MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

Nottingham University Hospital NHS Trust

Visit date: 24th June 2024

Report date 27th November 2024

Contents

Introduction

This report presents the findings of the review of University Hospital of Nottingham NHS Trust that took place on 24TH June 2024. The purpose of the visit was to review compliance with the Health Services for People with Haemoglobin Disorders Quality Standards Version 5.2, November 2023 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 NHS Midlands and Lancashire (ML). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

- 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/MLSCU response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in Nottingham 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:

- Nottingham University Hospital NHS Trust
- NHS England Midlands
- NHS Nottingham and Nottinghamshire Integrated Care Board (ICB)

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 Specialised Commissioning.

About the UKFHD and MLCSU

The UK Forum on Haemoglobin Disorders (UKFHD) is a multi-disciplinary group of healthcare professionals interested in all aspects of sickle cell disorders, 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 (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 the ML is available at https://haemoglobin.org.uk/ and https://www.midlandsandlancashirecsu.nhs.uk/our-expertise/nursing-and-urgent-care/

Acknowledgements

The UKFHD and NHSML would like to thank the staff and service users and carers of the Nottingham 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

Nottingham University Hospital NHS Trust

Trust-wide

General Comments

This review examined the health services provided for children, young people, and adults with haemoglobin disorders at Nottingham University Hospital NHS Trust. During the visit, reviewers attended both the City Hospital, where they visited the adult services, and Queen's Medical Centre, where they reviewed the paediatric service and emergency departments (EDs). Designated wards, assessment / day units, and outpatient departments were visited at both sites.

The East Midlands Sickle Cell and Thalassaemia Network (EMSTN) had been established in 2009 with the support of the East Midlands Specialised Commissioning Group. This network was created by regional haemoglobinopathy specialists and featured two primary hubs in Nottingham and Leicester, extending its outreach services to North Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire and Peterborough.

In Nottingham, the haemoglobin service for both paediatric patients (at Queen's Medical Centre) and adult patients (at Nottingham City Hospital) focused on the management and treatment of haemoglobin disorders such as sickle cell disorders and thalassaemia. The Nottingham hub played a crucial role in delivering comprehensive care, including diagnosis, treatment, and ongoing management of these conditions.

The University Hospitals of Leicester served as the Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell Disorders for both adults and children and young people (CYP). Additionally, Sandwell and West Birmingham Hospitals acted as the HCC for Thalassaemia and Rare Inherited Anaemias for adults, while Birmingham Women's and Children's Hospital served as the HCC for Thalassaemia and Rare Inherited Anaemias for children and young people (CYP).

The network also included several Local Haemoglobinopathy Teams (LHTs) providing services in various locations:

- United Lincolnshire Hospitals: Lincoln County Hospital and Pilgrim Hospital
- University Hospitals of Derby and Burton: Royal Derby Hospital and Queens Burton
- Sherwood Forest Hospitals: King's Mill Hospital

These LHTs ensured that comprehensive care was accessible across the East Midlands, facilitating the treatment and management of haemoglobin disorders closer to patients' homes.

Trust-wide Good Practice

Trust-wide Good Practice – children and young people

1. Outstanding patient feedback

Children and Young People, and their carers commended the care they received throughout their patient journey at NUH. Feedback about care within the Emergency Department and from the specialist team was overwhelmingly positive.

Trust-wide Good Practice – adults

1. Ring fencing the budget

The trust's good practice of ring-fencing allocated funds for the team ensured optimal utilisation to benefit patients. This initiative led to an increase in hours for psychologists, additional CNS posts, and upcoming plans for dedicated physiotherapy and Consultant Pain team sessions. Such strategic allocation of resources reflects a commitment to enhancing patient care and improving clinical outcomes within the healthcare setting.

2. Reducing the number of outlying wards

Reducing the number of outlying wards was a commendable initiative. The trust's support in this effort was particularly noteworthy, as it demonstrated a commitment to improving patient care for HD patients. Previously, the number of wards catering to these patients was significantly larger, but it had been successfully reduced to just three. This reduction not only streamlined patient management but also allowed for more focused and specialised care. It was noted that occasionally patients still end up on other wards due to capacity demands.

Ongoing efforts aimed to further decrease this number to a single dedicated ward. This consolidation would greatly enhance the training and expertise of the staff, ensuring that HD patients received the highest quality of care. By concentrating resources and personnel in one ward, the trust aimed to create a more cohesive and efficient treatment environment, ultimately benefiting both patients and healthcare providers.

