MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

East Midlands Sickle Cell Haemoglobinopathy Coordinating Centre

University Hospitals of Leicester NHS Trust

Visit date: 10th June 2024

Report date: 27th November 2024

Contents

Introduction

This report presents the findings of the review of the University Hospitals of Leicester NHS Trust that took place on 10th June 2024. The purpose of the visit was to review compliance with the Health Services for People with Haemoglobin Disorders Quality Standards Version 5.1, November 2021, which were developed by the UK Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit was organised by the Nursing and Urgent Care Team (NUCT) at the Midlands and Lancashire Commissioning Support Unit (MLCSU). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

- Haemoglobinopathy Coordinating Centre
- Specialist Haemoglobinopathy Team
- Local Haemoglobinopathy Team (or Linked Provider)

A comprehensive peer review of Local Haemoglobinopathy Teams (LHT) against the Local Haemoglobinopathy Team Quality Standards were not part of the 2024-2026 programme, however Haemoglobinopathy Coordinating Centres were given the option to request a review visit for any of their Local Haemoglobinopathy Teams in their review visit programme.

The aim of the standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Any immediate risks identified will include the Trust and UKFHD/NHS ML response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in Leicester health economy. Appendix 2 contains the details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- University Hospitals of Leicester NHS Trust
- NHS England-Midlands
- NHS Leicestershire and Rutland Integrated Care Board

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioners in relation to this report are NHS England, Midlands and NHS Leicester Leicestershire and Rutland Integrated Care Board.

About the UKFHD and NHS ML

The UK Forum on Haemoglobin Disorders (UKFHD) is a multi-disciplinary group of healthcare professionals interested in all aspects of sickle cell disorder, thalassaemia, and related conditions. The Forum is now a recognised and respected organisation involved in formulating national policy for screening and management of these conditions. The UKFHD aims to ensure equal access to optimal care for all individuals living with an inherited haemoglobin disorder or rare inherited anaemia. The mission of the UKFHD is to, advocate and influence policy, promote and review best practice, share ideas, and advise on research, educate health professionals, and support education of patients, whilst influencing and advocating on equitable prevention programmes for sickle cell and thalassaemia disorders.

NHS Midlands and Lancashire (NHS ML) Nursing and Urgent Care Team (NUCT) is a trusted partner for specialist, independent, clinical, and analytical guidance on a regional, national, and international scale. Our team has significant experience in developing, facilitating, and delivering peer review programmes.

More detail about the work of the UKFHD and NHSML are available at https://haemoglobin.org.uk/ and https://www.midlandsandlancashirecsu.nhs.uk/our-expertise/nursing-and-urgent-care/

Acknowledgements

The UKFHD and NHS ML would like to thank the staff and service users and carers of the Leicester Health Economy for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks, are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

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Review Visit Findings

East Midlands Sickle Cell Haemoglobinopathy Coordinating Centre

Introduction

This review looked at the co-ordination of health services provided for children, young people and adults with sickle cell disorders across the East Midlands. The HCC had close links with the Midlands Thalassaemia & Rare Inherited Anaemia HCC based in and led by Birmingham Women's and Children's NHS Foundation Trust and Sandwell and West Birmingham Hospitals NHS Trust.

University Hospitals of Leicester NHS Trust (UHL) was responsible for the East Midlands Sickle Cell Haemoglobinopathy Coordinating Centre (HCC) network. The East Midlands Sickle Cell Haemoglobinopathy Coordinating Centre (known as EMSTN) had been established in 2009 as an informal network prior to being designated by NHS England as a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell disorder in 2020.

The role of the HCC was to provide a high-quality service for people with sickle cell disorders, in line with the service specification laid out by the NHS England. The HCC was responsible for co-ordinating, supporting and promoting a system-wide networked approach to the delivery of haemoglobinopathy services and reducing unwarranted variation by reducing inequalities and to build on and spread best practice throughout the network, as well as improving timely access and offering a caring, adaptable and patient centred approach to management and long-term care of patients.

The East Midlands Sickle Cell HCC provided support and oversight for specialist (SHT) and local (LHT) haemoglobinopathy teams across Derbyshire, Leicestershire, Lincolnshire, Northamptonshire and Nottinghamshire, which included the two SHTs of the University Hospitals of Leicester (UHL) and Nottingham University Hospitals NHS Trust (NUH) and six other LHTs based at Northampton General Hospital NHS Trust, Kettering General Hospital NHS Foundation Trust, North West Anglia NHS Foundation Trust, Sherwood Forest Hospital NHS Trust, United Lincolnshire Hospital NHS Trust, University Hospitals of Derby & Burton NHS Foundation Trust.

As with other areas across England, the HCC was seeing an increase in patient numbers and the number of patients with complex needs across the region.

General comments and achievements

During the visit, reviewers met with members of the HCC and commissioners. From discussions during the visits the HCC appeared to be held in high regard by both the patients and staff and it was clear that they were working hard to deliver their agenda.

At the time of the visit the HCC had been successful in the appointment of the following key staff:

- Adult Clinical Lead (0.5PA)
- HCC Network Manager (1 WTE)
- HCC Lead Nurse (1WTE)
- HCC Transcranial Doppler Lead (0.2 WTE)
- HCC Data Manager (1WTE)

The following key staff post were vacant:

- Paediatric Clinical Lead

The HCC held monthly Network Board Meetings open to the whole HCC; SHTs, LHTs, and commissioners, as part of these meeting the annual programme of work and audit programmes were agreed. Meetings were held remotely to promote engagement across the region. The specialist services quality dashboard data for HCCs and SHTs was

monitored as well as audit and morbidity and mortality levels. Action plans, policy and HCC audits were also monitored as part of the business meeting agenda.

The HCC had met their regional NHSE specialist commissioner with commissioners from the ICB to discuss their annual work plans and report on progress and any concerns. Commissioners from NHSE and the ICB who met with the reviewing team reported having good relationships with the HCC. Reviewers did not meet with commissioners from NHS East Of England and the ICB covering the Peterborough patients within the scope of this review.

The East Midlands SCD HCC had also completed an audit of transcranial doppler ultrasound competences during the previous 12 months and reported achieving an overall TCD performance of 91% with an approximate 5% DNA rate. The report did not identify any outstanding significant issues or concerns.

The East Midlands SCD HCC held monthly regional clinical multidisciplinary meetings (MDTs) and the MDT had discussed a total of 96 cases between May 2022 and March 2023 (eight meetings). The meetings were supported by members of the Midlands Thalassaemia and Rare Inherited Anaemia HCC who joined the MDT on alternate months/or when specific advice was required. NHS Blood and Transfusion (NHSBT) would also offer advice around transfusions'.

The HCC had established mechanisms in place for providing education. A quarterly nursing education forum was held and the HCC had worked with colleagues in the West Midlands in holding a pan Midlands annual education and learning event.

Patient engagement had been challenging for the HCC, with difficulties in securing regular patient representatives at HCC meetings. To address this, the HCC was holding quarterly Patient Voice meetings

The trust as host for the HCC was also a designated provider of Specialist Haemoglobinopathy Teams (SHT) for adults, children and young people for their own catchment areas.

Good Practice

1. The welfare support service was excellent. The service had been established in collaboration with Citizens Advise Leicester and accessed through an online portal. This was a bespoke service for anyone within the EMSTN living with sickle cell or thalassaemia and provided advice on benefits, employment, housing, immigration, community care and other aspects such as family and discrimination. The service had evaluated well and was highly regarded by patients and staff throughout the network who met with the reviewing team.
2. The work programme included a wide breadth of areas and reviewers were impressed with the work the HCC were undertaking with smaller teams. The HCC had made good progress with achieving work plans despite challenges with workforce capacity.
3. The HCC had good engagement at MDTs with a high number of patients being discussed at the regional MDTS. In response to the numbers of patients being submitted for MDT discussion the HCC had needed to increase the frequency of MDT meetings. NHSBT attended regularly and colleagues from the Midlands Thalassaemia and RIA HCC attended on alternate months. There was a clear process for discussing serious adverse events and escalation of complex patients for discussion at the National Haemoglobinopathy Panel.
4. The HCC data manager had good relations with the LHTs across the region. The data manager had an honorary contract with each LHT site, a novel initiative which had enabled an increase in the level of data support that could be provided. The data manager worked with the LHTs to improve data entry and submission to the NHR, which had seen NHR registration across the network reaching 95%.

Immediate Risks: None were identified during the visit.

Serious Concern

1. HCC Governance

The HCC did not have a clear governance process for the management risks highlighted at HCC level including a process for communicating risk to its constituent SHTs, LHTs and commissioners at regional and at Integrated Care Board level. There was no formal governance structure in place for LHTs to link to the SHTs resulting in the HCC not having robust oversight of issues.

