion of adults with spinal metastases who are able to walk within 3 months of treatment.

b) Proportion of adults with spinal metastases who are able to walk within 2 years of treatment.

c) Rates of mortality within 30 days of treatment.

Data source: Local data collection. British Spine Registry Spinal tumour data (2013).

# What the quality statement means for service providers, healthcare professionals and commissioners

**Service providers** ensure that adequate capacity is available for whole-spine MRI scanning and treatment planning to be undertaken within 1 week for adults with suspected spinal metastases who present with spinal pain but with no neurological symptoms or signs.

Healthcare professionals ensure that they perform an MRI of the whole spine for adults with suspected spinal metastases who present with spinal pain but with no neurological symptoms or signs, and agree any necessary treatment plan within 1 week of the suspected diagnosis.

**Commissioners** ensure that they commission services that can provide MRI scanning and treatment planning by senior clinical advisers within 1 week of the suspected diagnosis of spinal metastases for adults who have spinal pain but no neurological symptoms or signs.

### What the quality statement means for patients, service users and carers

Adults with suspected spinal metastases (who have spinal pain only) have an MRI of their whole spine and, if necessary, have a plan for their treatment organised within 1 week of the suspected diagnosis.

#### Source guidance

• Metastatic spinal cord compression (NICE clinical guideline 75), <u>recommendation 1.4.3.3</u> (key priority for implementation).

### Definitions of terms used in this quality statement

#### Symptoms of spinal metastases

The following symptoms are suggestive of spinal metastases:

- progressive pain in the spine
- severe unremitting spinal pain
- localised spinal tenderness
- nocturnal spinal pain preventing sleep.

[Definition developed from <u>NICE clinical guideline 75</u> recommendation 1.3.2.1 and expert consensus]

#### Senior clinical advisers

Includes clinical oncologists, spinal surgeons and radiologists with experience and expertise in treating adults with spinal metastases. [Adapted from <u>NICE clinical guideline 75</u> recommendation 1.1.2.4]

#### Treatment plan

A treatment plan for adults with spinal metastases should be agreed by senior clinical advisers, and the names of those involved in the discussion should be included in the documentation. Treatment planning should take account of:

- spinal stability, which should be assessed both clinically and radiologically
- the degree of neurological disability
- the general health of the patient
- the prognosis, which should be estimated using a validated scoring system
- the primary site of tumour
- the presence of other spinal and extraspinal metastases
- the likely response of the tumour to radiotherapy or other adjuvant therapy
- the patient's care and treatment preferences.

[The full clinical guideline 75, section 6.1 and expert consensus]

# Quality statement 3: Imaging and treatment plans for adults with suspected metastatic spinal cord compression

### Quality statement

Adults with suspected metastatic spinal cord compression (MSCC) who present with neurological symptoms or signs have an MRI of the whole spine and any necessary treatment plan agreed within 24 hours of the suspected diagnosis.

# Rationale

Adults with suspected MSCC who present with neurological symptoms or signs need rapid access to imaging that will accurately identify spinal cord compression. Whole-spine MRI is central to the diagnosis, staging and planning of treatment. Neurological deficit at initial presentation is an important predictor of long-term functional outcome. To reduce the risk of avoidable disability for adults with suspected MSCC, it is important that both an MRI is performed and treatment is planned by senior clinical advisers, within 24 hours of the suspected diagnosis.

#### Quality measures

#### Structure

Evidence of local arrangements and written protocols to ensure that adults with suspected MSCC, who present with neurological symptoms or signs, have an MRI of the whole spine and any necessary treatment plan agreed within 24 hours of the suspected diagnosis.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-1E-110y (The MSCC Case Discussion Policy) and 11-1E-111y (The Audit of Timeliness of the Investigation of MSCC) <u>Manual for cancer services: acute oncology – including metatastic spinal cord</u> <u>compression measures</u> (2011).

#### Process

a) Proportion of adults with suspected MSCC who present with neurological symptoms or signs who receive an MRI of the whole spine within 24 hours of the suspected diagnosis.

