

# Sickle cell disease

Quality standard

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## Contents

Introduction .....	5
Why this quality standard is needed .....	5
How this quality standard supports delivery of outcome frameworks .....	6
Coordinated services.....	6
List of quality statements.....	8
Quality statement 1: Timely assessment and analgesia .....	9
Quality statement.....	9
Rationale .....	9
Quality measures .....	9
What the quality statement means for service providers, healthcare professionals and commissioners ..	10
What the quality statement means for patients, service users and carers.....	10
Source guidance.....	10
Definitions of terms used in this quality statement .....	11
Equality and diversity considerations.....	11
Quality statement 2: Regular assessment of pain relief .....	12
Quality statement.....	12
Rationale .....	12
Quality measures .....	12
What the quality statement means for service providers, healthcare professionals and commissioners ..	13
What the quality statement means for patients, service users and carers.....	14
Source guidance.....	14
Definitions of terms used in this quality statement .....	14
Equality and diversity considerations.....	14
Quality statement 3: Strong opioids and monitoring .....	15
Quality statement.....	15
Rationale .....	15
Quality measures .....	15

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What the quality statement means for service providers, healthcare professionals and commissioners ..	16
What the quality statement means for patients, service users and carers.....	16
Source guidance.....	17
Definitions of terms used in this quality statement .....	17
<b>Quality statement 4: Acute complications.....</b>	<b>19</b>
Quality statement.....	19
Rationale .....	19
Quality measures .....	19
What the quality statement means for service providers, healthcare professionals and commissioners ..	20
What the quality statement means for patients, service users and carers.....	20
Source guidance.....	20
Definitions of terms used in this quality statement .....	21
<b>Quality statement 5: Protocols and specialist support.....</b>	<b>22</b>
Quality statement.....	22
Rationale .....	22
Quality measures .....	22
What the quality statement means for service providers, healthcare professionals and commissioners ..	23
What the quality statement means for patients, service users and carers.....	23
Source guidance.....	23
<b>Quality statement 6: Discharge information .....</b>	<b>24</b>
Quality statement.....	24
Rationale .....	24
Quality measures .....	24
What the quality statement means for service providers, healthcare professionals, and commissioners .	25
What the quality statement means for patients, service users and carers.....	25
Source guidance.....	25
Definitions of terms used in this quality statement .....	25
Equality and diversity considerations.....	26

Using the quality standard.....	27
Quality measures .....	27
Levels of achievement .....	27
Using other national guidance and policy documents.....	27
Information for commissioners .....	27
Information for the public .....	28
Diversity, equality and language .....	29
Development sources.....	30
Evidence sources.....	30
Definitions and data sources for the quality measures .....	30
Related NICE quality standards .....	31
Published .....	31
Future quality standards.....	31
Quality Standards Advisory Committee and NICE project team .....	32
Quality Standard Advisory Committee.....	32
NICE project team .....	34
About this quality standard.....	35

This standard is based on CG143.

This standard should be read in conjunction with QS15.

## Introduction

This quality standard covers the management of sickle cell acute painful episode in people in hospital from the time of presenting to hospital until the time of discharge. For more information see the [topic overview](#).

### *Why this quality standard is needed*

Sickle cell disease is the name given to a group of lifelong inherited conditions that affect haemoglobin. Most people affected are of African or African-Caribbean origin, although the sickle gene is found in all ethnic groups. It is estimated that there are between 12,500 and 15,000 people with sickle cell disease in the UK<sup>[1]</sup>. The prevalence of the disease is increasing because of immigration into the UK and new births.

Acute painful sickle cell episode (also known as painful crisis) is an acute condition that occurs in people with sickle cell disease. In these people red blood cells behave differently under a variety of conditions, including dehydration, low oxygen levels and elevated temperature. Changes in any of these conditions may cause the red blood cells to block the small blood vessels, restricting blood flow. This damages the tissue, which causes pain.

Acute painful sickle cell episodes occur unpredictably, often without clear precipitating factors. Their frequency may vary from less than 1 episode a year to severe pain at least once a week. Pain can vary in both intensity and duration, and may be excruciating.

Most painful episodes are managed at home, with people usually seeking hospital care only if the pain is uncontrolled or they have no access to analgesia. The primary goal in the management of an acute painful sickle cell episode is to achieve effective pain control both promptly and safely. The management of acute painful sickle cell episodes for people presenting at hospital is variable throughout the UK, and is a frequent source of complaints.