The reviewers were concerned that although recent incidents had been added to the HCC risk log as awaiting coroners' reports, it was not clear of the harm review process which was in place to identify preliminary findings and shared learning from the events.

Concerns

1. Challenges of engagement with LHTs.

a) Reviewers were concerned at the variability of LHT engagement across the HCC which has the potential to lead to a lack of standardisation and assurance of care and ultimately health outcomes for patients. This will be particularly important to address as the LHTs provided services for an ever-increasing population of adults, children, and young people with haemoglobin disorders with a limited workforce. The lack of leadership time of the clinical leads meant that they were unable to develop engagement with their LHTs and proactively provide support for these teams.

b) SHT consultants across the HCC were also spending time visiting the LHTs to undertake patient annual reviews, whose combined numbers of patients was similar to the SHT and increasing but without sufficient resource.

2. Inconsistent care and pathways across the region

a) In the LHTs, there was a lack of robust pathways and support for young people transitioning from paediatric to adult services. The reviewers considered that increasing HCC focus on improving this important area of care across the region was necessary.

b) There was concern around the Peterborough pathway as the reviewers were told that only adult patients were referred from this service. The review team were concerned that if patients from Peterborough wished to transition to the service there were no clear mechanisms for this pathway.

3. Finance and Service Level Agreements

a) At the time of the visit the HCC had allocated the recent uplift funding to the LHTs. For example, reviewers were told that £90,000 HCC funding had been allocated to providing 0.6WTE of a CNS post and administrative support for the LHT at Northampton. With the rapid increase of patient numbers in all the SHTs and LHTs it is likely that the existing HCC funding would be insufficient, and reviewers were as concerned as the HCC that the HCC would face the risk that local teams would believe they do not hold responsibility for funding these positions.

b) The HCC/SHT did not have any service level agreements with local teams and their respective ICBs, despite the HCC undertaking significant work to address. Reviewers considered that this would be crucial to defining the responsibility of local teams, and commissioners in providing local services. It would also ensure UHL is not committed to providing ongoing and increasing funding to LHTs for care that should be commissioned locally, and HCC funding can be more equitably used to improve the care of patients across the HCC. Unfortunately, an ICB representative was unable to attend the peer review to enable further discussion or understand any new developments, either implemented or planned, to support equity of care provision across the network .

University Hospitals of Leicester NHS Trust

Trust-wide General Comments

University Hospitals Leicester NHS Trust (UHL) was commissioned as a Specialist Haemoglobinopathy Team (SHT) in caring for patients with Sickle Cell Disorders, Thalassaemia and Rare Inherited Anaemias. As an SHT the Trust linked with the Local Hospitals of Northampton General, Kettering General and Peterborough to support the care of patients across the EMSTN. The addition of Peterborough adult patients was a new formal relationship that was in the process of being developed, although historically most patients were under the care of the Leicester SHT.

The majority of the SHTs and the LHTs across the East Midlands covered high prevalence areas for patients requiring haemoglobinopathy care with demand growing, impacted by migration into the area. The majority of patients were living with a sickle cell disorder, although the number of patients living with thalassaemia was higher south of the region with increased numbers of patients with a rare inherited anaemia also being identified across the whole region.

UHL was a large acute trust, with care spread across three hospital sites in addition to community services. The main hospital sites were Leicester Royal Infirmary (LRI), where both adult and children's Emergency Department (ED) services were based as well as all haemoglobinopathy services. Glenfield Hospital (GGH) was a nationally and internationally renowned centre for specialist Cardio-Respiratory care and with reconfiguration, now hosted renal services. Leicester General Hospital (LGH) was primarily an elective care centre, with some on site maternity services as well as outpatient facilities. Blood bank facilities were present on all three sites.

Haemoglobinopathy services were split across the Cancer, Haematology, Urology, Gastroenterology and General Surgery (CHUGGS) and Women & Children's directorates. Overall governance for the adult SHT and the HCC sat with CHUGGS.

Recent NHSE funding had been received to expand the service and with this, the HCC had been able to employ a dedicated Band 7 Haemoglobinopathy CNS to lead on transition pathways, increase psychology funding and expand both adult and paediatric CNS time. The funding had also enabled a Citizen's Advice welfare role to become permanent following a trial period. This service had been well received by patients and had enabled staff to focus on clinical care. It had also enabled more outreach work into the local community to raise awareness of the services delivered.

The community team was in-house, hosted by UHL, who also delivered the screening programme, routine counselling to all carriers identified via the laboratory with close links to the fertility centre, foetal medicine and genetics team.

Outreach clinics in both the adult and paediatric services were held on the majority of the LHT sites based on patient numbers.

Trust-wide Good Practice

1. A welfare support service had been established in collaboration with Citizens Advise Leicester. This was a bespoke service for anyone within the EMSTN living with sickle cell or thalassaemia that provided advice on benefits, employment, housing, immigration, community care and other aspects such as family and discrimination.
2. A one-stop shop clinic model for the children and young people was available offering an all-day MDT clinic which involved a Consultant lead, haemoglobinopathy CNS, transition nurse, support worker, psychology (when post filled), phlebotomy and TCD services.

Trust-wide Concern

Trust-wide Serious Concern – children and young people

1.Time to analgesia

The most recent audit of compliance with the NICE guidance on the timeliness of analgesia in Paediatrics demonstrated that only 24% of children and young people received pain relief within 30 minutes compared to 64% the previous year. Reviewers were seriously concerned about this deterioration and that there was no clear action plan to address this. The Trust should prioritise the education of clinicians working within unscheduled care and identify clear actions to support timely access to analgesia for this cohort of patients.

Trust-wide Concern – children and young people

1 Consultant Staffing

The Paediatric Consultant Lead worked extremely hard, and the service was sustained on a 'above and beyond' commitment. The lead consultant did not have any PAs allocated to leadership of the SHT and the medical workforce establishment fell well below that required for this service and therefore impacted on the ability to partake in essential activity such as audits, research and updating protocols, alongside delivery of direct patient care. Medical staff recruitment has been previously unsuccessful, and a more attractive job plan was currently with the college for review. There has been success in recruiting to one training post through the deanery but unfortunately a second post was not approved.

2 CNS Staffing

The service had insufficient CNS staffing with only 1.2 WTE employed, although the reviewers acknowledged the recent investment into this. The service had additionally employed a screening nurse, a transition nurse and a support worker who delivered a valuable service.

Trust-wide Concern – adults

1. **Time to analgesia**
   Compliance with the NICE guidance on the timeliness of analgesia audit for those attending the ED department was inconsistent and ranged from 30% to 67% in recent audits. Reviewers were concerned that although patients could access the haematology triage system with the potential to divert ED, in practice 86% of all admissions for patients with a haemoglobin disorder was via the ED.

2. **Day Unit Provision**

a) The view of the patients, who met with the reviewing team, was that the day unit environment was poor with old furniture and chairs. Patients who attended for transfusions often had to sit on uncomfortable, upright chairs with wooden armrests for prolonged periods of time.

b) The move to the new planned care unit at LGH was also of concern as there were no plans for cover from a haematologist on site to provide advice and review for patients who would attend regularly with a haemoglobin disorder, and there was not provision for planned transfusions at the weekend.

3. **Consultant staffing**
   The lead consultant had only 0.25 PAs allocated for leadership of the SHT and 0.5 PAs for leadership of the HCC with no deputy for absences. Consultant medical time allocated to the service was 3.6PAs to care for 205 pts (149 SCD, 56 Thalassaemia &RIA) including clinical work, annual reviews, and provision of outreach clinics to LHTs which fell well below that required for this service and therefore impacted on the ability to partake in essential activity such as audits, research and updating protocols, alongside delivery of direct patient care.

Trust-wide Further Considerations

1. Consideration should be given to how the SHT could further their support to the linked LHTs both for medical advice, CNS time and if there is an opportunity to introduce support workers beyond UHL. Expanding the Transition and Screening Service to focus on the LTH catchment areas would also be beneficial for the wider

SHT population. The review team heard that SLAs were in development however on questioning management within the Paediatric service they were unaware of these. Formalised SLAs would support the SHT/LHT relationships.

2. Formal arrangements to access support for patients with acute and chronic pain was not in place. Development of arrangements with the pain team would improve the care for this group of patients.

Views of Service Users and Carers

Support Group available for patients and carers	Y/N
Sickle Cell Disorder – Children and Young People	Y
Thalassaemia – Children and Young People	Y
Sickle Cell Disorder – Adults	Y
Thalassaemia – Adults	Y

During the visit the visiting team met with four adults living with thalassaemia. From the children's perspective the review team met with one patient with sickle cell disorder and one family with a child living with thalassaemia.

