To:	**Trust Board**
From:	Kate Wilkins – Divisional Head of Nursing Hilliary Killer – Children's CBU Nurse Lead and General Manager Liz James – Matron, Children's CBU
Date:	**28 March 2013**
CQC regulation:	All applicable

Title:	**Improving the patient experience for children with Sickle Cell Disease**

Author/Responsible Director: Carole Ribbins – Director of Nursing

Purpose of the Report:

A short DVD presentation will be provided to demonstrate patient engagement in improving care pathways for children with Sickle Cell Disease.

The Report is provided to the Board for:

Decision		Discussion	X
Assurance		Endorsement	X

Summary / Key Points:
NICE recognises that when children present to hospital in painful sickle cell crisis, there are often issues in providing appropriate, timely analgesia. This paper demonstrates current work being implemented to improve the experience of children with Sickle Cell disease. The paper highlights effective joint working between health professionals, children and young people and their families.

Recommendations:
The Trust Board are asked to note and support the paper

Previously considered at another corporate UHL Committee?
No

Strategic Risk Register:	**Performance KPIs year to date:**

Resource Implications (eg Financial, HR):
Release of staff to attend training provided in the clinical area.
Printing costs of new documentation

Assurance Implications:

Patient and Public Involvement (PPI) Implications:
Engagement with children, young people and their families is a fundamental aspect of our business

Stakeholder Engagement Implications:

Equality Impact: **Standardised care for all children presenting with acute painful sickle cell crisis**
Information exempt from Disclosure:
Requirement for further review? **Re-audit of service to take place in 6 months**

UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

REPORT TO: **Trust Board**

DATE: **28 March 2013**

REPORT BY: **Kate Wilkins, Divisional Head of Nursing**
Hilliary Killer, Children's CBU Nursing lead and General Manager
Liz James, Matron

SUBJECT: **Improving the patient experience for children with Sickle Cell Disease**

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1. Background

Sickle Cell Disease is a congenital blood disorder. Changes in the shape of red blood cells cause blood vessels to block, resulting in pain or crisis (which can occur in any part of the body). Sickle Cell crisis can be life threatening making appropriate and timely treatment essential. More than 40 Children and young people in Leicester, Leicestershire and Rutland are under our care for treatment of Sickle Cell disease. These numbers are likely to increase due to the changing demographic of the local population.

NICE (2012) recognises that the majority of painful sickle cell episodes are managed by families at home. However where hospital admission is required, there are often issues in providing appropriate, timely analgesia for patients. An audit based on the criteria presented by NICE has demonstrated inconsistency in the standards of care received by our patients, and reflects NICE concerns that pain relief is not always timely and effective. This paper highlights the experience of a young person with Sickle Cell Disease (supported by an interview with her presented on DVD) and our work with the Children's Admissions Unit team to improve the care pathway for all children presenting with Sickle Cell crisis.

Sharon is a 16 year old girl who has Sickle Cell disease. Her story is shared on the DVD and helps to explain what Sickle Cell disease is and how it affects her every day life. When Sharon attends hospital in painful crisis, she finds it difficult to communicate and sometimes experiences delays in receiving appropriate medication to relieve her pain. In the DVD (http://vimeo.com/61011402), Sharon expresses her frustration that not all staff are aware of her condition and the care

she needs. The work currently being undertaken in conjunction with Sharon and other families to improve care when they come into hospital is outlined below.

Individualised care is essential for all children however, an accurate assessment is challenging when the child presents with severe pain. The aim of our current work is to involve families in decision making during outpatient consultations so a plan of care is in place for each child to be used during acute episodes. This allows appropriate, timely analgesia to be given followed by a full assessment and ongoing plan of care.

2. Current activity

In order to address the complaints and inconsistencies in care and to increase levels of satisfaction with the service, all clinical guidelines are being reviewed and made available to staff on insite. A teaching package specifically for clinical staff on the Children's Assessment Unit (CAU) is being designed regarding Sickle Cell disease and acute pain relief for patients in painful crisis.

Summary sheets for CAU staff which provide clear management plans for each child are being introduced in conjunction with families. A small patient held alert card is also being developed to prevent delays in treatment.

A review is being undertaken of analgesia available for patients on CAU to include the implementation of an alternative route of administration of morphine given intranasally. This can be given immediately to alleviate pain which can be so severe it is disabling and can impact on effective communication during admission.