Trust-wide Serious Concern

Trust-wide Serious Concern – children and young people

1. Consultant Staffing

Reviewers highlighted a serious concern in relation to consultant staffing capacity. There were insufficient medical staff trained in managing people with haemoglobin disorders (1.41 PA total for 102 patients) to adequately support regular reviews, emergency care, and clinics. Based on the UK Forum guidance on consultant staffing levels of 1.5 PA for every 50 patients for direct clinical duties staffing, the service is significantly under resourced.

2. Lack of dedicated Specialist Community Service Provision

At the time of the visit, reviewers were seriously concerned that there was no dedicated community service provision. Despite funding and plans being in place to recruit a Community Clinical Nurse Specialist (CNS), recruitment had not yet commenced, resulting in additional workload on the specialist hospital team to cover elements of the service and a lack of face-to-face support for parents receiving newborn red cell disorder diagnoses.

3. Concern Regarding Lack of Apheresis Service

A significant concern noted by reviewers was the lack of access to automated red cell exchange transfusion, resulting in patients receiving suboptimal treatment. Although reviewers were informed that an apheresis machine had been purchased, the business case submitted in March ‘24 for staffing of the service was still in the process of approval. Should this business case not be approved, the plan is to commence delivery of the service by the end of 2024 will be unachievable.

Trust-wide Serious Concern – adults

1. Consultant staffing

Consultant staffing presented ongoing challenges despite the commendable efforts of the dedicated workforce. A locum consultant was in post at the time of the visit and provided some support to the service. Other consultants within the non- malignant service undertook CPD and attended MDTs to discuss patients. However, the team still encountered difficulties due to inadequate consultant time to address the demand, with the workload consistently exceeding available capacity. The lead consultant was single-handedly managing both inpatient and outpatient HD services most weeks of the month, which was felt to be unsustainable.

Trust-Wide Concern

Trust-wide concern – children and young people

1. Access to Analgesia in the ED

Compliance with pain relief standards in the Emergency Department requires improvement with only 42% of patients receiving pain relief within 30 minutes of attendance at hospital (23/24 audit).

Trust-wide Concern – adults

1. Governance

There was a notable absence of policies and procedures relating to governance, with the existing policies being noted as out of date. This gap in documentation had raised concerns about the effectiveness of governance frameworks in ensuring compliance with regulatory standards and best practices.

2. Complaint process

Patient feedback indicated that there was no clear process for complaints. While the PALS service was advertised at the entrance of the wards, patients admitted with pain had not noticed these posters. Patients told the review team that when a complaint was made, inadequate feedback was received.

Trust-wide Further Considerations

Trust-wide Further Considerations – children and young people

1. Draft policy documents

Many of the policy documents were in draft form at the time of the review. Ensuring timely ratification of these documents is essential to guarantee they are easily accessible to all staff within the trust.

Trust-wide Further Consideration – adults

1 Lack of PCA on SRU

The reviewers found the lack of PCA pumps on the SRU to be concerning. This issue, coupled with patient feedback regarding poor pain management, highlighted a significant gap in patient care. Patients consistently reported inadequate pain relief, which underscored the necessity of having dedicated PCA pumps on the ward. Implementing these pumps would address pain management issues more effectively, ensuring patients received appropriate care during their stay. The reviewers emphasised that addressing this concern was essential for improving overall patient satisfaction and outcomes.

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	N

During the visit the visiting team met with 18 adults., 14 were living with a Sickle Cell Disorder, and four adults living with Thalassaemia. Under the adult section feedback will be elaborated. From the children's perspective reviewers met with three families caring for children and young people with a Sickle Cell Disorder, 2 families caring for children and young people with a Rare Inherited Anaemia or Thalassaemia and one person living with Thalassaemia. The views of the users were extensive and 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

This review assessed the healthcare services provided for children and young people with haemoglobin disorders at Nottingham University Hospital NHS Trust (NUH), which has 102 registered patients with red cell disorders. The University Hospitals of Derby and Burton (UHDB) Local Haemoglobinopathy Team (LHT) has 41 registered patients, and the United Lincolnshire Hospitals LHT has 14 registered patients.

The multidisciplinary team at NUH is led by a Paediatric Haematologist and comprises four Consultants with a combined total of 1.41 PAs, 1.7 WTE Clinical Nurse Specialists, and a 0.4 WTE psychology post. During the visit, reviewers toured the emergency department, wards, and outpatient areas at NUH, and engaged with patients, carers, and staff providing services across the local health economy at NUH and UHDB.