## 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 outcomes framework published by the Department of Health:

- [NHS Outcomes Framework 2014–15](#)

Table 1 shows the outcomes, overarching indicators and improvement areas from the framework that the quality standard could contribute to achieving.

**Table 1** [NHS Outcomes Framework 2014–15](#)

Domain	Overarching indicators and improvement areas
2 Enhancing quality of life for people with long-term conditions	<p><b>Overarching indicator</b></p> <p>2 Health-related quality of life for people with long-term conditions</p> <p><b>Improvement areas</b></p> <p>Ensuring people feel supported to manage their condition</p> <p>2.1 Proportion of people feeling supported to manage their condition</p>
4 Ensuring that people have a positive experience of care	<p><b>Overarching indicator</b></p> <p>4b Patient experience of hospital care</p> <p><b>Improvement areas</b></p> <p>Improving people's experience of accident and emergency services</p> <p>4.3 Patient experience of A&amp;E services</p>

### Coordinated services

The quality standard for sickle cell acute painful episode specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole sickle

cell acute painful episode pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with a sickle cell acute painful episode.

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 library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality sickle cell acute painful episode service are listed in [Related quality standards](#).

## 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 people with a sickle cell acute painful episode 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 people with a sickle cell acute painful episode. If appropriate, healthcare professionals 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> [Sickle cell acute painful episode](#). NICE clinical guideline 143 (2012)

## List of quality statements

Statement 1. People who present at hospital with an acute painful sickle cell episode have a pain assessment, a clinical assessment and appropriate analgesia within 30 minutes of presentation.

Statement 2. People with an acute painful sickle cell episode have an assessment of pain relief every 30 minutes until satisfactory pain relief has been achieved and then at least every 4 hours.

Statement 3. People with an acute painful sickle cell episode who are taking strong opioids are monitored for adverse events every hour for the first 6 hours after first administration or step up of pain relief and then at least every 4 hours.

Statement 4. People with an acute painful sickle cell episode are assessed for acute chest syndrome if they have 1 or more of the following: abnormal respiratory signs or symptoms, chest pain, fever, or signs and symptoms of hypoxia.

Statement 5. Healthcare professionals who care for people with an acute painful sickle cell episode have access to locally agreed protocols on treatment and management and specialist support from designated centres.

Statement 6. People with an acute painful sickle cell episode are given information before discharge on how to continue to manage their current episode.



## Quality statement 1: Timely assessment and analgesia

### *Quality statement*

People who present at hospital with an acute painful sickle cell episode have a pain assessment, a clinical assessment and appropriate analgesia within 30 minutes of presentation.

### *Rationale*

A thorough and rapid assessment at presentation is needed to ensure that people with an acute painful sickle cell episode have an accurate diagnosis. Pain assessment should be performed using an age-appropriate pain scoring tool. This ensures that adequate analgesia is given and will inform future management. If acute pain is not recognised and adequate analgesia is not given promptly, the pain may escalate, causing unnecessary distress and deterioration in the person's condition.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that people who present at hospital with an acute painful sickle cell episode have a pain assessment, a clinical assessment and appropriate analgesia within 30 minutes of presentation.

**Data source:** Local data collection.

#### **Process**

a) Proportion of people who present at hospital with an acute painful sickle cell episode and have a pain assessment, a clinical assessment and appropriate analgesia within 30 minutes of presentation.

Numerator – the number of people in the denominator who have a pain assessment, a clinical assessment and appropriate analgesia within 30 minutes of presentation.

Denominator – the number of people who present at hospital with an acute painful sickle cell episode.

**Data source:** Local data collection. Contained within [NICE clinical guideline 143 clinical audit tool](#), audit standards 2 and 3.

b) Proportion of people who present at hospital with an acute painful sickle cell episode who have their pain assessed using an age-appropriate pain scoring tool.

Numerator – the number of people in the denominator who have their pain assessed using an age-appropriate pain scoring tool.

Denominator – the number of people who present at hospital with an acute painful sickle cell episode.

**Data source:** Local data collection. Contained within [NICE clinical guideline 143 clinical audit tool](#), audit standard 1.