The views of the users were wide-ranging and are documented in the children's and adult specialist haemoglobinopathy team sections. The review team would like to thank them for their openness and willingness to share their experiences

Specialist Haemoglobinopathy Team (Children and Young People Services)

General Comments and Achievements

The team were highly dedicated and worked well together. The nursing team provided a holistic approach to care for their patients which was highly valued by the patients, families, and medical staff. The service was however highly dependent on the good will of the Haemoglobinopathy team to deliver a safe and quality service which was unsustainable especially with the growing demand on the service.

The Lead Consultant had zero PAs dedicated for the SHT and the lead paediatric consultant post for the HCC was vacant. The deputy lead consultant post was also vacant. The Psychology post was vacant and there was no administration support for the team.

Recent NHSE funding had enabled the service to expand and employ a dedicated Band 7 Haemoglobinopathy CNS to lead on transition pathways, as well as increase the psychology funding and paediatric CNS time. A unique support worker role had also been established which the team report allowed greater support to patients by a familiar face and release of qualified nursing time. There was also a dedicated in-house screening service.

The team attended lots of community events to raise awareness of the condition including the display of the Lord Major's Artwork competition along the main hospital corridor. The art pieces on display were from the pupils of the local school and provided information on Sickle Cell Disorder.

The team were particularly proud of the below initiatives:

- Providing a red cell apheresis program
- Dedicated phlebotomy service out of school hours
- Safe efficient robust system to oversee hydroxycarbamide monitoring and dosing
- Introduced regular iron chelation MDT for transfusion dependent patients
- Introducing electronic care pathways to be accessible when patients present to ED

Transition

A new Transition post was introduced in 2023 employing a Haemoglobinopathy CNS to lead on transition pathways across both children and adults SHTs. The service had commenced work to cover patients in the Leicester, Northampton, and Kettering Hospitals however at the time of the visit the focus had been on the Leicester patients transitioning to adult care.

The 'Ready, Steady, Go' transition programme was used with the child and family first meeting the Transition nurse at 11 years old in the annual review clinic. The nurse formally worked with the child and family from the age of 13 with one annual and one remote appointment a year. More complex patients had their last paediatric clinic as a joint clinic including the transition nurse and adult team.

The review team were concerned If patients from Peterborough wished to transition to the service there were no clear mechanisms for this pathway.

SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE[1]			
University Hospitals of Leicester NHS Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)		
	East Midlands Sickle Cell HCC *(hosted by University Hospitals Leicester NHS Trust) Trust)* Midlands Thalassaemia and Rare Inherited Anaemias HCC		
	Linked Local Haemoglobinopathy Teams (LHT)	Patient Distribution	
		SCD	Thal.
	Northampton General Hospital NHS Trust	62	<=5
	Kettering General Hospital NHS Foundation Trust	18	<=5

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[2]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in the last yr.
Sickle Cell Disorder	CYP	77	77	77	5	33	38
Thalassaemia & RIA	CYP	18	18	18	9	0	0

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual WTE/PA (at time of visit)
Consultant Haematologist/Paediatrician dedicated to work with patients with haemoglobinopathies	95	The lead consultant did not have any PAs allocated leadership of the SHT. 0.9PA for UHL clinical work (Another 0.25PA additional to contract to oversee RCE service) 0.3PA for outreach clinics in KGH/NGH
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with haemoglobinopathies	95	1.2 WTE CNS plus Band 7: 1 WTE to lead on transition (shared between adults and paeds)
Clinical Psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies	95	vacant – 0.7 Band 8a funding available

Urgent and Emergency Care

All emergency care in paediatrics was provided on the LRI hospital site. Patients and carers were able to contact the haemoglobinopathy specialist nursing team during routine working hours and had 24/7 access to nurse led triage advice through ward 27, the dedicated ward and daycare during the daytime.

Patients could be admitted directly to ward 27 if there was capacity, otherwise they were diverted to the children's ED and were triaged directly through to 'majors' with a pre-arranged plan. Similarly, patients self-referring without contacting ward 27 were admitted directly through the children's ED.

[1] Note, data have been rounded to the nearest 5 and numbers of 5 or lower suppressed, to ensure that no patient can be identified through publication of small numbers.
[2] *Those who have had hospital contact in the last 12 months. **No of patients who have had an annual review in the last year .

When presenting to ED patients had an electronic 'alert' on their hospital records to flag their haematology status and they had pocket cards with information about trust guidelines they could present to the ED staff. On booking into ED an electronic alert was sent to the haemoglobinopathy team to inform them of the attendance and care plans were available which were renewed during the patients' annual review clinic appointment.

The ED was a modern department with 22 cubicles (including three HDU), two resus bays and two cubicles for minor injuries. A short stay 12 cubicle area was adjacent which the team reported was not used for the haemoglobinopathy patients who went direct to the ward. The cubicle walls had a QR code displayed which linked clinical staff to the relevant online haemoglobinopathy guidelines.

There was a resident junior doctor on call for paediatrics supported by a Paediatric haematology/oncology consultant on call. Blood transfusions were commenced in ED if appropriate.

Inpatient and Day Care

Ward 27 was divided into two sections of paediatrics and a teenage unit funded by the Teenage Cancer Trust. The Paediatric side had 12 beds, including six side rooms for all haematology/oncology patients (not just haemoglobinopathy). The Specialty team reported that there were more beds physically available however availability was limited by ward staffing levels which carried over a 20% vacancy rate. A day care area was attached to the ward which had two chairs used mainly for very short stay attendance by the oncology patients. The day unit was open Monday – Saturday 0800-1800.

Patients admitted to Ward 27 were primarily cared for by the haematology/oncology team. Patients with a sickle cell disorder who were undergoing elective procedures were usually admitted and looked after on ward 27, including patients from Kettering and Northampton. Planned transfusions, both top-up and exchange were delivered through ward 27 with Saturday transfusion available for transfusion dependent thalassaemia and rare inherited anaemia patients.

The ward was well equipped with a parent's kitchen, play facilities (including games consoles and table football), and a dedicated social room that ward 27 patients ages 13-24 were able to access. In the teenage space there was a 'Junk Board' where the young people could write their feelings and thoughts down. A holistic therapist attended the ward each Wednesday with services offered to both the patients and their carers.

There were five other general paediatric wards where children could also be admitted for inpatient care and the review team visited ward 11 which was the ward used most frequently by the haemoglobinopathy patients if ward 27 was full. Use of general paediatric ward beds was described as not uncommon as often ward 27 was prioritised for the oncology patients and specifically those requiring bone marrow transplants. It was described that the demand for all inpatient paediatric capacity had outgrown the demand over recent years.

Ward 11 was a busy environment. The ward manager the reviewers spoke to on the day described that they do receive sickle cell patients on the ward however the ward staff received no specific haemoglobinopathy training either face to face or e-learning, they did have an annual teaching day but currently this was not on the agenda. The CNS supported the children when on the ward, and staff on the ward did have access to the current hemoglobinopathy disorder guidelines.

For children admitted on the other general paediatric wards, their care was primarily led by the general paediatric team with regular involvement and decision-making from the paediatric haemoglobinopathy team.

Out of hours care was provided by the general paediatric team with specialist support from the paediatric haematology/oncology consultant on call as well as adult haematology specialist registrar non-resident rota and the on-call adult haematology consultant.

High dependency and intensive care support for children when needed for children with haemoglobinopathy was provided on site.

Adult haematology higher specialist trainee doctors did their paediatric haematology training at UHL and gained experience of haemoglobinopathy in children and young people. They accessed the Trust online electronic

training package, policy and guidance meetings. Doctors in training rotated through ward 27 with opportunity to attend outpatient clinics.

Outpatients

An all-day MDT clinic was held on the first Thursday of each month which primarily focused on annual reviews and involved the Consultant lead, haemoglobinopathy CNS, transition nurse, support worker, psychology, phlebotomy and TCD services. These clinics were held in the main children's outpatient department on the first Thursday morning and afternoon of the month. Patients who required phlebotomy could be accompanied by a play worker who was available till 15.30 Monday to Friday.

The five nurse led clinics per month took place in the Children's Development Centre one floor below the Children's Outpatient Department. The Development Centre provided the benefit of a calmer space and the dedicated nurse led clinics with extended slots enabled the patients time to discuss non-medicalised aspects of their condition alongside receiving hydroxycarbamide monitoring. Bloods could be taken here to avoid the wait for phlebotomy in the busy clinic upstairs although a play worker was not available within the Development Centre.