The Specialist Haemoglobinopathy Team (SHT) at NUH demonstrated exceptional dedication to delivering outstanding service to patients and their families. The team was highly motivated, with a clear vision for their goals both locally and for their constituent Local Haemoglobinopathy Teams (LHTs), while being acutely aware of the challenges they faced. Patient feedback was overwhelmingly positive, commending the specialist team for their excellent care.

The Paediatric Specialist Haemoglobinopathy Team (SHT) is part of the East Midlands Sickle Cell and Thalassaemia Network (EMSTN), established in 2009. This network includes two hubs, Nottingham and Leicester (HCC), with outreach to nearby areas. It has been effective in sharing protocols, patient information, and conducting audit projects. The SHT provides Transcranial Doppler services for the LHTs. A regional data manager assists with documentation and National Haemoglobinopathy Register data entry for all areas within the network, overseen by a Network Manager who manages the entire EMSTN.

CARE OF CHILDREN AND YOUNG PEOPLE [1]			
Nottingham University Hospital Queens Medical Centre	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 *(hosted by Sandwell and West Birmingham Hospitals NHS Trust in partnership with Birmingham Women's and Children's Hospital NHS Foundation Trust)*		
	Linked Local Haemoglobinopathy Teams (LHT)	Patient Distribution	
		SCD	Thal.
	University Hospitals of Derby and Burton	31	10
	United Lincolnshire Hospital NHS Trust	13	<=5

[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.

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 last year
Sickle Cell Disorder	Children & Young People	94	94	90 completed or offered 4 new babies not eligible	6	32	53
Thalassaemia	Children & Young People	8	8	8 completed or offered	<=5	0	<=5

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual WTE (at time of visit)
Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies	102	1.41 total PA allocated for Sickle Cell & Thalassaemia Service divided between 4 consultants
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with haemoglobinopathies	102	1.75WTE
Clinical Psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies	102	0.4 PA

Urgent and Emergency Care

All children with a sickle cell disorder and thalassaemia who required emergency care initially attended the children's Emergency Department (ED). During normal working hours, families could also contact the Clinical Nurse Specialist (CNS) and if attendance at the ED was advised, the CNS would inform the ED team of their expected attendance and provide them with the patient's background and current issues. All patients were issued with NHS E alert cards.

Upon attendance in ED, the patient was triaged and guidelines for acute management of SCD or Thalassaemia were followed. The 2023/24 audit of compliance with the NICE guidance covering managing acute painful episodes reported that only 42% of patient's had received analgesia within 30 minutes of attendance at the ED. If a period of observation was necessary, they would be admitted to the 12-bedded Children's Assessment Unit (CAU), where they could stay for up to 12 hours before either being discharged or transferred to a paediatric ward.

For all admissions, the pathway dictated that the specialist CNS and paediatric haematology registrar should be contacted for advice. If unavailable, the haematology oncology consultant could be contacted via switchboard. Out of hours, a paediatric consultant was available on call for advice if needed. An automated email was also generated and sent to the specialist team from the patient's alert on their electronic patient record.

During the visit, it was evident that efforts were ongoing to improve staff training and the patient pathway in collaboration with the ED.

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

In-patient Care

The primary ward for admitting children and young people was the 15-bedded haematology/oncology ward (E39), which included a unit for teenagers and young adults. If ward E39 was unavailable, patients were accommodated in other children's wards.

From April 2023 to March 2024, there were 53 emergency admissions. The majority (36) were due to painful vaso occlusive crises, with other admissions for infections, line infections, and management of comorbidities.

A 2023/2024 admissions audit revealed that 54% of patients were admitted to ward E39, 35% to ward E37 (acute medical ward), 3% to ward E40 (neurosurgical ward covered daily by the oncology team as regular inpatients providing shared care), 3% to ward E17 (renal ward due to bed pressures), and 5% to an appropriate surgical ward for surgical admissions.

Patients on ward E39 received care from nurses and doctors trained to manage this specific patient group, skilled in handling complex cases. Paediatric haematologists and oncologists used a 'hot week' system for inpatient care, conducting twice-weekly joint consultant ward rounds. Paediatric haematologists were available for advice between consultant ward rounds if not on 'hot week' duty. All patients in other wards were reviewed as part of the daily ward round. Surgical admissions followed a predefined surgical pathway, with pre-admission care plans, and were admitted to ward D35. All admitted patients received regular input from a Clinical Nurse Specialist (CNS).

Post-admission follow-ups were offered to all children.

Day care

The day care area, shared with paediatric oncology, other haematology services, and rheumatology, was located adjacent to the inpatient ward, facilitating easy access to their facilities. It operated from 8 am to 8 pm Monday to Friday, and from 8 am to 4 pm on Saturdays, allowing for after-school blood transfusions and blood tests. The area included clinic rooms for private patient reviews. Records for children on transfusion programs and other frequent attendees were maintained in the day care area.