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

**Service providers** ensure that they have sufficient resources to assess both pain and clinical signs in people who present at hospital with an acute painful sickle cell episode and to give appropriate analgesia within 30 minutes of presentation.

**Healthcare professionals** ensure that they assess both pain and clinical signs in people who present at hospital with an acute painful sickle cell episode and give appropriate analgesia within 30 minutes of presentation.

**Commissioners** ensure that they commission services that have sufficient resources to assess both pain and clinical signs in people who present at hospital with an acute painful sickle cell episode and give them appropriate analgesia within 30 minutes of presentation.

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

People who go to hospital with a painful attack of sickle cell disease (acute painful sickle cell episode) have their pain, blood pressure, blood oxygen levels, heart rate, breathing rate and temperature checked, and are given the right amount of pain relief within 30 minutes of arriving.

### *Source guidance*

- Sickle cell acute painful episode (NICE clinical guideline 143), recommendations [1.1.3](#), [1.1.4](#) and [1.1.5](#).

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

### **Pain assessment**

A pain assessment should assess the severity of pain using an age-appropriate pain scoring tool. [NICE clinical guideline 143, recommendation 1.1.3]

### **Clinical assessment**

A clinical assessment should check whether the pain is due to an acute painful sickle cell episode or another cause, and should include assessment of the following clinical signs:

- blood pressure
- oxygen saturation
- pulse rate
- respiratory rate
- temperature.

[NICE clinical guideline 143, recommendations 1.1.5 and 1.1.6]

### **Appropriate analgesia**

Appropriate analgesia must take into account any pain relief taken by the patient for the current episode before presenting at hospital, and ensure that the drug, dose and administration route are suitable for the severity of the pain and the age of the patient. [NICE clinical guideline 143, recommendation 1.1.7]

### *Equality and diversity considerations*

Most people with sickle cell disease are of African or African-Caribbean origin. This may mean that language needs to be taken into account when deciding on the type of pain scoring tool to be used. Age, especially if the person is a young child, and any physical, sensory or learning disabilities also need to be taken into account.

In young children, people with learning disabilities and people in great pain, it may not be possible to determine the cause of the pain initially without a fuller examination.

## Quality statement 2: Regular assessment of pain relief

### *Quality statement*

People with an acute painful sickle cell episode have an assessment of pain relief every 30 minutes until satisfactory pain relief has been achieved and then at least every 4 hours.

### *Rationale*

Assessment of pain relief is important for determining the effectiveness of the analgesia given at the time of presentation. It is also important for ensuring that more painkillers are given when needed until the episode has ended or the patient is discharged. Using an age-appropriate pain scoring tool ensures consistency when assessing pain and helps healthcare professionals to ensure that pain relief is appropriate.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that people with an acute painful sickle cell episode have their pain relief reassessed every 30 minutes until satisfactory pain relief has been achieved and then at least every 4 hours.

**Data source:** Local data collection.

#### **Process**

a) Proportion of people with an acute painful sickle cell episode who have their pain relief reassessed every 30 minutes after pain relief is started until satisfactory pain relief has been achieved.

Numerator – the number of people in the denominator who have their pain relief reassessed every 30 minutes after pain relief is started until satisfactory pain relief has been achieved.

Denominator – the number of people with an acute painful sickle cell episode.

**Data source:** Local data collection.

b) Proportion of people with an acute painful sickle cell episode who have achieved satisfactory pain relief who have their pain relief assessed at least every 4 hours until discharge or the end of the episode.

Numerator – the number of people in the denominator who have their pain relief assessed at least every 4 hours until discharge or the end of the episode.

Denominator – the number of people with an acute painful sickle cell episode who have achieved satisfactory pain relief.

*Data source:* Local data collection.

c) Proportion of people with an acute painful sickle cell episode who have their pain relief reassessed using an age-appropriate pain scoring tool.

Numerator – the number of people in the denominator who have their pain relief reassessed using an age-appropriate pain scoring tool.

Denominator – the number of people with an acute painful sickle cell episode.

*Data source:* Local data collection.

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

**Service providers** ensure that they have sufficient resources to reassess pain relief in people with an acute painful sickle cell episode every 30 minutes until satisfactory pain relief has been achieved and then at least every 4 hours until discharge or the end of the episode.

**Healthcare professionals** ensure that they reassess pain relief in people with an acute painful sickle cell episode every 30 minutes until satisfactory pain relief has been achieved and then at least every 4 hours until discharge or the end of the episode.

