NICE National Institute for Health and Care Excellence

NICE support for commissioning for sickle cell acute painful episode

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1 Introduction

Implementing the recommendations from NICE guidance and other NICE-accredited guidance is the best way to support improvements in the quality of care or services, in line with the statements and measures that comprise the NICE quality standards. This report:

- Highlights the key actions that clinical commissioning groups (CCGs) and NHS England area teams and their partners should take to improve the quality of care for people experiencing sickle cell acute painful episode. Providers for the services outlined in this report will be district general hospitals and specialist centres. Priority actions are outlined in table 1.
- Identifies opportunities for collaboration and integration at a national, regional and local level.
- Identifies the benefits and potential costs and/or savings from implementing the changes needed to achieve quality improvement.
- Directs commissioners and service providers to other tools that can help them implement NICE and NICE-accredited guidance.

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. The statements draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement. For more information see NICE quality standards.

NHS England's CCG outcomes indicator set is part of a systematic approach to promoting quality improvement. The outcomes indicator set provides CCGs and health and wellbeing boards with comparative information on the quality of health services commissioned by CCGs and the associated health outcomes. The set includes indicators derived from NICE quality standards. By commissioning services in line with the quality standards, commissioners can contribute to improvements in health outcomes, particularly more effective pain management, improved integration of care between district general hospitals and specialist centres, and reduced stays in hospital and emergency admissions.

Commissioners can use the quality standards to improve services by including quality statements and measures in the service specification of the standard contract and establishing key performance indicators as part of tendering. They can also encourage improvements in provider performance by using quality standard measures in association with incentive payments such as the Commissioning for quality and innovation (CQUIN) 2013/14 guidance. NICE quality standards provide a baseline against which improvements can be measured and rewarded, enabling commissioners to address gaps in service provision, support best practice and encourage evidence-based care.

This report on the sickle cell acute painful episode quality standard should be read alongside:

- Sickle cell crisis. NICE quality standard 58 (2014).
- Sickle cell acute painful episode. NICE clinical guideline 143 (2012).

2 Overview of sickle cell acute painful episode

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. Two-thirds of people with sickle cell disease in England live in London, and most others live in the other big cities.

Acute painful sickle cell episodes (also known as painful crises) are caused by blockage of the small blood vessels. In people with sickle cell disease, 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 cells to block small blood vessels so that the blood does not flow normally. This damages the tissue, which causes pain.

The majority of 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.

This report 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.

2.1 Epidemiology of sickle cell acute painful episode

It is estimated that there are between 12,500 and 15,000 people with sickle cell disease in the UK. Most people affected by sickle cell disease are of African or African-Caribbean origin, although the disease also occurs in families from the Middle East, India and the eastern Mediterranean. The prevalence of the disease is increasing because of immigration into the UK and new births.

Around 350 babies are born in England each year with sickle cell disease. The NHS Sickle Cell and Thalassaemia Screening Programme means that more cases are being diagnosed. The distribution of sickle cell disease varies throughout England; two thirds of people with sickle cell disease live in Greater London and most others live in other inner city areas.

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. Repeated episodes may result in organ damage.

In the financial year 2012/13, Hospital Episode Statistics from the Health and Social Care Information Centre revealed approximately 13,300 finished consultant episodes with sickle cell anaemia with crisis as the primary diagnosis.

3 Summary of commissioning and resource implications

The cost of meeting the quality standard for sickle cell acute painful episode depends on current local practice and the progress organisations have made in implementing NICE and NICE-accredited guidance. Implementing the quality statements in the quality standard should contribute to improvements outlined in the NHS Outcomes Framework 2014/15, domain 4.3: Improving people's experiences of accident and emergency services. The key commissioning implications that CCGs and NHS England specialised services need to consider are:

- Better awareness that most people with sickle cell disease live in London and other big cities, and of how to treat sickle cell disease and its related effects by healthcare professionals working in district general hospitals.
- Enhanced liaison between district general hospitals and specialist centres, leading to better integration of services.
- Improved, standardised pathways and protocols once a patient presents at an accident and emergency department, through enhanced contract monitoring and clinical auditing.
- Better (and culturally appropriate) information given to people with an acute painful sickle cell episode who are discharged from hospital.

Sickle cell and thalassaemia services fall under the remit of the direct specialised services function of NHS England, specifically Cancer and Blood Programme of Care B08 – Haemoglobinopathies. CCGs are responsible for commissioning secondary, emergency and urgent care. Where possible, NHS England and CCGs should work in an integrated, collaborative way to achieve the best outcomes throughout the care pathway.