Some children had indwelling port devices for venous access, which the nursing staff were trained to manage. Additionally, some nurses on the unit were skilled in venepuncture and cannulation. If these nurses were unavailable, the day care clinical fellow would establish intravenous access.

During the visit, the review team were informed that Clinical Nurse Specialists (CNSs) supported the day care staff one Saturday per month due to unexpected long-term sickness. This support had enabled the service to continue operating on weekends and provided the CNS team an opportunity to assist and support haemoglobinopathy patients and their families.

Outpatients

Nottingham University Hospital (NUH) had two large children's outpatient departments providing general paediatric clinics as well as a wide range of subspecialty clinics. The Children's Outpatient Department was open from 9 am to 6 pm, Monday to Friday. Clinics were held on the 1st, 3rd, 4th, and 5th Thursday mornings, and the 2nd and 4th Fridays of the month. Each clinic was attended by Paediatric Haematology Consultants and Clinical Nurse Specialists (CNS). The 5th-week Thursday clinic, occurring four times per year, was a Transition Clinic with longer appointment slots. These clinics were attended by the Adult Haemoglobinopathy Consultant, Transition CNS, and Clinical Psychologist, in addition to the regular staff, to facilitate smooth transitions for patients.

The clinical psychologist had an allocated room to see clients and their families either alongside or independently from the clinic on the 5th Thursday. The clinic area included a phlebotomy department with a nurse and a play specialist assigned to each shift. Older children (12yrs and above) could use the hospital

phlebotomy department after a clinic appointment or for blood tests at any other time. Blood-taking services were also available at the treatment centre on-site at NUH, which offered an out-of-hours service.

Transcranial Doppler (TCD) scans were performed at NUH, usually on the same day as the child's outpatient appointment.

Endocrinology reviews for young people requiring monitoring were offered during the transition clinic in October each year, led by the lead consultant for Endocrinology at NUH.

The children's outpatients also housed the sleep study service and had separate outpatient facilities for routine monitoring of audiology, ENT, and ophthalmology as needed.

A paediatrician with an interest in Haemoglobinopathy ran the Hydroxycarbamide clinic on the 1st Monday of the month, held in the day care unit, accompanied by a CNS. The review team were informed that this clinic tended to be overbooked to accommodate all patients and to enable them to be seen every 3 months. Plans were in place to set up a nurse-led clinic to run alongside this clinic in the future.

The lead consultant also conducted 'on-demand'/ad hoc clinics for pregnant women and their partners who were considered 'high risk' of having a child with a red cell disorder. They provided support through the decision-making process and addressed any questions related to how the diagnosis could potentially affect their child, and their longer-term outcomes.

Community-based Care

At the time of the visit, there was no dedicated community provision; however, funding and plans were in place to recruit a Community Clinical Nurse Specialist (CNS). Historically, recruitment had been challenging for this post due to finding an appropriately skilled candidate. To address this, a developmental post was being considered, starting at a Band 6 level and progressing to Band 7 with additional training and experience.

Due to this gap in community provision, breaking bad news for newborn red cell disorder diagnoses was conducted by the Lead Consultant over the telephone, depriving parents of the opportunity for face-to-face support during this distressing time. School care plans were completed by the hospital CNS team. Additionally, for patients in Nottingham with indwelling catheters or those requiring phlebotomy at home, referrals were made to the Nottingham Children's Community Team.

Views of Service Users and Carers

Service user Feedback

The review team met three families caring for children and young people with living with a sickle cell disorder, two families caring for children and young people with Rare Inherited Anaemias/ Thalassaemia and one child living with Thalassaemia.

Sickle Cell Disorder service user feedback

- The Nottingham Paediatric SHT were described as phenomenal. They appreciated having a direct line post-COVID, noting it was much better than their previous experience in London. They felt their health outcomes would improve due to the high level of care provided.
- The paediatric service was praised as very good and amazing. They ensured blood tests were taken at the right time and even visited the school to provide care.
- Effective shared care arrangements with schools were in place, helping to coordinate care and support for the children.
- One parent noticed that during their son's admission, pain relief was prescribed on a PRN (as needed) basis, leading to delays until the pain peaked again, which is inappropriate during a crisis. They suggested that pain medication should be administered in proper rotations to manage pain effectively and that there should be a discussion with patients about the dosage when the drugs are prescribed. Additionally, they

noted that when any opiate is prescribed, a laxative should also be available PRN. They expressed uncertainty about the current protocol and mentioned they had to request these provisions for their son.