Numerator – the number of adults in the denominator who receive an MRI of the whole spine within 24 hours of presenting with suspected MSCC and neurological symptoms or signs.

Denominator – the number of adults with suspected MSCC who present with neurological symptoms or signs.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-1E-111y (The Audit of Timeliness of the Investigation of MSCC) <u>Manual for cancer services</u>: <u>acute oncology</u> – <u>including metatastic spinal cord compression measures</u> (2011). British Spine Registry <u>Spinal</u> <u>tumour data</u> (2013).

b) Proportion of adults with MSCC confirmed by MRI of the whole spine, who presented with neurological symptoms or signs, who have a treatment plan agreed within 24 hours of the suspected diagnosis.

Numerator – the number of adults in the denominator who have a treatment plan agreed within 24 hours of presenting with suspected MSCC and neurological symptoms or signs.

Denominator – the number of adults with MSCC confirmed by MRI of the whole spine who presented with neurological symptoms or signs, who have a diagnosis of MSCC confirmed after an MRI of the whole spine.

*Data source*: Local data collection. NICE <u>audit support</u> for <u>Metastatic spinal cord compression</u> (NICE clinical guideline 75). British Spine Registry <u>Spinal tumour data</u> (2013).

#### Outcome

a) Proportion of adults with MSCC who are able to walk within 3 months of treatment.

b) Proportion of adults with MSCC who are able to walk within 2 years of treatment.

c) Rates of mortality within 30 days of treatment.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-1E-113y Manual for cancer services: acute oncology – including metatastic spinal cord compression measures (2011). British Spine Registry <u>Spinal tumour data</u> (2013).

# What the quality statement means for service providers, healthcare professionals and commissioners

**Service providers** ensure that adequate capacity is available for whole-spine MRI scanning and treatment planning to be undertaken within 24 hours for adults with suspected MSCC who present with neurological symptoms or signs.

Healthcare professionals ensure that they perform an MRI of the whole spine for adults with suspected MSCC who present with neurological symptoms or signs, and that if a diagnosis of MSCC is confirmed they agree a treatment plan within 24 hours of the suspected diagnosis.

**Commissioners** ensure that they commission services that can provide MRI scanning and treatment planning by senior clinical advisers within 24 hours of the suspected diagnosis, for adults with suspected MSCC who present with neurological symptoms or signs.

#### What the quality statement means for patients, service users and carers

Adults with suspected MSCC have an MRI of their whole spine and, if a diagnosis of MSCC is confirmed by the MRI, a plan for their treatment organised within 24 hours of the suspected diagnosis.

### Source guidance

• Metastatic spinal cord compression (NICE clinical guideline 75), <u>recommendation 1.4.3.3</u> (key priority for implementation).

### Definitions of terms used in this quality statement

#### Symptoms and signs of MSCC

The following symptoms and signs are suggestive of MSCC:

- progressive pain in the spine
- severe unremitting spinal pain
- spinal pain aggravated by straining (for example, at stool, when coughing or sneezing, or when moving)
- pain described as 'band like'

- localised spinal tenderness
- nocturnal spinal pain preventing sleep
- neurological symptoms: radicular pain, any limb weakness, difficulty in walking, sensory loss, or bladder or bowel dysfunction
- neurological signs of spinal cord or cauda equina compression.

[Definition developed from <u>NICE clinical guideline 75</u> recommendations 1.3.2.1 and 1.3.2.2 and expert consensus]

#### Senior clinical advisers

Includes clinical oncologists, spinal surgeons and radiologists with experience and expertise in treating adults with MSCC. [NICE clinical guideline 75 recommendation 1.1.2.4]

#### Treatment plan

A treatment plan for adults with MSCC should be agreed by senior clinical advisers, and the names of those involved in the discussion should be included in the documentation. Treatment planning should take account of:

- spinal stability, which should be assessed both clinically and radiologically
- the degree of neurological disability
- the general health of the patient
- the prognosis, which should be estimated using a validated scoring system
- the primary site of tumour
- the presence of other spinal and extraspinal metastases
- the likely response of the tumour to radiotherapy or other adjuvant therapy
- the patient's care and treatment preferences.