**Commissioners** ensure that they commission services that have sufficient resources to reassess pain relief in people with an acute painful sickle cell episode every 30 minutes until satisfactory pain relief has been achieved, and then at least every 4 hours until discharge or the end of the episode.

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

People with a painful attack of sickle cell disease (acute painful sickle cell episode) have their pain relief checked every 30 minutes until they are comfortable and then at least every 4 hours until they leave hospital or their episode has ended.

### *Source guidance*

- Sickle cell acute painful episode (NICE clinical guideline 143), recommendation [1.1.12](#).

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

### **Assessment of pain relief**

Assessment of pain relief should be done using an age-appropriate pain scoring tool and by asking questions such as:

- How well did that last painkiller work?
- Do you feel that you need more pain relief?

[[NICE clinical guideline 143](#), recommendation 1.1.12]

### **Satisfactory pain relief**

Satisfactory pain relief depends on the individual patient and is reached when the patient confirms that they are satisfied with their level of pain relief. [adapted from [NICE clinical guideline 143](#)]

### **Timing of assessments**

Assessment of pain relief should be done every 30 minutes until satisfactory pain relief has been achieved and then at least every 4 hours when pain relief is satisfactory, until either discharge or the end of the acute painful sickle cell episode. [adapted from [NICE clinical guideline 143](#)]

## *Equality and diversity considerations*

Most people with sickle cell disease are of African or African-Caribbean origin. This may mean that language needs to be taken into account when deciding on the type of pain scoring tool to be used. Age, especially if the person is a young child, and any physical, sensory or learning disabilities also need to be taken into account.

## Quality statement 3: Strong opioids and monitoring

### *Quality statement*

People with an acute painful sickle cell episode who are taking strong opioids are monitored for adverse events every hour for the first 6 hours after first administration or step up of pain relief and then at least every 4 hours.

### *Rationale*

Monitoring for adverse events in people with an acute painful sickle cell episode who are taking strong opioids is important to ensure patient safety. Monitoring is initially done hourly because the risk of adverse events is higher in the first 6 hours after first administration or a step up of pain relief.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that people with an acute painful sickle cell episode who are taking strong opioids have monitoring for adverse events every hour for the first 6 hours after first administration or step up of pain relief and then at least every 4 hours.

**Data source:** Local data collection.

#### **Process**

a) Proportion of people with an acute painful sickle cell episode taking strong opioids who are monitored for adverse events every hour for the first 6 hours after first administration or step up of pain relief.

Numerator – the number of people in the denominator who are monitored for adverse events every hour for the first 6 hours after first administration or step up of pain relief.

Denominator – the number of people with an acute painful sickle cell episode taking strong opioids.

**Data source:** Local data collection.

b) Proportion of people with an acute painful sickle cell episode taking strong opioids who have had hourly monitoring for adverse events for the first 6 hours after first administration or step up of pain relief and who are then monitored for adverse events at least every 4 hours until discharge or the end of the episode.

Numerator – the number of people in the denominator who are monitored for adverse events at least every hour 4 hours until discharge or the end of the episode.

Denominator – the number of people with an acute painful sickle cell episode taking strong opioids who have had hourly monitoring for adverse events for 6 hours following first administration or step up of pain relief.

*Data source:* Local data collection.

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

**Service providers** ensure that they have sufficient resources for people with an acute painful sickle cell episode who are taking strong opioids to be monitored for adverse events every hour for the first 6 hours after first administration or step up of pain relief and then at least every 4 hours until discharge or the end of the episode.

**Healthcare professionals** ensure that people with an acute painful sickle cell episode who are taking strong opioids are monitored for adverse events every hour for the first 6 hours after first administration or step up of pain relief and then at least every 4 hours until discharge or the end of the episode.

**Commissioners** ensure that they commission services that provide sufficient resources for people with an acute painful sickle cell episode who are taking strong opioids to be monitored for adverse events every hour for the first 6 hours after first administration or step up of pain relief and then at least every 4 hours until discharge or the end of the episode.

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

**People with a painful attack of sickle cell disease** (acute painful sickle cell episode) who are taking strong painkillers (strong opioids) are checked for possible side effects every hour for the first 6 hours and then at least every 4 hours until they leave hospital or their episode has ended.