- One parent reported shared care between Derby and Nottingham to be satisfactory, with no experiences of discrimination in any setting. However, they mentioned encountering blockages in the Derby ED, indicating a need for staff education. The CNS was noted to know the family well and provide good support.
- Another parent stated that during a crisis on the ward in Derby, they observed discriminatory behaviour, noting a tendency for staff to care for non-black patients first suggesting an area requiring attention to ensure equitable care for all patients.
- Overall, the feedback was overwhelmingly positive about the service, with patients and their families commending the specialist team for providing outstanding care. When asked if there was anything they would change, the majority stated that there was nothing they would alter.

Thalassaemia and Rare Inherited anaemias

- Feedback from users highlighted the excellence of the paediatric service, with praise for the lead CNS described as marvellous, informative, and adept at keeping families informed. Service users expressed trust in the process, noting they could contact the team at any time and appreciated the team's extensive knowledge about thalassaemia
- A young person with thalassaemia expressed a desire for more age-appropriate activities in the day unit, noting that the current offerings were predominantly tailored for babies and young children.
- One parent stated that they would be interested in receiving more information regarding national events.
- Overall, the feedback was overwhelmingly positive about the service, with patients and their families commending the specialist team for their knowledge, empathy and support.

Good Practice

1. Team Cohesion and Collaboration

The team was noted for being cohesive and collaborative, with clear communication and mutual respect among colleagues. This teamwork translated into positive benefits for patients, as supported by patient feedback. The service was also recognised for its excellent collaboration with nurses across the region, enhancing overall patient care and support. Additionally, the Specialist Haemoglobinopathy Team (SHT) lead consultant was commended by colleagues for his accessibility, high levels of commitment, and support.

2 Joint Clinic Annual Review

Reviewers identified the Joint Clinic Annual Review, which included Transcranial Doppler (TCD) and Psychology clinics, as an exemplary practice. This approach provided patients with a comprehensive one-stop service, integrating various aspects of care into a single visit.

3 Weekend Transfusion Clinics

The introduction of Saturday weekend transfusion clinics (set up by one of the CNS's) was recognised as a significant enhancement, improving access to necessary treatments and accommodating patients' schedules more flexibly.

4 Iron Chelation MDT

The formalisation of the Iron Chelation Multidisciplinary Team (MDT) was another notable practice. This MDT regularly reviewed blood results, medications, transfusion amounts, and patient compliance, ensuring tailored and up-to-date treatment plans.

5 Endocrine Consultant in Transition Clinics

The attendance of an endocrine consultant at transition clinics was highlighted as an important practice. This ensured that young patients transitioning to adult care received comprehensive endocrine evaluations and continuity of care.

6 High-Risk Pregnancy Clinics

The provision of ad hoc consultant clinics for high-risk pregnancy couples was outstanding and innovative. These clinics offered specialised consultant support and detailed information, helping couples navigate the complexities of high-risk pregnancies from red cell disorders.

7 Social Worker and Benefits Advisory Portal

The implementation of a social worker and benefits advisory portal across the Haemoglobinopathy Coordinating Centre (HCC) network demonstrated good results. This service provided critical support to patients and their families, addressing social and financial concerns effectively.

8 Apheresis Service Plans

The service's plans to involve the dialysis service to implement an apheresis service showcased their commitment to innovative and efficient ways of working. This development aimed to enhance treatment options and patient outcomes.

9 Patient Education and Awareness Events

The specialist team organised education and awareness events for patients, highlighting their dedication to patient empowerment and knowledge.

10 Effective Networking and Resource Utilisation

The effective networking and resource utilisation were exemplified by the Network Manager and National Haemoglobinopathy Register (NHR) data manager post across the East Midlands Sickle Cell and Thalassaemia Network (EMSTN). These roles demonstrated the network's success in data management and coordination.

11 Youth Service - Aspire

The youth service, Aspire, received commendation from patients, indicating its effectiveness and positive impact on young people.

12 Newborn Screening Carrier Clinic

The newborn screening carrier clinic, led by one of the CNS's and initiated in February 2023, was reported to be working well. This clinic played a crucial role in early detection and management of haemoglobinopathy carriers.

13 Parent and Child Coffee Mornings

The introduction of coffee mornings for parents and children/young people, following patient feedback, demonstrated the service's commitment to incorporating patient input and providing support opportunities.