[The full clinical guideline 75, section 6.1 and expert consensus]

# Quality statement 4: Coordinating investigations for adults with suspected metastatic spinal cord compression

# Quality statement

Adults with suspected metastatic spinal cord compression (MSCC) who present with neurological symptoms or signs have their diagnostic investigations coordinated by an MSCC coordinator.

# Rationale

Some adults with cancer who have a high risk of developing bone metastases are at high risk of developing MSCC. When people present with suspected MSCC, it is important that diagnostic investigations are undertaken promptly. The principal role of the MSCC coordinator for adults with suspected MSCC is to liaise with healthcare professionals and ensure that investigations are organised and undertaken without delay. For those with neurological symptoms or signs it is particularly important that an MSCC coordinator is available at all times to ensure that initial management for adults with MSCC is both comprehensive and timely.

# Quality measures

#### Structure

a) Evidence of local arrangements for identifying individuals responsible for performing the role of MSCC coordinator.

b) Evidence of local arrangements to ensure that adults with suspected MSCC who present with neurological symptoms or signs have their diagnostic investigations coordinated by an MSCC coordinator.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-3Y-304 Manual for cancer services: acute oncology – including metatastic spinal cord compression measures (2011).

#### Process

Proportion of adults with suspected MSCC who present with neurological symptoms or signs who have an assessment of their requirement for, and urgency of investigations, undertaken by an MSCC coordinator.

Numerator – the number of adults in the denominator who have an assessment of their requirement for, and urgency of investigations, undertaken by an MSCC coordinator.

Denominator – the number of adults with suspected MSCC who present with neurological symptoms or signs.

Data source: Local data collection.

# What the quality statement means for service providers, healthcare professionals, and commissioners

Service providers ensure that an MSCC coordinator is available at all times to coordinate the diagnostic investigations for adults with suspected MSCC who present with neurological symptoms or signs.

Healthcare professionals ensure that adults with suspected MSCC who present with neurological symptoms or signs have their diagnostic investigations organised by the MSCC coordinator.

**Commissioners** ensure that they commission services that provide access to an MSCC coordinator, available at all times, to coordinate diagnostic investigations for adults with suspected MSCC who are referred from primary or secondary care.

### What the quality statement means for patients, service users and carers

Adults with suspected MSCC who have neurological symptoms or signs have their tests and investigations arranged by a coordinator.

### Source guidance

• Metastatic spinal cord compression (NICE clinical guideline 75), recommendations 1.1.2.1, <u>1.1.2.2 and 1.1.2.3</u>.

### Definitions of terms used in this quality statement

#### Adults at high risk of MSCC

Adults with cancer who have, or who are at high risk of developing, bone metastases, and adults with cancer, who present with spinal pain. [Adapted from <u>NICE clinical guideline 75</u> recommendation 1.3.1.1]

#### MSCC coordinator role

The role involves coordinating the ongoing care of adults with MSCC and the diagnostic investigations of people at risk of developing MSCC who present with relevant symptoms. An MSCC coordinator should be available 24 hours a day, 7 days a week, acting as a single point of contact for healthcare professionals to liaise with.

The MSCC coordinator's responsibilities and the support they should receive are described in <u>NICE</u> <u>clinical guideline 75</u> recommendations 1.1.2.3 and 1.1.2.5.

The <u>Manual for cancer services: acute oncology – including metastatic spinal cord compression</u> <u>measures</u> (2011; measure 11-3Y-304) lists the criteria that the MSCC coordinator service should fulfil.

#### Symptoms and signs of MSCC

The following symptoms and signs are suggestive of MSCC:

- progressive pain in the spine
- severe unremitting spinal pain
- spinal pain aggravated by straining (for example, at stool, when coughing or sneezing, or when moving)
- pain described as 'band like'
- localised spinal tenderness
- nocturnal spinal pain preventing sleep
- neurological symptoms: radicular pain, any limb weakness, difficulty in walking, sensory loss, or bladder or bowel dysfunction
- neurological signs of spinal cord or cauda equina compression.

