NICE National Institute for Health and Care Excellence

NICE quality standard

Sickle cell disease

Quality standard

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This standard is based on CG143.

This standard should be read in conjunction with QS15.

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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.

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.

What the quality statement means for different audiences

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.

Peoplewho 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 disease: managing acute painful episodes in hospital. NICE guideline CG143 (2012), recommendations 1.1.3 to 1.1.5

Definitions of terms used in this quality statement

Presentation

The arrival time in the emergency department.

Pain assessment

A pain assessment should assess the severity of pain using an age-appropriate pain scoring tool. [NICE's guideline on sickle cell disease, 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.

Be aware that some pulse oximeters can underestimate or overestimate oxygen saturation levels, especially if the saturation level is borderline. Overestimation has been reported in people with dark skin. See also the NHS England Patient Safety Alert on the risk of harm from inappropriate placement of pulse oximeter probes. [NICE's guideline on sickle cell disease, 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's guideline on sickle cell disease, 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 different audiences

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.

Peoplewith 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 disease: managing acute painful episodes in hospital. NICE guideline CG143 (2012), 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's guideline on sickle cell disease, 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's guideline on sickle cell disease]

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's guideline on sickle cell disease]

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 different audiences

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.

Peoplewith 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 disease: managing acute painful episodes in hospital. NICE guideline CG143 (2012), 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. [NICE's full guideline on palliative care for adults: strong opioids for pain relief]

Monitoring for adverse events

Monitoring for adverse events is defined as a clinical assessment that includes a sedation score. [NICE's guideline on sickle cell disease, recommendations 1.1.5 and 1.1.16]

A clinical assessment should also assess:

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

- temperature.

Be aware that some pulse oximeters can underestimate or overestimate oxygen saturation levels, especially if the saturation level is borderline. Overestimation has been reported in people with dark skin. See also the NHS England Patient Safety Alert on the risk of harm from inappropriate placement of pulse oximeter probes.

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's guideline on sickle cell disease 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 different audiences

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.

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 disease: managing acute painful episodes in hospital. NICE guideline CG143 (2012), 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.

Be aware that some pulse oximeters can underestimate or overestimate oxygen saturation levels, especially if the saturation level is borderline. Overestimation has been reported in people with dark skin. See also the NHS England Patient Safety Alert on the risk of harm from inappropriate placement of pulse oximeter probes. [NICE's guideline on sickle cell disease, 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 different audiences

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.

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 disease: managing acute painful episodes in hospital. NICE guideline CG143 (2012), 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 different audiences

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.

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 disease: managing acute painful episodes in hospital. NICE guideline CG143 (2012), 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's guideline on sickle cell disease, 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.

Update information

Minor changes since publication

April 2023: We added a definition of what is meant by presentation to statement 1.

March 2023: We added text to the definitions sections in statements 1, 3 and 4 to indicate that pulse oximetry may be less reliable in people with dark skin. We also added a link to the NHS patient safety alert on the risk of harm from inappropriate placement of pulse oximeter probes.

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.

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, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See our webpage on quality standards advisory committees for details about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

Equality issues were considered during development and equality assessments for this quality standard are available. Any specific issues identified during development of the

quality statements are highlighted in each statement.

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.

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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 (RCGP)
- Royal College of Nursing (RCN)
- Royal College of Paediatrics and Child Health