15. Play specialist

The play specialist in the day unit was highly commended for her valuable contributions. She had established strong and collaborative relationships with the specialist team undertaking several additional roles that significantly benefit patients and their families. One notable contribution was the creation of colourful and informative boards designed specifically for patients and carers. These boards served as a vital resource, providing clear and engaging information that helped patients and their families understand their care and treatment plans better.

Immediate Risk

No immediate risks were identified during the visit.

Serious Concerns

1. Consultant Staffing

Reviewers highlighted a serious concern in relation to consultant staffing capacity. There were insufficient medical staff trained in managing people with haemoglobin disorders (1.41 PA total for 102 patients) to adequately support regular reviews, emergency care, and clinics. Based on the UK Forum guidance on consultant staffing levels of 1.5 PA for every 50 patients for direct clinical duties staffing, the service is significantly under resourced.

2. CNS Staffing at Derby Local Haemoglobinopathy Team

At the time of the visit, there was no allocated Clinical Nurse Specialist (CNS) post at the Derby and Burton LHT, resulting in the consultant being very stretched as they had to cover all clinics independently. Although additional network funding had been secured through specialised commissioning, it was still in the process of being divided across the network. The SHT had requested funding for a 1.0 WTE CNS for the Derby and Burton LHT.

3. Lack of dedicated Specialist Community Service Provision

At the time of the visit, reviewers were seriously concerned that there was no dedicated community service provision resulting in additional workload on the specialist hospital team to cover elements of the service and a lack of face-to-face support for parents receiving newborn red cell disorder diagnoses. However, funding to recruit to a community CNS post had been agreed and recruitment was due to commence.

4. Concern Regarding Lack of Apheresis Service

A significant concern noted by reviewers was the lack of access to automated red cell exchange transfusion, resulting in patients receiving suboptimal treatment. Although a machine had been purchased, the business case submitted in March for staffing the service was still in the process of approval. If this business case is not approved, the plan is to commence delivery of the service by the end of 2024 will be unachievable.

Concerns

1. Psychology Support for the service

Despite having a comprehensive psychology pathway, the dedicated psychology capacity for the service was inadequate. At the time of the visit there was 0.4 WTE dedicated Psychologist in post which is insufficient to provide a comprehensive psychological service across the SHT and did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE psychologist for every 300 patients. Reviewers were concerned that the lack of specialist psychology for children and young people may result in them having difficulties in coping with challenges associated with their condition'.

2. Access to Analgesia in the Emergency Department

Compliance with pain relief standards in the Emergency Department required improvement with only 42% of patients receiving pain relief within 30 minutes (23/24 audit).

Further Considerations

1. Further consideration should be given to the capacity of the Hydroxycarbamide clinic, as reviewers were informed that these clinics are frequently overbooked to accommodate all patients.

2. Updated Service Level Agreements should be established for LHTs. Reviewers were informed that obtaining approval for these agreements has been an ongoing challenge. However, the network manager had devised a strategy to leverage the opportunity of new network funding as an incentive to achieve sign-off

3. Many of the policy documents were in draft form at the time of the review. Ensuring timely ratification of these documents is essential to guarantee they are easily accessible to all staff within the trust

4. To ensure the highest standard of care in Transcranial Doppler (TCD) ultrasound, the Trust should recognise that while staff may possess significant experience, maintaining ongoing proficiency through regular practice is equally critical. Consideration should be given to how clinicians can meet the recommended benchmark of performing at least 40 scans per annum to ensure skill retention. Strategies such as access to additional scanning sessions, or partnerships with other departments or hospitals to share caseloads may support staff in achieving this standard.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

The team reviewed the healthcare services provided to adults with haemoglobin disorders at Nottingham University Hospital NHS Trust (NUH). There were 235 adult patients registered, with 173 with living with a sickle cell disorder and 62 living with thalassaemia or a rare inherited anaemia. Additionally, University Hospitals of Derby and Burton (UHDB) reported a total of 61 patients with a haemoglobinopathy disorder, while United Lincolnshire Hospitals had 13 patients. The review involved visits to both the City Hospital for adult services and Queens Medical Centre where the emergency department pathway for haemoglobinopathy patients was also reviewed.

During the visit, several key developments and achievements were noted. The team were informed that funding had been secured to increase the provision of psychological services from 0.4 to 1.0 WTE, with the new recruit starting in Autumn 2024. Funding was also secured for an expanded Clinical Nurse Specialist (CNS) establishment, including a community post, The development of a Red Cell Clinical Fellow post proved to be successful. The CNS team had completed King's courses, prescribing course and psychology training. This supported their work toward enhanced communication and practical skills.