A dedicated phlebotomy clinic after school hours had commenced In February 2024 each Thursday with the aim to reduce school absence, improve hydroxycarbamide compliance and offer a better patient experience.

Community-based Care

The team at UHL provided an integrated community service to the Leicester city and Leicestershire population. Educational visits were offered for all children and young people to visit nurseries, schools, and colleges to discuss needs of the patient in the learning environment with 40 visits completed this current 2023-2024 academic year.

The nurse led screening service moved into the Haemoglobinopathy team at UHL in 2017. The service provided carrier information and counselling throughout the lifespan from newborn screening to new carriers identified in later years alongside local delivery of the National Sickle Cell and Thalassaemia Antenatal and Newborn Screening Programmes. A recent audit had shown an 18% increase in screening referrals over previous year (2023-2024) and a 54% increase over the last 5 years (2019-2024).

Views of Service Users and Carers

Service user Feedback

The review team met with one young person with Sickle Cell Disorder who was on the ward during the visit and one family caring for a young child with thalassaemia within the dedicated service user meeting.

- The patients and families were aware of the information available. They described that they could contact the CNS if they had any questions who were responsive however the parent spoken to was unsure what symptoms to look out for and when to seek emergency advice.
- There was good support available when their child needed their blood tests.
- Within clinic it was described that they mostly see different Registrars, and they also see the nurse specialist every 6 months. Their GP did receive copies of the clinic letters.
- Appointments for other specialists could often be late providing the example that at the time of the review they were awaiting eye and dental appointments. Access to local dentists was problematic due to closed patient lists in the area.
- The parents had told nursery about their child's condition and had provided letters to the nursey they received from the hospital.

- The parents reflected that their child loves the hospital environment and was able to lead a normal life in living with the condition.
- It was stated that the sickle cell team were amazing and extremely supportive. When the child had to miss school for a long time they spoke to the school and made sure the child was supported and could sit their exams. “They know a lot about sickle cell and they feel well supported by the team”
- The nurses were nice and know about sickle cell disorders. They helped ensure the child was not in pain and comfortable
- The parent stated “ I trust the hospital team to look after my child.”

Good Practice

1. There was a dedicated phlebotomy clinic after school hours which had commenced in February 2024 each Thursday with the aim to reduce school absence, improve hydroxycarbamide compliance, and offer a better patient experience.
2. A welfare support service had been established in collaboration with Citizens Advice Leicester. This was a bespoke service for anyone within the EMSTN living with sickle cell or thalassaemia that provided advice on benefits, employment, housing, immigration, community care and aspects such as family and discrimination.
3. Transfusion was available at the weekends on the dedicated ward 27. The service also continued providing transfusions up the age of 24 years if appropriate for the individual.
4. The nurse led screening service provided carrier information and counselling throughout the lifespan from newborn screening to new carriers identified in later years alongside local delivery of the National Sickle Cell and Thalassaemia Antenatal and Newborn Screening Programmes.
5. The appointment of the dedicated CNS to lead on transition pathways. The Ready, Steady, Go transition programme was used with the child and family, with their first meeting with the Transition nurse at 11 years old when they attended their annual review.
6. A support workers role had been established which the team reported allowed greater support to patients by seeing a familiar face and release of qualified nursing time.
7. The SHT had presence at the local university fresher week to promote awareness of the service to young people with Sickle Cell or Thalassaemia moving into the area including a dedicated clinic for new students at the start of the academic year.
8. A one-stop shop clinic model was available offering an all-day MDT clinic involved the Consultant lead, haemoglobinopathy CNS, transition nurse, support worker, psychology (when post filled), phlebotomy and TCD services.
9. Supported by funding from the Teenage Cancer Trust ward 27 provided excellent inpatient and day care facilities for Children and Young People admitted with a haemoglobin disorder.
10. The data analyst had an honorary contract across the LHTs which they reported was a great support.

Immediate Risk

The review team identified no immediate risks during the Children and Young People Services visit.

Serious Concerns

1 Lack of endocrine monitoring and input

Endocrine monitoring is important in the management of all haemoglobinopathies but particularly so the Thalassaemia's and Rare Anaemias. Endocrine monitoring should be part of the annual review process and the review team were seriously concerned that this monitoring was not part of the annual review at ULH which misses a vital opportunity for endocrine input at an appropriate age to support development. The review team recommend that endocrine monitoring is implemented as part of the annual review process, in keeping with the guidance from the recently released Thalassaemia guidelines.

2 Time to analgesia

The recent audit demonstrated that only 24% and children and young people received pain relief within 30 minutes compared to 64% previous year. Reviewers were seriously concerned about this deterioration and that there was no clear action plan to address this. The Trust should prioritise the education of clinician working within unscheduled care and identify clear actions to support education leading to timely access to analgesia for this cohort of patients.

Concerns

1. Consultant Staffing

a) The Paediatric Consultant Lead worked extremely hard, and the service was sustained on a 'above and beyond' commitment. The lead consultant did not have any PAs allocated for leadership of the SHT and the medical workforce establishment fell well below that required for this service and therefore impacted on the ability to partake in essential activity such as audits, research and updating protocols, alongside delivery of direct patient care. Medical staff recruitment has been previously unsuccessful, and a more attractive job plan was currently with the college for review. There has been success to recruit one training post through the deanery but unfortunately a second post was not approved.

b) The review team heard from the LHTs who expressed concern that if the lead consultant was on leave the support would defer to an adult specialist within the SHT. Advice was often therefore sought using WhatsApp group outside of the SHT processes.

2. CNS Staffing

a) The service had insufficient CNS staffing with only 1.2 WTE employed, although the reviewers noted the recent investment into this. The service additionally employed a screening nurse, a transition nurse and a support worker who delivered a valuable service.

b) The LHTs reported feeling uninvested in both CNS and support worker roles considering their growing patient numbers. Reviewers were told that £90,000 HCC funding had been allocated to providing 0.6WTE of a CNS post and administrative support for the LHT at Northampton. With the rapid increase of patient numbers in all the SHTs and LHTs it is likely that the existing HCC funding would be insufficient to ensure equity and sharing of experience across the whole for the benefit of the patients living outside the Leicester catchment.

3. Psychology input

The previous clinical psychologist left the team in early 2024 resulting in a vacancy for this position with no confirmed plans at the time of the visit to fill this post. In the interim patients were referred to the general paediatric psychology team however actions should be put in place to urgently recruit to this essential role.

Further Considerations

1 Some local guidance was out of date. The governance processes should be strengthened to address this and support maintenance of up-to-date local guidance moving forward. Consideration should be given to

how the management team may support the clinical team to do this considering the demands of the clinical time for direct patient care.

2 Consideration should be given to how the SHT could increase their support to the LHTs both for medical advice, CNS time, and if there is an opportunity to introduce support workers beyond UHL. Expanding the Transition and Screening Service to focus on the LHT catchment areas would also be greatly received. The review team heard that SLAs were in development however on questioning management they were unaware of these. Formalised SLAs would support the SHT/LHT relationships.

3 School care plans should be in place for all red cell patients and not just those with a sickle cell disorder. The review team recommend that the school care plans should be expanded to cover patients with thalassaemia and rare inherited anaemias.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

The reviewers met a hard-working dedicated SHT team who were supported by the directorate lead and were clearly engaged with Trust leadership. The reviewers were particularly impressed by the collective ownership which the haematology team as a whole demonstrated for their patient population and the proactive working with local groups in the area.

The recent NHSE funding had enabled the SHT to expand and employ a dedicated Band 7 transition nurse to lead on the transition pathway, as well as being able to increase the psychology provision and adult CNS time. A support worker role had also been established which the team reported allowed greater support to patients across the patient pathway and had been proven to release time for all clinical staff to focus on other aspects of patient care. There was also a dedicated screening service hosted by the trust.

Training for doctors in training also included SIMs training on acute haemoglobin disorders, and an e-learning package for the care of patients with sickle cell disorders was available on the trust system (HELM) for staff across all directorates. There was limited training on the care of people living with thalassaemia and RIA.

Adult services were primarily delivered from the Osborne building, the dedicated Haematology and Oncology building for UHL. Inpatient and outpatient care was delivered from this site, although an annual review clinic was held at the outpatient unit at LGH twice per month. Weekly adult clinics were delivered on Thursday afternoon every week, in addition to weekly nurse led hydroxycarbamide clinics. There was a weekly obstetric haematology clinic delivered in maternity with a dedicated obstetric haematology specialist nurse who supported pregnant women with haemoglobin disorders.

The nursing team supported a range of activities including red cell exchange (planned and emergency), nurse led clinics, a non-urgent advice service, monitoring of iron chelation, education and specialist support.

