Sickle cell crisis

NICE quality standard

Draft for consultation

November 2013

Introduction

This quality standard covers the management of sickle cell crisis 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 of haemoglobin formation. 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. The prevalence of the disease is increasing because of immigration into the UK and new births.

Acute painful sickle cell episodes (also known as painful crises) are caused by blockage of the small blood vessels. The red blood cells in people with sickle cell disease behave differently under a variety of conditions, including dehydration, low oxygen levels and elevated temperature. Changes in any of these conditions may cause the cells to block small blood vessels so that the blood does not flow normally. 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 fluctuate 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 this 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 measureable 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 2013/14 (Department of Health, November 2012)

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 2013/14

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 ii *children and young people (placeholder)*
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition**

4 Ensuring that people have a positive experience of care	***Overarching indicator*** 4b Patient experience of hospital care ***Improvement areas*** **Improving people's experience of accident and emergency services** 4.3 Patient experience of A&E services ***Improving children and young people's experience of healthcare (placeholder)***
Alignment across the health and social care system ** Indicator complementary with Adult Social Care Outcomes Framework (ASCOF)	

Coordinated services

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

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 crisis 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 in sickle cell crisis 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 in sickle cell crisis. If appropriate, healthcare professionals should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

List of quality statements

Statement 1. People who present at hospital with an acute painful sickle cell episode have an 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 presentation 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. People with an acute painful sickle cell episode are cared for by healthcare professionals who have access to locally agreed protocols for treatment and management and specialist support for sickle cell care from designated centres.

Questions for consultation

Questions about the quality standard

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

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

Quality statement 1: Timely assessment and analgesia

Quality statement

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

Rationale

A thorough assessment at presentation is needed to ensure that people with an acute painful sickle cell episode have an accurate diagnosis and pain assessment using an age-appropriate pain scoring tool. This ensures adequate analgesia is given and can in some cases 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 an 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 an assessment and appropriate analgesia within 30 minutes of presentation.

Numerator – the number of people in the denominator who have an 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 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 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 an acute painful sickle cell episode have their pain, blood pressure, blood oxygen levels, heart rate, breathing rate and temperature assessed, and are given appropriate 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

Assessment

Assessment should include assessing the severity of pain using an age-appropriate pain scoring tool, assessing to see if the pain is due to an acute painful sickle cell episode or another cause, and assessing the patient’s clinical signs including:

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

[NICE clinical guideline 143, recommendations 1.1.3 and 1.1.5]

Appropriate analgesia

Appropriate analgesia must take into account any analgesia 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 affected with sickle cell disease are of African or African-Caribbean origin which may result in possible language difficulties that need to be taken into account when deciding on the type of pain scoring tool to be used. The age of the person especially young children and any additional needs such as physical, sensory or learning disabilities also need to be taken into account.

In young children, people with cognitive difficulties or 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 received at the time of presentation and for ensuring that repeated doses of painkillers are given when needed. 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 until satisfactory pain relief has been achieved and then at least every 4 hours.

Numerator – the number of people in the denominator who have their pain relief reassessed every 30 minutes until satisfactory pain relief has been achieved and at then least every 4 hours.

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

Data source: Local data collection. Contained within NICE clinical guideline 143 clinical audit tool, audit standard 8.

b) 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.

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.

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.

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

People with an acute painful sickle cell episode have their pain relief assessed every 30 minutes until they are comfortable and then at least every 4 hours.

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]

Assessment of pain relief should be done at least every 4 hours when pain relief is satisfactory, until either discharge or the end of the acute painful sickle cell episode.

Equality and diversity considerations

Most people affected with sickle cell disease are of African or African-Caribbean origin which may result in possible language difficulties that need to be taken into account when deciding on the type of pain scoring tool to be used. The age of the person especially young children and any additional needs such as 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 presentation 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 presentation.

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 presentation and then at least every 4 hours.

Data source: Local data collection.

Process

Proportion of people with an acute painful sickle cell episode who are taking strong opioids who have monitoring for adverse events every hour for the first 6 hours after presentation and then at least every 4 hours.

Numerator – the number of people in the denominator who have monitoring for adverse events every hour for the first 6 hours after presentation and then at least every 4 hours.

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

Data source: Local data collection. Contained within NICE clinical guideline 143 clinical audit tool, audit standard 11.

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 have monitoring for adverse events every hour for the first 6 hours after presentation and then at least every 4 hours.

Healthcare professionals 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 presentation and then at least every 4 hours.

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 have monitoring for adverse events every hour for the first 6 hours after presentation and then at least every 4 hours.

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

People with an acute painful sickle cell episode who are taking strong opioids are checked for possible side effects every hour for the first 6 hours after going to hospital and then at least every 4 hours.

Source guidance

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

Definitions of terms used in this quality statement

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 assess:

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

Monitoring for adverse events should be done at least every 4 hours after the first 6 hours, until either discharge or end of the acute painful sickle cell episode.

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 and is often missed as a possible complication. Monitoring by clinical assessment, acting on any changes and assessing for acute chest syndrome may lead to a 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 coronary 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: 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 an 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

People with an acute painful sickle cell episode are cared for by healthcare professionals who have access to locally agreed protocols for treatment and management and specialist support for sickle cell care 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 a high quality of care for all people with an acute painful sickle cell episode, healthcare professionals need to access locally agreed protocols that set out how to treat and manage acute painful sickle cell episodes and 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

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

Data source: Local data collection.

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

Service providers ensure that locally agreed protocols to treat and manage 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 for 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 an 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.

Status of this quality standard

This is the draft quality standard released for consultation from 19 November to 17 December 2013. It is not NICE's final quality standard on sickle cell crisis. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 17 December 2013. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the NICE website from April 2014.

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 by commissioners, providers, healthcare professionals and social care and public health practitioners, patients, service users and carers alongside the documents listed in Development sources.

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 in sickle cell crisis 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 in sickle cell crisis 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 Standards 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)
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Mr Barry Attwood

Lay member

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

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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.

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