## Source guidance

- Sickle cell acute painful episode (NICE clinical guideline 143), recommendation [1.1.16](#).

## Definitions of terms used in this quality statement

### Strong opioids

Strong opioids are drugs that have a similar action to morphine. They are mainly used for pain relief. Examples include morphine, diamorphine, fentanyl, oxycodone and buprenorphine. [Opioids in palliative care, [NICE clinical guideline 140](#) – full guideline]

### Monitoring for adverse events

Monitoring for adverse events is defined as a clinical assessment that includes a sedation score. [[NICE clinical guideline 143](#), recommendation 1.1.16]

A clinical assessment should also assess:

- blood pressure
- oxygen saturation
- pulse rate
- respiratory rate
- temperature.

### Step up of pain relief

A step up of pain relief is either moving from a milder painkiller such as non-steroidal anti-inflammatory drugs/paracetamol to mild opioids and then to stronger opioids or an increase in dosage of analgesia. [Adapted from [Analgesic Ladder](#), World Health Organization (1986) and expert opinion]

### Timing of monitoring

Monitoring for adverse events should be done every hour for the first 6 hours and then at least every 4 hours, until either discharge or end of the acute painful sickle cell episode. Certain groups, for example, children and people on patient-controlled analgesia, may need to be monitored more

frequently according to local protocols. [adapted from [NICE clinical guideline 143](#) and expert opinion]

## Quality statement 4: Acute complications

### *Quality statement*

People with an acute painful sickle cell episode are assessed for acute chest syndrome if they have 1 or more of the following: abnormal respiratory signs or symptoms, chest pain, fever, or signs and symptoms of hypoxia.

### *Rationale*

Acute chest syndrome is a major cause of morbidity and mortality in people with sickle cell disease. It can progress rapidly and is not always recognised as a possible complication. Monitoring by clinical assessment, acting on any changes and assessing for acute chest syndrome may lead to this complication being identified and treatment started earlier.

### *Quality measures*

#### Structure

a) Evidence of local arrangements to ensure that healthcare professionals caring for people with an acute painful sickle cell episode are aware of acute chest syndrome as a potential complication.

*Data source:* Local data collection.

b) Evidence of local arrangements to ensure that people with an acute painful sickle cell episode are assessed for acute chest syndrome if they have 1 or more of the following: abnormal respiratory signs or symptoms, chest pain, fever, or signs and symptoms of hypoxia.

*Data source:* Local data collection.

#### Process

Proportion of people with an acute painful sickle cell episode with 1 or more of the following: abnormal respiratory signs or symptoms, chest pain, fever, or signs and symptoms of hypoxia who are assessed for acute chest syndrome.

Numerator – the number of people in the denominator who are assessed for acute chest syndrome.

Denominator – the number of people with an acute painful sickle cell episode who have 1 or more of the following: abnormal respiratory signs or symptoms, chest pain, fever, or signs and symptoms of hypoxia.

*Data source:* Local data collection.

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

**Service providers** ensure that healthcare professionals caring for people with an acute painful sickle cell episode are aware of acute chest syndrome as a potential complication and that people with an acute painful sickle cell episode need to be assessed for acute chest syndrome if they have 1 or more of the following: abnormal respiratory signs or symptoms, chest pain, fever, or signs and symptoms of hypoxia.

**Healthcare professionals** ensure that they are aware of acute chest syndrome as a potential complication of an acute painful sickle cell episode and assess for acute chest syndrome if people have 1 or more of the following: abnormal respiratory signs or symptoms, chest pain, fever, or signs and symptoms of hypoxia.

**Commissioners** ensure that they commission services that have staff trained to recognise acute chest syndrome as a potential complication of acute painful sickle cell episode and to assess for acute chest syndrome if people with an acute painful sickle cell episode have 1 or more of the following: abnormal respiratory signs or symptoms, chest pain, fever, or signs and symptoms of hypoxia.

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

**People with a painful attack of sickle cell disease** (acute painful sickle cell episode) who have any breathing problems, chest pain or fever are assessed for a serious lung condition called acute chest syndrome.

### *Source guidance*

- Sickle cell acute painful episode (NICE clinical guideline 143), recommendation [1.1.19](#).

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

### **Signs and symptoms of hypoxia**

- Oxygen saturation of 95% or below, or
- An escalating oxygen requirement to maintain oxygen saturations of 95% or above.