Planned transfusion procedures, both top up and exchange, were performed in the Osborne Treatment Centre by apheresis trained staff. A Saturday transfusion service was available for transfusion dependent thalassaemia patients.

Psychology information was clear and concise with psychology input available both in clinics and outside of the main clinic times.

The SHT had been active in undertaking relevant research.

Outreach clinics were provided to the LHTs based in Northampton, Kettering and Peterborough.

When asked the team were particularly proud of the below initiatives:

- Team expansion due to local investment including funding for increased psychology provision

- Role of the support worker
- Relationship with inpatient teams including Emergency Department
- Prospective pain audit data collection

SPECIASLIST HAEMOGLOBINOAPTHY TEAM – ADULTS [3]							
University Hospitals Leicester NHS Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)						
	East Midlands Sickle Cell HCC *(hosted by University Hospitals Leicester NHS Trust) Trust)* Midlands Thalassaemia and Rare Inherited Anaemias HCC						
	Linked Local Haemoglobinopathy Teams (LHT)					Patient Distribution	
						SCD	Thal.
	Northampton General Hospital NHS Trust					89	5
	Kettering General Hospital NHS Foundation Trust					36	<=5
	North West Anglia NHS Foundation Trust					14	6
PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[4]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disorder	Adults	149	149	149	18	44/83pts	173
Thalassaemia & RIA	Adults	56	56	56	23	<=5	13

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant Haematologist dedicated to work with patients with haemoglobinopathies	205	0.25 for local lead role (SHT) and 0.5 for lead role (HCC). 3.6 PA across all aspects of care (including AR outreach clinics) + 0.25 CPD PA
Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies	205	Band 7: 0.8 WTE Band 6: 2.0 WTE Band 7: 1 WTE to lead on transition (shared between adults and paeds)
Nurse for adult patients dedicated to work with patients with haemoglobinopathies in the community	205	1.8 WTE
Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies	205	0.3 band 8a (currently), Funded to increase to 1.3 – recruitment ongoing

[3] Note, data have been rounded to the nearest 5 and numbers of 5 or lower suppressed, to ensure that no patient can be identified through publication of small numbers.

[4] *Those who have had hospital contact in the last 12 months. **No of patients who have had an annual review in the last year .

Emergency Care

All emergency care was provided on the LRI hospital site. Patients had open access to a 24/7 nurse led triage phone advice service delivered across haematology and oncology. During normal working hours, patients were also able to seek advice from the specialist CNS team. Patients could be admitted directly to Osborne Assessment Unit (OAU) if there was capacity; otherwise, they were diverted to ED for care and clinical staff informed of admission. Patients self-presenting without involvement of the triage service were admitted via ED. Admissions were then alerted to ED staff as well as the haemoglobinopathy specialist team. Electronic individualised care plans were available for all patients on the trust systems and were updated as part of the patients annual review.

Inpatient Care

All adult patients requiring an inpatient admission were admitted under the haematology team. Inpatient care was overseen by a Consultant Haematologist of the week system. Specialist input was provided by the lead clinician for the SHT, alongside the 'red team' as well as inpatient CNS support during normal working hours.

Out of hours care was provided by dedicated haematology/oncology doctor in training, as well as a specialist registrar on a non-resident rota and the on-call consultant haematologist.

The main bed base for haematology was ward 41, in the Osborne building. Ward 41 consisted of 21 beds, including five side rooms for all haematology patients (not just haemoglobinopathy). Patients could also be admitted to Ward 39/40 also an oncology and haematology ward, which had 36 beds including 12 side rooms.

Additionally, patients could be seen on the OAU which had eight beds, one side room and assessment chairs. Access was available 24 hours per day 7 days per week for acute haematology admissions.

Sub-cutaneous patient-controlled analgesia had recently been introduced and rolled out to haematology/oncology wards with training on-going.

At the time of the visit there was an infection prevention issue requiring building works and the usual bed base for patients with haemoglobin disorders had changed to accommodate this with the existing process for clinical oversight remaining unchanged.

Critical care support for unwell patients was delivered by an outreach team and patients were also supported by the adult ICU team who were based on site at LRI.

The adult haemoglobinopathy team would be notified of any patient's undergoing elective procedures and requiring admission under a different speciality base by the alert system and subsequently reviewed on site by the specialist team.

Inpatient maternity care was provided solely via the LRI maternity service, in conjunction with the haematology team.

Day Unit

The day unit was based within the Osborne Treatment Centre and open Monday-Saturday 0800-1800. The unit contained 3 apheresis reclining chairs (currently only using two at any one time due to staffing capacity) and was quite cramped with some patients receiving their transfusions on ordinary upright chairs. Some patients living with thalassaemia could receive their transfusion at the weekends which they appreciated especially if working during the week. The unit total capacity was for 23 patients (21 if a bed was required).

Additional day unit capacity on a 'planned care' unit was due to open at another trust site - Leicester General Hospital in the autumn and at the time of the visit it was not clear how many patients would transfer to this service. There was no option for weekend transfusions to be delivered from this unit and medical cover would not be by a member of the haematology team.

Outpatient

Consultant led clinics were held on Thursday afternoons in the Osborne outpatient department and a Tuesday clinic from the Coleman Centre, and LGH. The nurse led clinics were remote only and offered hydroxycarbamide monitoring and post inpatient follow up calls.

Community-Based Care

The team at UHL provided an integrated community service to the Leicester city and Leicestershire population.

Views of Service Users and Carers

For this review the UKFHD were piloting meeting with patients and carers before the visit. Unfortunately, for the Leicester Sickle Cell patient and family meeting 20 patients had registered but none attended.

The review team spoke to four adults living with thalassaemia at the Leicester Thalassaemia patient and family previsit meeting held on 4th June 2024.

Feedback from those living with thalassaemia is detailed below:

- Two patients attended for their transfusions at the weekend, and two attended during the week. They reported that it was good to have the option for weekend transfusions as they were working during the week.
- The lead haemoglobinopathy clinician was 'great' and the CNS team very supportive.
- Support Groups and access to education events: three of the patients had a local WhatsApp group which provided support but none of those who spoke to the reviewing team were aware of any other support groups or any education days.
- Transition: None of those who met with the reviewing team had transitioned from children to adult services within the last 5 years, so this area was not discussed.
- All patients were aware of how to contact the team and that the team were responsive.
- If they needed to reschedule appointments this was relatively straightforward via the day unit reception staff.
- Phlebotomy: Most times they would go to the general phlebotomy unit which was a struggle as away from the day unit and they would experience long queues. More recently they were able to have their bloods undertaken in the day unit.
- Transfusion: Staff in general were experienced in cannulation and they did listen if patients offered advice though other staff were less experienced. All the patients commented that they knew who could cannulate otherwise "it could be scary". Most staff would ask for assistance after two cannulation attempts – unless the unit was busy. All said they would not let staff undertake more than three attempts.
- Social care support: Some had heard that a social worker had commenced and would help with welfare and benefits advice, and support with personal independent plan (PIP) completion. Not all who met with the reviewing team had received the text message from ESTMN letting them know about the support available.
- Emergency pathway: they had been given a contact number for the assessment unit so that they could bypass the ED. "One number and everything and it starts from there". If they were very unwell, they were aware they needed to call 999. If they attended the ED, then triage worked well though they did not consider that staff understood their condition and the implications were that there was a delay before the on-call haematology team would be notified.
- They thought that care plans were paper based and kept in the day unit in a generic folder and were not accessible if they attended the ED. They did not think that their records were 'flagged' to alert professionals

about their condition. Not all those at the meeting received copies of their care plans, though they did get a copy of their annual review letter sent to their GP.