Robust joint multidisciplinary team working is established including: community, ambulance, children's emergency department, specialist nurses and psychology teams. This improves the patient experience as communication is good and the standard of care across the MDT is consistent.

Our knowledge of the issues for patients has been assisted through feedback from children and their families. We are adapting our own behaviour and practices to meet those needs through the above actions.

2.1 Progress to date

Documentation

The review of current guidelines for the management of sickle cell disease has started and will be completed over the next 6 months. The teaching package is completed and training of CAU staff will commence in April 2013.

Summary sheets are ready to use (appendix 1) which provide clear management plans for each child. We are working with IMT to produce these summaries on ICE to aide information sharing with community colleagues.

The Hand Held Patient alert cards for urgent treatment are designed and will be ready for implementation in April 2013.

Pain Relief

The team are currently reviewing alternative analgesia using intranasal Diamorphine to enable staff to administer effective pain relief more quickly. This practice will be implemented by the end of April 2013. CAU staff are also being trained in the use of pain management techniques which can be used in conjunction with morphine such as Entonox.

Team Working

Joint multidisciplinary team working is robust through fortnightly local MDT meetings. Full psychosocial meetings including adult colleagues take place monthly. Regional meetings for staff involved in the care of children with Sickle Cell disease occur four times each year. Strong links are also maintained with the community MDT.

The CBU requires very little investment to implement the changes needed to improve the standard of care provided for children with Sickle Cell disease.

3. Measurements of Improvement

The success of the project will be measured by re-auditing in 6 months time using NICE criteria. Success will also be measured through improvement in the national patient survey results; the monthly patient experience survey results; and a reduction in complaints relating to pain management.

4. Recommendations

Trust Board members are asked to:

- Support and note the content of this report.
- We would like to submit a brief summary in 6 months time to demonstrate the impact of our ongoing engagement with this group of patients

The full NICE report is available at www.nice.org.uk Sickle Cell Acute Painful Episode 27 June 2012, CG143

Appendix 1

Summary sheet-

General protocols/guidelines for Sickle Cell Disease are available on the Document Management System reference 0706044100

Patient ID	**Diagnosis:** **SICKLE CELL DISEASE** Haemoglobin S Baseline Hb	**Medication:** Penicillin Folic Acid Exjade Vitamin D Hydroxycarbomide

Treatment for painful crisis:

- If pain relief has been unsuccessful at home, follow the guideline/algorithm as overleaf. As agreed by ED Consultants, CAU Consultants, and Specialist Pain Nurse
- **Ensure Intranasal Diamorphine/Oral morphine is given within 15 minutes of presentation**

If presenting with fever: Document Management System reference 56922

- **Children with Sickle Cell Disease are particularly susceptible to severe overwhelming blood borne infections -**always look for a focus of infection and if febrile organise cultures
- If two temperatures of 38.0℃ and one at 38.5℃, patient should receive IV antibiotics

Other potential crisis in Sickle Cell Disease

- Aplastic crises
- Sequestration crisis
- Acute chest syndrome
- Girdle syndrome
- Priaprism
- Acute Neurological Complications- **Any new neurological signs in children with sickle cell disease should be evaluated as potentially being a stroke**

Criteria for admission

- Not drinking well or having diarrhoea/vomiting
- Pyrexia
- Neurological symptoms
- Oral analgesia not sufficient
- Parents/staff feel management at home is not appropriate

Transfusion

- Blood group
- Previous blood transfusion yes no
- Consent for transfusion in medical records yes no
- **If blood transfusion is required ensure phenotypically matched blood is ordered**

Requiring Surgery: Document Management System reference 4586237899

- Consult haematologist, and avoid hypoxia, hypotension, hypothermia or dehydration

In working hours contact

- Dr Kotecha, Consultant Oncology/Haematology on X 5875/5309 or via switchboard
- Libby Tadd, Specialist Nurse- 0795 8010060
- Sarah Roberts, Specialist Pain Nurse- bleep 4101 if admitted in painful crisis

Out of hours contact

- on call Haematology/Oncology Consultant

Date……. This summary will be reviewed in 6 months and revised in the event of changes

Leicester Children's Hospital, Leicester Royal Infirmary

Paediatric Acute Sickle Pain Management

EXCLUSIONS:

- Severe acute chest syndrome (Use Fentanyl PCA)
- Girdle syndrome
- Vomiting