[Definition developed from <u>NICE clinical guideline 75</u> recommendations 1.3.2.1 and 1.3.2.2 and expert consensus]

# Quality statement 5: Coordinating care for adults with metastatic spinal cord compression

#### Quality statement

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

### Rationale

The care and treatment of adults with MSCC may involve a number of specialties including oncology, surgery and radiology. It is important that the ongoing investigations and treatments are undertaken promptly because early intervention has a positive effect on MSCC outcomes. The principal role of the MSCC coordinator for adults with MSCC is to liaise with the relevant specialists and organise treatment and any ongoing investigations, ensuring that the ongoing care of adults with MSCC is both comprehensive and timely.

#### Quality measures

#### Structure

a) Evidence of local arrangements for identifying individuals responsible for performing the role of MSCC coordinator.

b) Evidence of local arrangements to ensure that adults with MSCC have their ongoing care coordinated by an MSCC coordinator.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-3Y-304 (The MSCC Coordinator Service) <u>Manual for cancer services</u>: <u>acute oncology – including metatastic</u> <u>spinal cord compression measures</u> (2011).

# What the quality statement means for service providers, healthcare professionals, and commissioners

**Service providers** ensure that an MSCC coordinator is available to coordinate the ongoing care for adults with MSCC.

Healthcare professionals ensure that they arrange access to the MSCC coordinator who will coordinate the ongoing care for adults with MSCC.

**Commissioners** ensure that they commission services that provide access to an MSCC coordinator who will coordinate the ongoing care for adults with MSCC.

#### What the quality statement means for patients, service users and carers

Adults with MSCC have their treatment organised by a coordinator who will oversee important aspects of care on their behalf.

#### Source guidance

• Metastatic spinal cord compression (NICE clinical guideline 75), <u>recommendations 1.1.2.1</u>, <u>1.1.2.2 and 1.1.2.3</u>.

#### Definitions of terms used in this quality statement

#### MSCC coordinator role

The role involves coordinating the ongoing care of adults with MSCC and the diagnostic investigations of people at risk of developing MSCC who present with relevant symptoms. An MSCC coordinator should be available 24 hours a day, 7 days a week, acting as a single point of contact for healthcare professionals to liaise with.

The MSCC coordinator's responsibilities and the support they should receive are described in <u>NICE</u> <u>clinical guideline 75</u> recommendations 1.1.2.3 and 1.1.2.5.

The <u>Manual for cancer services: acute oncology – including metatastic spinal cord compression</u> <u>measures</u> (2011; measure 11-3Y-304) lists the criteria that the MSCC coordinator service should fulfil.

# Quality statement 6: Treatment of metastatic spinal cord compression

# Quality statement

Adults with metastatic spinal cord compression (MSCC), who present with neurological symptoms or signs, start definitive treatment (if appropriate) within 24 hours of the confirmed diagnosis.

# Rationale

Treatment while patients are still able to move or walk around is effective in maintaining their ability to walk and functional independence. Delay in treatment may have irreversible consequences, such as loss of motor and bladder functions. Starting definitive treatment as a matter of urgency is important for adults with MSCC because it can help to prevent further neurological deterioration, which may lead to paraplegia. People who develop paraplegia have a significantly impaired quality of life and shortened survival, and so it is important to identify possible ways of preventing or improving the outcome of MSCC.

# Quality measures

#### Structure

Evidence of local arrangements and written protocols to ensure that adults with MSCC who present with neurological symptoms or signs start definitive treatment (if appropriate) within 24 hours of the confirmed diagnosis.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-1E-112y (The Audit of Timeliness of Definitive Treatment of MSCC) <u>Manual for cancer services: acute</u> <u>oncology – including metatastic spinal cord compression measures</u> (2011).

#### Process

Proportion of adults with MSCC who present with neurological symptoms or signs who start definitive treatment (if appropriate) within 24 hours of the confirmed diagnosis.

Numerator – the number of adults in the denominator who start definitive treatment within 24 hours of the confirmed diagnosis.

Denominator – the number of adults with MSCC who present with neurological symptoms or signs for whom it is appropriate to start definitive treatment within 24 hours.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-1E-112y (The Audit of Timeliness of Definitive Treatment of MSCC) <u>Manual for cancer services: acute</u> <u>oncology – including metatastic spinal cord compression measures</u> (2011).