- All said that their GPs received their clinical letters, and some were prepared when they went to see them others were not, and they spend a lot of time 'retelling their story'.
- Information: Some had received a booklet many years ago which covered 'what to do in an emergency' and some information about iron chelation, vaccination and travel advice. There was very little information visible in the clinics and they commented that there was a poster about sickle cell disorder but nothing visible about thalassaemia.
- All felt that they could advocate for themselves but they were concerned that patients new to the service may not be forthcoming to express themselves.
- As patient experts they considered that challenge was not well received, and they were made to feel as if they were being difficult. Appointments with haematology and other specialties seemed rushed with very little time for them to ask questions – staff 'do not have time to listen'. They commented that they were sometimes seen by the doctors in training who they considered did not have sufficient knowledge in the care of the patient with thalassaemia so by the time they had found a parking space and waited they considered they could have answered the questions over the phone. Being able to see the lead haemoglobinopathy consultant was highly valued.
- All considered that they were receiving the relevant monitoring for complications of their condition; endocrine, T2 and ophthalmology review. Although some were concerned that appointments with some specialities (endocrine and bone) were being cancelled and therefore their health monitoring delayed. One person had to request to be seen by the rheumatology team only to be told their issues were just because of their condition so to 'grin and bear it'.
- Medication: Access to Desferral pumps could be sorted though there had been delays in delivery of medication as transitioning to a new supplier.
- Prescriptions: were usually sorted in clinic, outside of clinic this could take over a week to get sorted. Patients commented that they would have to ask to have their testosterone levels to be checked. One patient had no understanding about the side effects of iron chelation other than what they would read on their medication box.
- Patients were asked to give feedback and patient survey done regularly usually on transfusion days.
- When asked what would make a difference, the patients referenced staff education about Thalassaemia, especially for the new nurses. Better understanding of staff that patients with long term conditions are often experts and this should be valued. The layout of the day unit could also be improved.
- Overall, they were clear that they did not want to seem critical, but they were very conscious of the staff shortages when they attended and the need to improve staff knowledge about thalassaemia and the environment of the day unit. They felt that thalassaemia was not given the priority on the day unit and that their department was not funded in the same way as other wards. They commented that that other wards seem 'lavish' and we get the 'leftovers'.

Good Practice

1. The SHT had collaborated with the local universities so that they attended during the new students university 'fresher' week, to promote awareness of the haemoglobinopathy service to young people with Sickle Cell or Thalassaemia moving into the area. This also included the provision of a dedicated clinic for new students at the start of each academic year.
2. Reviewers were impressed that the SHT had completed 100% of their patient annual reviews

3. The SHT hosted the community and counselling services which had resulted in them being able to offer counselling to all patients including patients with a sickle cell or thalassaemia trait.

4. The SHT had developed a clinical support worker (CSW) role. The CSWs supported the whole patient pathway including phlebotomy and would contact patients following discharge from the acute setting. Staff considered that the introduction of this role had massively reduced the time they were spending on non-clinical activity and enabled them to focus on other aspects of clinical care. Patients who met with the reviewing team also commented on how helpful the CSWs were in providing information and support.

5. A Psychosocial MDT meeting was held every month whereby the team would discuss any patients who had required an inpatient stay, those who were pregnant, complex patients and any patients who had upcoming surgery or young people who were transitioning to adult services . This had enabled the MDT to identify any patients where targeted psychological support or specialist input would be beneficial.

6. The Haematology dietician provided a service to inpatients as well as for those attending as an outpatient.

Immediate Risk

No immediate risks were identified during the visit.

Concern

1. Day Unit Provision

The day unit environment was cramped with old furniture and chairs. Patients who attended for transfusions often had to sit on uncomfortable, upright chairs with wooden armrests for prolonged periods of time. The unit had a few recliner chairs but patients reported that oncology patients tended to get priority for these.

Reviewers were told that there were plans to move the hemoglobinopathy day unit service to the new planned care unit at LGH however this unit was not going to be able to support a weekend transfusion service and there were no plans to provide haematology cover if patients required a review or other clinical interventions when attending. From discussion it was unclear which patients would be transferred to the new day unit and what the contingency plans were for specialist review if required during transfusion.

2. Consultant staffing

Reviewers were concerned that the service was very reliant on the lead clinician who in their opinion was working 'above and beyond' to sustain the service. The lead consultant had only 0.75 PAs allocated leadership of the SHT and the HCC and there was no deputy for absences. Medical staffing was 3.6PAs to care for 205 pts (149 SCD, 56 Thalassaemia or rare inherited anaemia) including clinical work, annual reviews and provision of outreach clinics to LHTs which fell well below that required for this service and therefore impacted on the ability to partake in essential activity such as audits, research and updating protocols, alongside delivery of direct patient care.

3. Lack Patient information guidelines in ED and training for thalassaemia 'e' learning

Guidelines for the acute care of patients with thalassaemia attending the ED were not in place and the e-learning training on HELM only covered patients living with a sickle cell disorder.

4. Access to Psychology

Access to psychology was insufficient for the 792 pts registered with the service. There was only 0.3 WTE psychology provision in place which did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of 1 WTE HCPC Senior Psychologist for every 300 patients. Reviewers were aware that funding had been agreed to increase access to psychology but at the time of the visit this additional support was not yet available.

5. Transition

a) The Trust wide guidance covering transition was out of date with a review date of March 2024 and did not cover the allocation of a named coordinator for the transfer of care, communication of clinical information

from paediatric to adult services and arrangements for monitoring during the time immediately after transfer to adult care. There was also no consideration of haemoglobinopathy-related areas such as transfusion provision.

b) At the time of the visit only patients deemed complex had the opportunity to have a joint meeting with the paediatric and adult services and young people transitioning from other areas did not have access to support.

c) The SHT had recently appointed a CNS to lead on the transition pathway to ensure transition support was in place for young people across the adults and paediatric SHTs and for young people cared for by the LHTs. Reviewers acknowledged that the development of a robust transition programme and service was progressive with Transition Nurse now well established in post, but reviewers were concerned that young people particularly from the LHTs may be admitted to adult services if unwell before having undergone a formal transition process. Of particular note would be those young people who are transiting from Peterborough who may move to UHL or the adult service provided by the Cambridge SHT.

Further Considerations

1. Reviewers considered that the SHT should explore whether they could further increase their support to the LHTs both for medical advice, CNS time and if there is an opportunity to introduce support workers beyond UHL. From discussion with LHTs representative during the visit, expanding the Transition and Screening Service to focus on the LTH catchment areas would also be greatly received.
2. A network wide competence framework had been developed but not yet implemented across all key areas. Reviewers were told that there were plans to formally assess and develop a process for ongoing monitoring of staff competences.
3. The review team heard that SLAs were in development however on questioning trust management representative during the visit said they were unaware of these. Formalising SLAs would support the SHT/LHT relationships and clarify the responsibilities expected for each team.
4. Formal arrangements to access support for patients with acute and chronic pain was not in place. Development of arrangements with the pain team would improve the care for this group of patients.
5. The SHT had not had fully completed all the audits expected of a specialist team, for example the transfusion pathway audit and an audit of patients who were admitted to other areas.
6. The SHT had not yet undertaken the UKTS survey for patients living with Thalassaemia.
7. The role of administrator was vacant at the time of the visit. This was resulting in clinical staff spending clinical time on administrative work.
8. A number of guidelines were not in place or incomplete. The guidance covering transfusion did not cover all the requirements of the Quality standard for patients with a haemoglobin disorder. The guidance on the use of hydroxycarbamide did not include the latest national guidance for the monitoring and compliance in achieving maximum tolerated dose of hydroxycarbamide, from discussions at the time of the visit, in practice best practice guidance had been implemented. The. The fertility and pregnancy guidance did not cover fertility preservation, assisted conception or pre-implantation genetic diagnosis.
9. The draft guidance covering the care of patients with thalassaemia was comprehensive but in the process of being ratified.

Commissioning

The review team had discussions with the regional specialist commissioner from NHS England Midlands and Leicester and NHS Leicestershire and Rutland Integrated Care Board. Several of the issues in this report will require the active involvement of the Trust leadership team and commissioners to ensure that timely progress is made.

Appendix 1 - Membership of Visiting Team

Visiting Team		
Ralph Brown	HCC Network Manager	Imperial College Healthcare NHS Trust
Hannah Coyle	NHS England Quality Manager (Specialised Commissioning)	NHS England
Amanda Hogan	Newborn and SCT pathway implementation lead	NHS England
Lisa Kirk	Adult Haemoglobinopathy Nurse Specialist	Sheffield Teaching Hospital NHS Foundation Trust
Sarah McDonald	Paediatric Haemoglobinopathy Nurse Educator	Manchester University Hospitals NHS Foundation Trust
Roanna Maharaj	User Representative	UK Thalassaemia Society
Helen Murphy	Paediatric Clinical Nurse Specialist	Cardiff and Vale University Health Board
Elizabeth Naamorkor-Caulley	User Representative	Manchester Sickle Cell Society
Srinivasan Narayanan	Consultant Haematologist	University Hospital Southampton NHS Foundation Trust

Clinical Leads		
Sabiha Kausar	Consultant Haematologist (Paediatrics)	Manchester University Hospitals NHS Foundation Trust
Clare Samuelson	Consultant Haematologist (Adults)	Sheffield Teaching Hospital NHS Foundation Trust

MLCSU Team		
Kelly Bishop	Assistant Director of Nursing and Urgent Care	Nursing and Urgent Care Team - NHS ML
Sarah Broomhead	Professional Lead	Nursing and Urgent Care Team - NHS ML
Allison Cape	Deputy Director of Nursing	Nursing and Urgent Care Team - NHS ML