Research initiatives included the opening of a Natural History Study at NUH, reflecting the team's commitment to advancing the understanding and treatment of haemoglobin disorders. The apheresis service had seen significant improvements, with the transition of many established apheresis patients from regular femoral lines to either Portacath or Graft/fistula vascular access solutions. Two ultrasound machines were purchased through a competitive trust technology procurement process, and an apheresis machine was acquired for QMC through Medtech funding.

Outreach efforts had increased engagement with Local Haemoglobinopathy Teams (LHTs) and established a transition pathway and dedicated nurse, ensuring continuity of care for patients moving from paediatric to adult services. The prioritisation of inpatient care was evident, with reduced numbers of sickle cell patients on outlier wards by prioritising bed availability on Stirland Ward. Additionally, a CNS care plan clinic and updated Emergency Department guidelines were implemented to improve patient care.

Despite these advancements, challenges were acknowledged, such as variable pain audit data and local patient experiences at LHTs, the vacant psychology post, lack of a second substantive consultant to support the service, and high staff turnover in admission areas, wards, and ED. Previous instability and a small team had made education and service improvement difficult, but significant progress had been made in the last 2 years, which was visible during the visit.

The adult team was comprised of dedicated professionals, including the Red Cell Lead, Adult CNSs; Locum Consultant; Fellow; and a Clinical Psychologist, commencing in September 2024. The team was further supported by antenatal screening midwives, an apheresis team, a transition CNS, patient support workers, red cell laboratory staff, blood bank staff, administrative support, and a PA.

Overall, the peer review highlighted the considerable advancements and ongoing challenges in providing comprehensive care for adults with haemoglobin disorders at Nottingham University Hospital NHS Trust.

CARE OF ADULTS[3]							
Nottingham University Hospital NHS Trust- City Hospital	Linked Haemoglobinopathy Coordinating Centres (HCC)						
	East Midlands Sickle Cell HCC *(hosted by University Hospitals Leicester NHS Trust)* Midlands Thalassaemia and Rare Inherited Anaemias HCC *(hosted by Sandwell and West Birmingham Hospitals NHS Trust in partnership with Birmingham Women's and Children's Hospital NHS Foundation Trust)*						
	Linked Local Haemoglobinopathy Teams (LHT)				Patient Distribution		
					SCD	Thal.	
	Sherwood Forest Hospitals NHS Foundation Trust (Kings Mill Hospital)				Numbers included in NUH data		
	United Lincolnshire Hospitals NHS Trust (Lincoln County Hospital, Pilgrim Hospital Boston)				15	0	
	University Hospitals of Derby and Burton NHS Foundation Trust				46	20	

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	166	166	146 – DNA 20	26	36	189
Thalassaemia	Adults	58	58	55- DNA 3	20	<=5	<=5

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant haematologist dedicated to work with patients with haemoglobinopathies	224	8.5 PA (with additional time provided by Locum consultant)
Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies	224	2.4 WTE (In post additionally 1WTE on Mat leave)
Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies in the community	224	0
Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies	293	1WTE funded post but is currently vacant

[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

During the visit, the ED had been crowded, with all 30 major cubicles and 8 resus bays occupied. The triage nurse assessed patients on arrival, stating that the process would be the same for haemoglobinopathy patients. It had also been noted that there was inconsistent flagging in the system for haemoglobinopathy patients; some patients had flags while others did not. Care plans were available on the Electronic Patient Record (EPR). The triage nurse commented that she had not seen a haemoglobinopathy patient in a long while due to the direct admissions process and the low number of haemoglobinopathy patients compared to the overall volume of patients attending the ED. Despite the busy department, she assured the reviewers that haemoglobinopathy patients would be prioritised according to their needs.

The ED registrar appeared knowledgeable about haemoglobinopathies and had stated that the acute pathway for sickle cell crisis was in the process of being updated to specify timing for pain relief. Significant issues with space and overcrowding had been evident, with patients being seen along the corridor and in the middle of the main majors' department. The sister in charge remarked that the department had not been busy at the time, even though the observed wait time from triage to being seen had been 30 minutes, which could extend up to 3 hours in the ambulatory area during peak times. This further supported the need for a 24/7 admission process to the Specialist Receiving Unit (SRU).

The ED team expressed that they had opportunities for training and that the specialist teams had been very responsive. However, nurse staffing in the ED had been a concern as they were not working to the Royal College of Nursing (RCN) and ED recommended staffing ratios due to vacancies.