#### Outcome

a) Proportion of adults with MSCC who are able to walk within 3 months of treatment.

b) Proportion of adults with MSCC who are able to walk within 2 years of treatment.

c) Rates of mortality within 30 days of treatment.

*Data source*: Local data collection. Department of Health Acute Oncology Measures 11-1E-113y Manual for cancer services: acute oncology – including metatastic spinal cord compression measures (2011). British Spine Registry Spinal tumour data (2013).

# What the quality statement means for service providers, healthcare professionals, and commissioners

Service providers ensure that for adults with MSCC presenting with neurological symptoms or signs adequate capacity is available and that there are local protocols in place to enable healthcare professionals to start definitive treatment (if appropriate) within 24 hours of the confirmed diagnosis.

Healthcare professionals ensure that for adults with MSCC who present with neurological symptoms or signs they start definitive treatment (if appropriate) within 24 hours of the diagnosis being confirmed.

**Commissioners** ensure that for adults with MSCC who present with neurological symptoms or signs they commission services that can start definitive treatment (if appropriate) within 24 hours of the confirmed diagnosis.

# What the quality statement means for patients, service users and carers

Adults with MSCC for whom treatment is appropriate start their treatment as quickly as possible (ideally within 24 hours of being diagnosed with MSCC).

#### Source guidance

• Metastatic spinal cord compression (NICE clinical guideline 75), recommendation 1.5.3.1.

### Definitions of terms used in this quality statement

#### Definitive treatment

Definitive treatment for MSCC includes surgery and radiotherapy. [Department of Health Acute Oncology Measures (The Audit of Timeliness of Definitive Treatment of MSCC) <u>Manual for cancer</u> <u>services: acute oncology – including metatastic spinal cord compression measures</u> (2011)]

#### Symptoms and signs of MSCC

The following symptoms and signs are suggestive of MSCC:

- progressive pain in the spine
- severe unremitting spinal pain
- spinal pain aggravated by straining (for example, at stool, when coughing or sneezing, or when moving)
- pain described as 'band like'
- localised spinal tenderness
- nocturnal spinal pain preventing sleep
- neurological symptoms: radicular pain, any limb weakness, difficulty in walking, sensory loss, or bladder or bowel dysfunction.
- neurological signs of spinal cord or cauda equina compression.

[Definition developed from <u>NICE clinical guideline 75</u> recommendations 1.3.2.1 and 1.3.2.2 and expert consensus]

# Equality and diversity considerations

Survival times for adults with MSCC vary from just a few weeks to over a decade. The person's age should not affect the decision to undertake definitive treatment.

# Quality statement 7: Supportive care and rehabilitation

# Quality statement

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

# Rationale

It is important that personalised management planning for adults with MSCC starts on admission because rehabilitation and supportive care are integral to the promotion of independence and quality of life for adults with MSCC. Emphasis should be on an individualised, person-centred management planning process, led by a key worker, which takes into account care relating to all existing healthcare issues the person may have, including cancer. Communication between secondary, primary and tertiary care needs to ensure a seamless transfer between services and continuity of care for patients.

# Quality measures

#### Structure

Evidence of local arrangements and written protocols to ensure that management planning for adults with MSCC includes an assessment of ongoing care and rehabilitation needs.

Data source: Local data collection.

#### Process

Proportion of adults with MSCC who are discharged from hospital with a management plan that includes an assessment of ongoing care and rehabilitation needs.

Numerator - the number of adults in the denominator who have a management plan on discharge.

Denominator - the number of adults with MSCC who are admitted to hospital.

Data source: Local data collection.

# What the quality statement means for service providers, healthcare professionals and commissioners

**Service providers** ensure that staff are trained on how to develop management plans, including how to undertake an assessment of ongoing care and rehabilitation needs for adults with MSCC, and have protocols in place for starting management planning on admission.

Healthcare professionals involve adults with MSCC in developing management plans that include an assessment of ongoing care and rehabilitation needs for adults with MSCC when they are admitted to hospital.