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Appendix 2 - Compliance with the Quality Standards

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varies depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Percentage of Quality Standards met

Service	Number of Applicable QS	Number of QS Met	% Met
EMSTN Sickle Cell Haemoglobinopathy Coordinating Centre (HCC)– All Ages	13	10	77%
Specialist Haemoglobinopathy Team (SHT) Children and Young People	45	17	39%
Specialist Haemoglobinopathy Team (SHT) Adults	49	24	50%

East Midlands Sickle Cell Haemoglobinopathy Coordinating Care Centre - All Ages

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-198S	**Network-wide Involvement of Children, Young People and Families (SCD)** The Sickle Cell Disorder HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702).	Y	The Patient and Public voice group recommenced and acted as the patient forum for the HCC and fed into the Network Board Meeting via the HCC Network Manager and HCC Lead Nurse.
H-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The named lead had limited time allocated for leadership of the HCC. The Lead was also the lead for the SHT and had only 0.75PA for both network roles. The HCC had a named paediatric advisory lead.
H-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	Lead Nurse for HCC (1WTE)
H-202A	**Lead Manager** A lead manager should be available with: a Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs b Responsibility for liaison with other services within the network The lead manager should have appropriate time for their role.	Y	
H-203	**Lead for Transcranial Doppler Ultrasound** The HCC should have a nominated lead for Transcranial Doppler Ultrasound screening.	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-602S	**HCC Service Organisation (SCD)** A Sickle Cell Disorder HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including: a Telephone or email advice for outpatient and inpatient care b Advice on emergencies outside of normal working hours	N	EMSTN Network wide SOP was in draft and awaiting Board agreement. It was not clear about the arrangements in place for telephone or email advice or advice outside of normal working hours. The references appeared out of date in the draft policy.
H-605S	**HCC Multidisciplinary Discussion (SCD)** MDT meetings for the discussion of more complex patients with sickle cell disorder should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use.	Y	Regional MDT meetings were held on second Friday of each month. Referral criteria were in place and a process for escalation to National Haemoglobinopathy Panel.
H-609	**NHS Blood and Transplant Liaison** The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies.	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-702S	**HCC Business Meetings (SCD)** The Sickle Cell Disorder HCC should organise at least two meetings each year with its referring SHTs and LHTs to: a Agree network-wide information for patients and carers of all ages b Agree network-wide policies, procedures and guidelines, including revisions as required c Agree the annual network education and training programme d Agree the annual network audit plan, review results of network audits undertaken and agree action plans e Review and agree learning from any positive feedback or complaints involving liaison between teams f Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams g Review progress with patient experience and clinical outcomes (QS H-797) across the network and agree any network-wide actions to improve performance h Consider the TCD annual monitoring report and agree any actions required (QS H-704)	Y	Business meetings were attended by the SHTs, Northampton and Kettering LHTs but no other LHTs across the network. The SHT had not delegated annual review to any LHTs so attendance for LHTs was optional
H-703	**HCC Annual Programme of Work** The HCC should meet with their commissioners at least annually in order to: a Review progress on the previous year's annual programme of work b Review progress with improving patient experience and clinical outcomes across the network (QS H-797) c Agree the annual programme of work for the forthcoming year	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-704	**Transcranial Doppler (TCD) Monitoring Report** The HCC TCD lead should monitor and review at least annually: a The list of staff undertaking TCD ultrasound and whether they have undertaken 40 procedures in the last year (QS HC-209) b Results of internal quality assurance systems (QS HC-504) c Results of National Quality Assurance Scheme (NQAS) for TCD ultrasound (when established) or local peer review arrangements (until NQAS established) d Number of TCD ultrasounds performed and the number of abnormal TCDs across the network e Whether any changes to the TCD Standard Operating Procedure (QS HC-504) are required	Y	
H-707	**Research** The HCC should have agreed a list of research trials available to all patients within the network and SHTs should actively participate in these trials.	Y	
H-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Not all the documentation see was appropriately governed.

Specialist Haemoglobinopathy Team for Children and Young People with Haemoglobin Disorders

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-101	**Haemoglobin Disorder Service Information** Written information should be offered to children, young people and their families, and should be easily available within patient areas, covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i Contact the service for help and advice, including out of hours ii Access social services iii Access benefits and immigration advice iv Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent) v Give feedback on the service, including how to make a complaint vi Get involved in improving services (QS HC-199)	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-102	**Information about Haemoglobin Disorders** Children, young people and their families should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Parental or self-administration of medications and infusions	N	Limited information on the inheritance of the condition or the side effects. a,b,c,e,f, were not covered from a Thalassaemia information perspective
HC-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	N	QS not achieved for patients living with Thalassaemia
HC-104	**What to Do in an Emergency?** All children and young people should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents [SCD and Th] c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health (if appropriate) d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HC-106	**Information about Transcranial Doppler Ultrasound** Written information should be offered to children, young people and their families covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	Y	
HC-107	**School or College Care Plan** A School or College Care Plan should be agreed for each child or young person covering at least: a. School or college attended b. Medication, including arrangements for giving / supervising medication by school or college staff c. What to do in an emergency whilst in school or college d. Arrangements for liaison with the school or college e. Specific health or education need (if any)	N	No Care Plans for Thalassaemia Patients. College care plans were limited but reviewers were told this was through patient choice.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	Y	
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	N	Policy was Trust wide and not service specific – reviewers acknowledged this is progressive with a CNS leading on Transition pathways now well established in post
HC-197	**Gathering Views of Children, Young People and their Families** The service should gather the views of children, young people and their families at least every three years using: a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder' b. UKTS Survey for Parents of Children with Thalassaemia	N	There was no formal information about the UKTS survey for patients living with Thalassaemia.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	Y	The Leicester Haemoglobinopathy Patient Voice Group was in operation.
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The lead Consultant had no time allocated for leadership of the SHT.
HC-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	Insufficient resource available.
HC-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	There was an insufficient allocation of medical staff with appropriate competencies available.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of children and young people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	N	Service dependent was on one specialist paediatric consultant. No alternative paediatric cover was available.
HC-206	**Doctors in Training** If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders.	Y	
HC-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	Ward nurses who spoke to the reviewing had not had training in the care of children and young people with haemoglobin disorders. The competence framework submitted after the visit had no clear formal governance process. Limited evidence provided of CNS formal competencies or peer assessment of.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	At the time of the visit the psychology post was vacant.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	Y	
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	No admin support or funded position in place at the time of visit
HC-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required: a. Social worker / benefits adviser b. Play specialist / youth worker c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Child and adolescent mental health services	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	Y	
HC-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders.	N	Training for in urgent care of children and young people with haemoglobin disorders was mandated. A training log was not available. An audit of compliance with the NICE Guidance on timely access to analgesia had been undertaken. See concern section of the report

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HC-195)	N	Trust wide guidelines were not service specific. The policy was out of date and did not cover haemoglobinopathies i.e. about transfusions.
HC-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for children, young people and their families.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-504	**Transcranial Doppler Ultrasound Standard Operating Procedure** A Standard Operating Procedure for Transcranial Doppler ultrasound should be in use covering at least: a. Transcranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Transcranial Doppler ultrasound (QS HC-209) d. Arrangements for ensuring staff performing Transcranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	Y	
HC-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Arrangements for accessing staff with cannulation competences f. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion g. Patient pathway for Central Venous Access Device insertion, management and removal	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: Indications for chelation therapy a. Choice of chelation drug/s, dosage and dosage adjustment b. Monitoring of haemoglobin levels prior to transfusion c. Management and monitoring of iron overload, including management of chelator side effects d. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 e. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible	Y	
HC-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring complications e. Indications for discontinuation	Y	
HC-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred For children and young people with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration For children and young people with thalassaemia: l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-510	**Clinical Guidelines: Chronic Complication** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea f. Endocrine and growth problems, including endocrinopathies and osteoporosis g. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology h. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease i. Growth delay / delayed puberty j. Enuresis k. Urological complications, including priapism l. Dental problems	N	Sickle Cell – Guidelines require inclusion of (l) dental problems. Thalassaemia – guidelines require (f), (i) and (l)
HC-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of children and young people with sickle cell disorder and thalassaemia during anaesthesia and surgery.	Y	
HC-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by an HCC / SHT b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission c. Patient discussion at local multidisciplinary team meetings (QS HC-604) d. Referral of children for TCD screening if not provided locally e. 'Fail-safe' arrangements for ensuring all children and young people have TCD ultrasound when indicated f. Arrangements for liaison with community paediatricians and with schools or colleges g. Follow up of patients who 'were not brought' h. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care i. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together j. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	N	East Midlands Haemoglobinopathy Coordination Centre SOP was in draft. Applies to: University Hospitals of Leicester NHS Trust University Hospitals of Derby and Burton NHS Foundation Trust University Hospitals of Northamptonshire NHS Group North West Anglia NHS Foundation Trust.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HC-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HC-503) d. National Haemoglobinopathy Registry data collection (QS HC-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HC-607) (if applicable) g. Participation in HCC-agreed audits (HC-706)	N	SLAs were not in place with LHTs.
HC-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when required, representatives of support services (QS HC-301).	N	No psychologist in post.
HC-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of children and young people with haemoglobin disorders b. Two-way exchange of information between hospital and community services	N/A	Service provided inhouse.
HC-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each SCD HCC Business Meeting (QS HC-702).	Y	
HC-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HC-702).	Y	
HC-608	**Neonatal Screening Programme Review Meetings** The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results, identify issues of mutual concern and agree action.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	
HC-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions	N	'a' The audit for transfusion did not include the number of cannulation attempts. b. There was no evidence that the contemporaneous data on admission alerts had been collated and reviewed.
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS HC-702d).	N	No HCC specific audits evidenced.
HC-707	**Research** The service should actively participate in HCC-agreed research trials.	N	None for Paediatrics.
HC-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HC-197) compared with other services c. Results of audits (QS HC-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	a), b), and c) not seen by review team.
HC-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	N	No evidence of learning from events. Risk log available but no risk register.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-799	**Document Control** All information for children, young people and their families, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Some of the documents provided were not version controlled.