Table 1 summarises the priority commissioning actions and potential resource implications for commissioners working towards achieving this quality standard. See section 4 for more detail on commissioning and resource implications.

Table 1 Priority commissioning actions and potential resource implications for sickle cell acute painful episode

Quality improvement area	Commissioning actions	Provider	Resource implications
Timely assessment and analgesia, regular assessment of pain relief, strong opioids and monitoring, and acute complications.	CCGs and NHS England should work collaboratively to ensure that all acute settings can offer timely and regular assessment, appropriate analgesia, monitoring for adverse events and assessment for acute complications. CCGs and NHS England should enhance contract monitoring and seek evidence of compliance by auditing current practice.	District general hospitals/specialist sickle cell centres should ensure that treatment, assessment and monitoring are in line with statements 1 to 4.	Increased costs (for providers) associated with additional staff time will vary locally. Reducing the length of hospital stay may lead to savings for CCGs due to an increase in lower tariff short-stay spells and a corresponding reduction in higher tariff long-stay spells. Efficiencies and savings for providers are also possible through reduced bed occupancy, reduced ward nursing time and reduced non-pay and support costs.
Protocols and specialist support	CCGs should work with specialist centres to ensure that locally agreed protocols are in place, and that healthcare professionals receive support from designated specialist centres.	District general hospitals/specialist sickle cell centres should work collaboratively to establish specialist networks and put protocols in place.	Savings for commissioners and providers may be possible from reduced length of hospital stay as discussed above when specialist support is available.
Discharge information	CCGs should monitor providers to ensure that appropriate information is given before discharge to each person admitted for an acute painful sickle cell episode.	District general hospitals/specialist sickle cell centres should ensure that appropriate discharge information is given to patients on how best to manage their condition.	Potential savings for CCGs from a reduction in the number of emergency department and non-elective admissions for sickle cell acute painful episode. Efficiency savings for providers may also be possible if the provider is currently performing at a higher A&E marginal

			activity rate and implementing the quality statement supports a reduction in the penalty costs associated with excess activity.

4 Commissioning and resource implications

This section considers the commissioning implications and potential resource impact of implementing the recommendations to achieve the NICE quality standard for sickle cell acute painful episode.

4.1 Timely assessment and analgesia, regular assessment of pain relief, strong opioids and monitoring, and acute complications

Quality statement 1: Timely assessment and analgesia

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.

Quality statement 2: Regular assessment of pain relief

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.

Quality statement 3: Strong opioids and monitoring

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.

Quality statement 4: Acute complications

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.

A thorough assessment at presentation ensures that people with an acute painful sickle cell episode have an accurate diagnosis and are given adequate analgesia. Assessment can also in some cases inform future management. If acute pain is not recognised and adequate analgesia not given promptly, the pain may escalate, causing unnecessary deterioration in the person's condition. Expert opinion suggests that prompt provision of adequate pain relief is not standard practice nationally, and that initial treatment is highly variable.

Assessment of pain relief is important for determining the effectiveness of the analgesia given at the time of presentation and for ensuring that repeated doses of painkillers are given when needed until the episode has ended or the person is discharged. Monitoring for adverse events in people taking strong opioids for an acute painful sickle cell episode is important for patient safety. The risk of adverse events is higher in the first 6 hours after first administration or after a step up in pain relief.

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.

CCGs should seek assurance that staff within acute settings are able to offer people with an acute painful sickle cell episode pain assessment and clinical assessment (which should include the steps outlined in recommendations 1.1.3, 1.1.5 and 1.1.6 of NICE clinical guideline 143), together with monitoring for adverse events and assessment for acute chest syndrome, within the timeframes outlined in quality statements 1 to 3. CCGs and NHS England area teams may wish to enhance contract monitoring by using the clinical

audit tool for NICE clinical guideline 143 (see below) to audit current practice against quality statements 1 to 4.

CCGs should ensure that staff in district general hospitals are aware that most people with sickle cell disease are of African or African-Caribbean origin. This may mean using a pain scoring tool that accounts for any difficulties a person may have in reading, speaking or understanding English.

Implementing quality statements 1 to 4 may mean that staff spend more time with each person because of additional assessment and monitoring. Costs associated with this are expected to vary locally but are not expected to be significant in most areas.

Expert opinion is that implementing statements 1 (timely assessment and analgesia), 2 (regular assessment of pain relief) and 3 (strong opioids and monitoring) is likely to reduce the length of hospital stay for people admitted with an acute painful sickle cell episode. There is a lack of robust data on current practice in these areas and their effects on length of hospital stay, but potential savings from a reduced hospital stay are likely to vary locally.