**Commissioners** ensure that they commission services that train their staff on how to develop management plans including how to undertake an assessment of ongoing care and rehabilitation needs for adults with MSCC, and have protocols in place for starting management planning on admission.

# What the quality statement means for patients, service users and carers

Adults with MSCC have a plan of the ongoing care they agree they will receive after they have been discharged from hospital, which will include plans for rehabilitation.

### Source guidance

• Metastatic spinal cord compression (NICE clinical guideline 75), <u>recommendation 1.6.5.4</u> (key priority for implementation).

### Definitions of terms used in this quality statement

#### Management planning and ongoing care

For adults with MSCC, this should start on admission and it should involve: the patient; their families and carers with the patient's consent; their primary oncology site; surgical, specialist palliative care and rehabilitation teams and community support, including primary care, as needed. The management plan should address physical and psychological needs. Management planning should include, but not be limited to, consideration of: pressure ulcers, continence, maintenance of circulatory and respiratory functioning, psychological adjustment and location of care. [NICE clinical guideline 75 recommendation 1.6.5.4 and expert consensus]

#### Key worker

Person who, with the patient's consent and agreement, takes the leading role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice, regardless of the patient's location. The role may be undertaken by the MSCC coordinator or by a different named individual. Different practitioners are likely to perform this function on behalf of individual patients over time. [Adapted from the <u>full clinical guideline 75</u>, appendix 6, glossary; NICE cancer service guidance on <u>Supportive and palliative care</u>, recommendation 1.29 and expert consensus]

# Equality and diversity considerations

Survival times for adults with MSCC vary from just a few weeks to over a decade. MSCC is closely associated with the end of life because of its high incidence in the late stages of advanced malignancy. The timing of discussions about ongoing care and rehabilitation should be sensitive to the emotional adjustments that the patient and carer may be experiencing.

The person's age should not affect the content of the discharge plan or their access to rehabilitation services. Healthcare professionals should consider whether adults with MSCC who are experiencing the later stages of cancer may benefit more from readjustment rather than rehabilitation.

# Using the quality standard

# Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its <u>Indicators for Quality Improvement Programme</u>. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's <u>What makes up a NICE quality standard?</u> for further information, including advice on using quality measures.

# Levels of achievement

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

# Using other national guidance and policy documents

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in <u>Development sources</u>.

# Information for commissioners

NICE has produced <u>support for commissioning</u> that considers the commissioning implications and potential resource impact of this quality standard. This is available on the NICE website.

# Information for the public

NICE has produced <u>information for the public</u> about this quality standard. Patients, service users and carers can use it to find out about the quality of care they should expect to receive; as a basis for asking questions about their care, and to help make choices between providers of social care services.

# Diversity, equality and language

During the development of this quality standard, equality issues have been considered and <u>equality</u> <u>assessments</u> are available.

Good communication between healthcare professionals and adults with MSCC is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Adults with MSCC should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

### **Development sources**

Further explanation of the methodology used can be found in the quality standards process guide on the NICE website.

#### Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

• <u>Metastatic spinal cord compression</u>. NICE clinical guideline 75 (2008).

# Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- National Spinal Taskforce (2013) <u>Commissioning spinal services getting the service back on</u> <u>track</u>.
- Department of Health (2011) <u>Commissioning cancer services</u>.
- Department of Health (2011) Improving outcomes: a strategy for cancer.
- National Cancer Peer Review Programme (2011) <u>Manual for cancer services: acute oncology –</u> including metatastic spinal cord compression measures.
- Department of Health (2010) <u>A guide to practice-based commissioners in developing good</u> <u>cancer care services</u>.
- Department of Health (2007) <u>Cancer Reform Strategy</u>.
- <u>Supportive and palliative care</u>. NICE cancer service guidance (2004).

# Definitions and data sources for the quality measures

- British Spine Registry <u>Spinal tumour data</u> (2013).
- National Cancer Peer Review Programme (2011) <u>Manual for cancer services: acute oncology –</u> <u>including metatastic spinal cord compression measures</u>.