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Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-101	**Haemoglobin Disorder Service Information** Written information should be offered to patients and their carers, and should be easily available within patient areas, covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HA-199)	N	Information about where to go in an emergency for patients with thalassaemia was not seen. All other aspects were met Psychology information was concise.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-102	**Information about Haemoglobin Disorders** Patients and their carers should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	From the information seen, 'e', 'g ii' and 'i' were not covered. The travel advice (g.i) was only for patients with a sickle cell disorder. For patients living with thalassaemia there did not appear to be information covering when to seek emergency support. Psychology information was concise.
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	Y	However, the patients who met with the reviewing team would value more information being included.
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	**N**	Patients living with thalassaemia received a copy of their review letters but commented that these were very brief. Reviewers did not see a template/example letter to identify if the information required by the QS was included.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	N	The view of the patients, who met with the reviewing team, was that the day unit environment was poor with old furniture and chairs – see main report
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	N	At the time of the visit only patients deemed complex had the opportunity to have a joint meeting with the paediatric and adult services. Therefore, not all young people transitioning from other services had access to support. The SHT had recently appointed transition nurse ensure transition support was in place for young people across both SHTs and for young people cared for by the LHTs.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	N	The UKTS survey for patients living with Thalassaemia had not been undertaken. A Sickle Cell Survey undertaken 22/23 had 32 responses and analysis and themes had been included in the annual report. 23/24 survey had been undertaken.
HA-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback b. Mechanisms for involving patients and their carers in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HA-797) c. Examples of changes made as a result of feedback and involvement	Y	The Patient and Public Voice Group had recommenced and acted as the patient forum for the HCC and the SHT. Other mechanisms were in place to change services following feedback e.g. the crib sheet and more targeted training for ED staff.
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The nominated Lead Clinician had only 0.25 for SHT leadership including liaison with the LHTs.
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	Medical staffing was 3.6PAs to care for 205 pts (149 SCD, 56 Thalassaemia) including clinical work, annual reviews and provision of outreach clinics to LHTs rather than the expected 8.425 PAs. All consultants provided cover for haematology/oncology and inpatient work. The lead did have 0.25PA allocated for haemoglobinopathy CPD.
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	For doctors in training a SIMS training package was in place which included training on SCD emergencies.
HA-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	A network wide competence framework had been developed but not yet implemented but had plans to do so. e-learning SCD training was available on 'HELM' but training was not yet available covering thalassaemia.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	At the time of the visit there was only 0.3WTE band 8a for 205pts. There was funding to increase to 1.3 WTE and recruitment was in progress. There was no competence framework in place for psychology staff.
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	The admin role was vacant at the time of the visit. 1.0 WTE data manager in post for the HCC and SHT.
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	Y	
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	Automated red cell exchange transfusion was not available 24/7 although in practice the on call service would provide 24/7 input for some scenarios. A business case had been agreed to increase capacity as part of the Medtech funding with intention to provide 24/7 cover. In practice there was a lack of access to the pain team . All other aspects of the QS were met

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	N	Audit of compliance with the NICE guidance for analgesia within 30 minutes ranged from 30% to 67%. Training was accessible on the hospital system 'HELM' covering sickle cell disorders but not thalassaemia. The SHT did provide some additional training but a process to assess staff competences was not in place.
HA-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HA-195)	N	The Trust wide guidance covering transition was out of date with a review date of March 2024 and did not cover 'c, d, or 'f'
HA-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for patients and carers.	Y	The guidelines did not cover new patient guidelines but there was a template for letters. There was a section covering new patient guidance in the draft thalassaemia guidelines.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	**N**	The transfusion guidelines did not cover all the requirements of the QS for patients with haemoglobin disorders. The draft thalassaemia guidance had some information on the transfusion patient pathway 'e', e.g. the number of cannulation attempts, but had not yet been ratified for use. Reviewers considered that the protocol for 'Bii' would benefit from review as was not practical or helpful for staff if access needed to be arranged in an emergency. For example, how to get vascular access and contacting the on call apheresis team.
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	N	The draft thalassaemia guidance would meet the requirements of the QS once agreed. There was no guidance covering those with SCD or RIA who may need chelation therapy.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring of complications e. Indications for discontinuation	N	The criteria and process would benefit review as did not appear to reflect the latest national guidance for the monitoring and compliance in achieving maximum dose of hydroxycarbamide. In practice patients did have good access to hydroxycarbamide and the guidance should be updated to reflect this.
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	N	The draft guidance once agreed would meet the requirements of the QS.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred. For patients with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision iv. For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine	**N**	The draft thalassaemia guidance once agreed would meet the requirements of the QS. This QS was met for Sickle Cell Disorders

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-510	**Clinical Guidelines: Chronic Complications** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Pulmonary hypertension f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea g. Endocrine problems, including endocrinopathies and osteoporosis h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology i. Chronic pain j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease k. Urological complications, including priapism and erectile dysfunction l. Dental problems	N	The draft thalassaemia guidance once agreed would meet the requirements of the QS apart from 'i' chronic pain The guidance for those with a sickle cell disorders was comprehensive but did not include 'l' dental problems
HA-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery.	N	The draft thalassaemia guidance once agreed had a section on perioperative care. Network wide perioperative guidelines was also in place.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	**N**	Guidance did not cover 'a' for patients with haemoglobin disorders.
HA-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	N	East Midlands Haemoglobinopathy Coordinating centre SOP was in draft but once agreed would apply to all the trusts across the network. • University Hospitals of Leicester NHS Trust • Nottingham University Hospitals NHS Trust • University Hospitals of Derby and Burton NHS Foundation Trust • University Hospitals of Northamptonshire NHS Group • United Lincolnshire Hospitals NHS Trust • North West Anglia NHS Foundation Trust
HA-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HA-503) d. National Haemoglobinopathy Registry data collection (QS HA-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HA-607) (if applicable) g. Participation in HCC-agreed audits (HA-706)	N	There were no SLAs in place with LHTs

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when requested, representatives of support services (QS HA-301).	Y	
HA-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services	n/a	Integrated acute and community service
HA-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each Sickle Cell Disorder HCC Business Meeting (QS HA-702).	Y	
HA-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HA-702).	Y	
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	N	'a' had been completed but there was no data on the number of cannulation attempts. The audit appeared to show significant delays to the start of transfusions (60 mins) which action had been taken to address. 'b' had not been completed as there was a system for alerts to be prospectively collected if patients were admitted to other areas. There was no evidence that the contemporaneous data on these admission alerts had been collated and reviewed An audit covering pregnancy outcomes and thalassaemia monitoring had been completed
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	Y	Regional pain audit undertaken Audit of adults with sickle cell disorder undergoing planned and emergency transfusion had also been completed by the SHT sites.
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	
HA-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HA-197) compared with other services c. Results of audits (QS HA-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	Reviewers did not see any evidence that meetings with patient and carer representatives / patient voice meetings had covered the requirements of the QS. 'b' could not be completed for thalassaemia as the relevant survey had not been undertaken. The HCC held quarterly Patient Voice meetings.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	Y	
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Some of the documents provided were not version controlled.

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