[[NICE clinical guideline 143](#), recommendation 1.1.19]

## Quality statement 5: Protocols and specialist support

### *Quality statement*

Healthcare professionals who care for people with an acute painful sickle cell episode have access to locally agreed protocols on treatment and management and specialist support from designated centres.

### *Rationale*

The distribution of sickle cell disease varies throughout England; two-thirds of people with sickle cell disease live in London, and most others live in the other big cities. Therefore the demand for treatment and management of acute painful sickle cell episode differs across the country. To ensure high-quality care for all people with an acute painful sickle cell episode, healthcare professionals need to be able to access locally agreed protocols that set out treatment and management. They also need to know how to access specialist support from designated centres when needed.

### *Quality measures*

#### **Structure**

a) Evidence of local arrangements to ensure that locally agreed protocols on how to treat and manage acute painful sickle cell episodes are available and reviewed regularly.

*Data source:* Local data collection.

b) Evidence of local arrangements to ensure that all healthcare professionals who care for people with an acute painful sickle cell episode have access to specialist support from designated centres.

*Data source:* Local data collection.

#### **Outcome**

a) Staff awareness of how to access locally agreed protocols for treatment and management of acute painful sickle cell episodes.

*Data source:* Local data collection.

b) Staff awareness of how to access specialist support from their designated specialist centre.

*Data source:*Local data collection.

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

**Service providers** ensure that locally agreed protocols for treating and managing acute painful sickle cell episodes are available and regularly reviewed, and that healthcare professionals who care for people with an acute painful sickle cell episode are aware of and have access to these protocols. Service providers ensure that healthcare professionals know how to access specialist support for sickle cell care from designated centres.

**Healthcare professionals** who care for people with an acute painful sickle cell episode ensure that they have access to locally agreed protocols on treatment and management and know how to access specialist support for sickle cell care from designated centres.

**Commissioners** ensure that they commission services for people with an acute painful sickle cell episode, which have access to locally agreed protocols for treatment and management. Commissioners should engage with local and specialist services to designate centres that can offer specialist support, and should ensure that the specialist centres have the resources to do this.

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

**People with a painful attack of sickle cell disease** (acute painful sickle cell episode) are cared for by healthcare professionals who can follow locally agreed procedures for managing the condition and can get support from specialist centres if needed.

### *Source guidance*

- Sickle cell acute painful episode (NICE clinical guideline 143), recommendations [1.1.1](#) and [1.1.25](#).

## Quality statement 6: Discharge information

### *Quality statement*

People with an acute painful sickle cell episode are given information before discharge on how to continue to manage their current episode.

### *Rationale*

People with an acute painful sickle cell episode who are discharged from hospital need written information on accessing specialist advice, managing side effects of treatment and obtaining additional medication. This applies to everyone whether they are still taking strong opioids at the time of discharge or whether the episode ended while they were in hospital. Because sickle cell disease is a rare condition everyone should have this information so that they can discuss their needs with other healthcare professionals who are involved in continuing care.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that people with an acute painful sickle cell episode are given information before discharge on how to continue to manage their current episode.

**Data source:** Local data collection.

#### **Process**

Proportion of people with an acute painful sickle cell episode (or their parents or carers if appropriate) who are given information before discharge on how to continue to manage their current episode.

Numerator – the number of people in the denominator (or parents or carers if appropriate) who are given information on how to continue to manage their current episode.

Denominator – the number of people with an acute painful sickle cell episode who are discharged from hospital.

**Data source:** Local data collection.



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

**Service providers** ensure the availability of information on how to continue to manage acute painful sickle cell episodes. They should also ensure protocols are in place for people to be provided with this information before discharge.

**Healthcare professionals** give people with an acute painful sickle cell episode, information before discharge on how to continue to manage their current episode.

**Commissioners** ensure that they commission services in which people with an acute painful sickle cell episode are given information before discharge on how to continue to manage their current episode.

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

**People with a painful attack of sickle cell disease** (acute painful sickle cell episode) are given information before they leave hospital on how to get specialist support, how to get extra medication and how to manage any side effects of the treatment.

### *Source guidance*

- Sickle cell acute painful episode (NICE clinical guideline 143), recommendation [1.1.28](#).