- <u>Metastatic spinal cord compression</u>. NICE clinical guideline 75 (2008).
- Metastatic spinal cord compression: audit support. NICE clinical guideline 75 (2008).
- National Collaborating Centre for Cancer (2008) Metastatic spinal cord compression
- <u>Supportive and palliative care</u>. NICE cancer service guidance (2004).

# Related NICE quality standards

# Published

- <u>Faecal incontinence</u>. NICE quality standard 54 (2014).
- Lung cancer. NICE quality standard 17 (2012).
- Patient experience in adult NHS services. NICE quality standard 15 (2012).
- Breast cancer. NICE quality standard 12 (2011).

# Future quality standards

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Haematological malignancies.
- Neurological problems.
- Pain management (young people and adults).
- Prostate cancer.
- Radiotherapy services.
- Referral for suspected cancer.

# Quality Standards Advisory Committee and NICE project team

# **Quality Standards Advisory Committee**

This quality standard has been developed by Quality Standards Advisory Committee 3. Membership of this Committee is as follows:

Dr Hugh McIntyre (Chair) Consultant Physician, East Sussex Healthcare Trust

Dr Alastair Bradley General Medical Practitioner, Tramways Medical Centre/Academic Unit of Primary Medical Care, University of Sheffield

Jan Dawson Public Health Nutrition Lead, Manchester City Council

Ms Lisa Edwards Registered Social Worker

Matthew Fay General Practitioner, West Yorkshire

Dr Malcolm Fisk Co-Director, Ageing Society Grand Challenge Initiative, Coventry University

Margaret Goose Lay member

Ms Julia Hickling Director, Advancing Quality Alliance

Dr Raymond Jankowski Deputy Director of Public Health, NHS Hertfordshire

Ms Sian Jones Programme Manager – Commissioning, NHS Bristol Mrs Geeta Kumar Clinical Director – Women's services, Betsi Cadwaladr University Health Board (East)

Mrs Rhian Last Clinical Lead, Education for Health

Neena Modi Professor of neonatal medicine/Consultant, Chelsea and Westminster NHS Foundation Trust

Ms Ann Nevinson Lay member

Dr Jane O'Grady Director of Public Health, Buckinghamshire County Council

Professor Gillian Parker Professor of Social Policy Research and Director, Social Policy Research Unit, University of York

Mr David Pugh Mental Capacity Act and Mental Health Act Implementation Manager, Gloucestershire County Council

Dr Eve Scott Head of Safety and Risk, Christie NHS Foundation Trust

Dr Jim Stephenson Consultant Medical Microbiologist, Epsom and St Helier NHS Trust

Mr Darryl Thompson Psychosocial Interventions Development Lead, South West Yorkshire Partnership NHS Foundation Trust

Mrs Julia Thompson Strategic Commissioning Manager, Sheffield City Council

The following specialist members joined the Committee to develop this quality standard:

#### Dr Hannah Gunn

Consultant in Palliative Care, Northumbria Healthcare NHS Foundation Trust and Marie Curie Hospice, Newcastle

Mr Rodney Laing Consultant Neurosurgeon, Cambridge University Hospitals NHS Foundation Trust, Cambridge

Dr Imogen Locke Consultant Clinical Oncologist, The Royal Marsden NHS Foundation Trust, London

Mr Michael Scanes Patient/carer member

Mr Alistair Stirling Consultant Spinal Surgeon, The Royal Orthopaedic Hospital NHS Foundation Trust, Birmingham

#### NICE project team

Nick Baillie Associate Director

Shirley Crawshaw Consultant Clinical Adviser

Terence Lacey Technical Adviser

Rachel Neary Programme Manager

Julie Kennedy Lead Technical Analyst

Esther Clifford Project Manager

Lee Berry Coordinator

# About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the <u>quality</u> <u>standards process guide</u>.

This quality standard has been incorporated into the NICE pathway for <u>metastatic spinal cord</u> <u>compression</u>.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

#### Changes after publication

April 2015: Minor maintenance.

April 2014: Statement 6 has been updated for clarity.

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### Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

### Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Royal College of General Practitioners
- Royal College of Nursing
- <u>Society and College of Radiographers</u>