A non-elective 'short stay' admission for 'sickle cell crisis' (less than 2 days) costs a CCG around £500, whereas a non-elective admission that lasts for 2 or more days costs around £2100 (2014/15 national tariff). The cost of an excess bed-day for a non-elective admission for an acute painful sickle cell episode is around £240. Reducing the length of hospital stay is therefore likely to lead to savings for CCGs for these patients. Reducing the length of hospital stay may also lead to efficiency savings for providers through reduced bed occupancy, reduced ward nursing time and reduced non-pay and support costs.

Further savings may also be possible from the earlier detection of acute chest syndrome as a result of implementing quality statement 4.

Commissioners and others may wish to refer to the clinical audit tool for NICE clinical guideline 143 on sickle cell acute painful episode.

For statement 2, 3 and 4 commissioners may wish to refer to recommendations 1.1.12, 1.1.16 and 1.1.19 of NICE clinical guideline 143.

4.2 Protocols and specialist support

Quality statement 5: Protocols and specialist support

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.

Because most people with sickle cell disease in the UK live in London or other big cities, the demand for treatment and management of acute painful sickle cell episode differs across the country. CCGs and NHS England (through specialised commissioning) should work collaboratively to ensure that healthcare professionals can access locally agreed protocols that set out how to treat and manage acute painful sickle cell episodes, and to ensure access to specialist support from designated centres when needed.

NHS England specialised commissioning and CCGs should, where possible, support the development of networks across geographical areas. A network can be delivered from specialist/designated centres (where protocols and governance arrangements should be agreed) to a number of district general hospitals. A network would have identified healthcare professionals to provide support and advice and, where capacity allows, a lead nurse to provide education for nurses and other healthcare professionals within accident and emergency and acute settings. These arrangements will vary between different networks based on the prevalence of sickle cell disease and the resources available.

Specialist support from designated centres should improve the care given to people with an acute painful sickle cell episode and may, in turn, lead to reduced length of hospital stay and associated savings for CCGs and district

general hospitals. There may be additional costs in setting up local protocols and securing specialist support from designated centres, but these are unlikely to be significant.

4.3 Discharge information

Quality statement 6: Discharge information

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

Some people with an acute painful sickle cell episode are discharged from hospital while still experiencing pain and taking strong opioids. It is therefore important that people are provided with information before discharge to help them to continue to manage their pain, access specialist advice, manage side effects of treatment and obtain additional medication.

Hospital Episode Statistics show that there were about 13,300 different recorded hospital admissions for sickle cell anaemia with crisis as the primary diagnosis during 2012/13, with about 3500 individuals being admitted. This indicates that some people are being admitted more than once (3.75 on average) with acute painful sickle cell episode in the same year. Providing appropriate information before discharge may enable people with acute painful sickle cell episodes to better manage their own care, when they leave hospital. This could lead to a reduction in the number of hospital admissions and emergency department attendances. CCGs should ensure that providers of acute care give appropriate information to all people with an acute painful sickle cell episode before discharge. CCGs may wish to audit this.

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 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.

Implementing this quality statement could lead to savings for CCGs from a reduction in the number of emergency department and non-elective admissions for sickle cell acute painful episode. Assuming each individual person is admitted an average of 3.75 times, preventing 1 non-elective admission per person could save CCGs over £7 million nationally; preventing 1 accident and emergency attendance per person could save CCGs over £350,000 nationally.

This could also lead to efficiency savings for providers if the provider is currently performing at a higher A&E marginal activity rate and implementing the quality statement supports a reduction in the penalty costs associated with excess activity.

Commissioners and others may wish to refer to the educational resource for NICE clinical guideline 143 on sickle cell acute painful episode.

5 Other useful resources

5.1 Policy documents

- NHS England (2013) NHS standard contract for specialised services for haemoglobinopathy care (all ages).

5.2 Useful resources

- Royal College of Nursing (2011) Caring for people with sickle cell disease and thalassaemia syndromes.
- Public Health England (2011) NHS sickle cell and thalassaemia screening programme.
- West Midland Quality Review Service (2013) Services for adults with haemoglobin disorders – Peer review programme 2012–2013 overview report.

5.3 NICE implementation support

- Sickle cell acute painful episode. NICE costing report (2012).
- Sickle cell acute painful episode. NICE clinical audit tool (2012).

5.4 NICE pathways

- Sickle cell acute painful episode