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

#### **Discharge information**

Written information on:

- how to obtain specialist support
- how to obtain additional medicines
- how to manage any side effects of the treatment they have received in hospital

[[NICE clinical guideline 143](#), recommendation 1.1.28]

## *Equality and diversity considerations*

All discharge information given to people with an acute painful sickle cell episode should be culturally appropriate and accessible to people with additional needs, such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with an acute painful sickle cell episode should have access to an interpreter or advocate if needed.

It may be appropriate in some cases, particularly with children and young people or those with learning disabilities, to provide information to parents and carers as well as the person with the acute painful sickle cell episode.

## 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 [Indicators for Quality Improvement Programme](#). 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 [What makes up a NICE quality standard?](#) 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 [Development sources](#).

### *Information for commissioners*

NICE has produced [support for commissioning](#) 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 [information for the public](#) 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 [equality assessments](#) are available.

Good communication between healthcare professionals and people with a sickle cell acute painful episode 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. People with a sickle cell acute painful episode 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.

- [Sickle cell acute painful episode](#). NICE clinical guideline 143 (2012).

## *Definitions and data sources for the quality measures*

- [Sickle cell acute painful episode: clinical audit tool](#). NICE clinical guideline 143 (2012).

## Related NICE quality standards

### *Published*

- [Patient experience in adult NHS services](#). NICE quality standard 15 (2012).

### *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:

- Pain management (young people and adults).

## Quality Standards Advisory Committee and NICE project team

### *Quality Standard Advisory Committee*

This quality standard has been developed by Quality Standards Advisory Committee 2.

Membership of this committee is as follows:

**Dr Michael Rudolf (Chair)**

Consultant Physician, Ealing Hospital NHS Trust

**Mr Barry Attwood**

Lay member

**Professor Gillian Baird**

Consultant Paediatrician, Guys and St Thomas NHS Foundation Trust

**Dr Ashok Bohra**

Consultant Surgeon, Dudley Group of Hospitals NHS Foundation Trust

**Mrs Julie Clatworthy**

Governing Body Nurse, Gloucestershire CCG

**Mr Derek Cruickshank**

Consultant Gynaecological Oncologist/Chief of Service, South Tees Hospitals NHS Foundation Trust, Middlesbrough

**Miss Parul Desai**

Consultant in Ophthalmology and Public Health, Moorfields Eye Hospital NHS Foundation Trust

**Mrs Jean Gaffin**

Lay member

**Mrs Belinda Black**

Chief Executive, Sheffcare Ltd

**Dr Joanne Greenhalgh**

Principal Research Fellow in Healthcare Evaluation, University of Leeds



**Dr John Harley**

General Practitioner, Woodlands Family Medical Centre, Stockton-on-Tees

**Dr Ulrike Harrower**

Consultant in Public Health, NHS Somerset

**Professor Richard Langford**

Consultant in Anaesthesia and Pain Medicine, Barts Health NHS Trust

**Dr Tessa Lewis**

General Practitioner, All Wales Prescribing Advisory Group

**Miss Ruth Liley**

Assistant Director of Quality Assurance, Marie Curie Cancer Care

**Ms Kay MacKay**

Director Enhancing Quality and recovery, Enhancing Quality and recovery Kent Surrey and Sussex

**Mr David Minto**

West Sector Operations Manager, Northumbria Healthcare

**Dr Lindsay Smith**

General Practitioner, West Coker, Somerset

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

**Ms Hellen Adom**

Lay member

**Dr Michele Afif**

Consultant Paediatrician, North West London Hospitals NHS Trust

**Dr Brigitta Brander**

Consultant Anaesthesia and Pain Management, University College London Hospitals

**Dr Jo Howard**

Consultant Haematologist, Guy's and St Thomas' NHS Foundation Trust

**Dr Kisha Moore**

Consultant Emergency Physician, Ealing Hospital, London

**Dr Kate Ryan**

Consultant Haematologist, Central Manchester University Hospitals NHS Foundation Trust

**Mrs Louise Smith**

Sickle Cell and Thalassaemia Clinical Nurse Specialist, Alder Hey Children's Hospital, Liverpool

***NICE project team***

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Project Manager

**Jenny Harrison**

Co-ordinator

## 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 [quality standards process guide](#).

This quality standard has been incorporated into the [NICE pathway for sickle cell acute painful episode](#).

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

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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](#)
- [Royal College of Paediatrics and Child Health](#)