For patients already known to the Haemoglobinopathy service, there was a 24-hour 7-day haematology helpline available for urgent admissions. The haematology nurse on call liaises with the ward, registrar, and nurse in charge on Specialist Receiving Unit (SRU) regarding pending admissions, ensuring patients are directed to SRU for assessment as needed. If one of the known patient did visit the ED, every Monday an email was sent to the Haemoglobinopathy team to alert them of any of their patients that would have visited the ED the previous week. Patients experiencing painful crises who did not require admission would be directed to access the haematology day case unit, depending on the unit's capacity on that day.

Patients unknown to Nottingham University Hospitals (NUH) may initially present to the ED and subsequently be transferred to Specialist Receiving Unit SRU. An emergency alert system was in place, with email alerts sent to the Haemoglobinopathy team, Non-Malignant Haematology Consultants, and Specialist Registrars (StRs) for all admitted patients to their speciality,

In-patient Care

The inpatient haemoglobinopathy areas at Nottingham University Hospitals (NUH) consisted of three main wards: Toghill, Fletcher, and Stirland, collectively providing comprehensive care for haemoglobinopathy patients. Toghill Ward had 22 beds, comprising six double-bedded areas and ten single rooms, all equipped with either positive or negative air pressure systems for protective isolation or barrier nursing. This ward catered to patients with general and malignant haematological disorders. Fletcher Ward housed the Bone Marrow Transplant Unit, an 18-bed unit with all single rooms featuring positive pressure ventilation. This unit primarily served patients undergoing haemopoietic stem cell transplantation and young patients undergoing AML induction chemotherapy, accepting patients from the wider region, including Nottinghamshire, Derbyshire, and Lincolnshire. Stirland Ward, which opened in 2023, was shared with Oncology, and typically had around ten beds occupied by haematology patients.

The environments in these wards were noted to be clean and tidy, with infection control measures strictly encouraged as per protocol. Posters on the walls and verbal prompting ensured adherence to these measures. There was some information on sickle cell disorders on the walls, but in comparison there was a noticeable lack of information about thalassemia. In one of the wards, nurses who spoke to the review team had not heard of thalassemia.

When the main haematology wards were full, patients were looked after on other wards such as Burns, Harvey, Bramley, and Barclay; but it was reiterated that every effort was made to create bed availability prior to outlying patients.

The Haemoglobinopathy Consultant had done the bulk of ward attending duties since starting in the role, but since September 2023, a Locum Consultant supported the ward, covering one week in three. Ward rounds were conducted twice weekly, with additional reviews by the Lead Consultant as needed for acutely unwell patients. Admissions to the Specialist Receiving Unit (SRU) were managed by the Attending Malignant Haematology Consultant on weekends and a designated Malignant Consultant from Monday to Friday (excluding Tuesdays). The Haemoglobinopathy Consultant was available for advice during working hours, with additional support from the Non-Malignant Haematology Consultant on call in their absence.

The SRU served as the main specialty admission area for Haematology, Oncology, Renal, Diabetes/Endocrinology, and Infectious Diseases, with a capacity of 20 beds, including four side rooms. Haemoglobinopathy patients who required an emergency admission or assessment were instructed to contact the haematology nurse on call for triage. If admission was necessary and the patient did not require specialist input from Cardiology, Stroke or Antenatal teams, patients would then be directed to SRU and the unit informed of their imminent arrival. Patients experiencing painful crises who did not require admission would be directed to access the haematology day case unit, depending on the unit's capacity on that day.

Patient management and care coordination included a surgical pathway with pre-admission care plans, admitting patients to SRU unless they required specialist team interventions. Out-of-hours support involved an emergency helpline for urgent reviews and admissions, with nurses completing a screening form for direct admission to SRU. In cases where SRU was at capacity, patients were diverted to the ED. It was highlighted that every effort was made to create capacity on SRU initially rather than directing patients to ED wherever possible.

Day Unit

The adult Day Case Unit consisted of 22 beds where many haematology patients were seen daily for assessment, treatment, and various procedures, including chemotherapy administration, blood transfusions, and bone marrow aspiration and biopsies. The unit also included the Apheresis unit, which was equipped with four Spectra Optia apheresis machines. This allowed for all therapeutic apheresis procedures to be carried out for patients from across the region, including those from other local hospitals in Derbyshire and Lincolnshire.

The Day Case Unit operated a booking system for patients to attend and undergo procedures including transfusion. The unit was open from 8 am to 8 pm Monday to Friday and on Saturdays from 8 am to 4 pm.

Sickle cell and thalassaemia patients on a top-up transfusion programme were either transfused in the Haematology Day Case Unit or the Same Day Emergency Care (SDEC) unit, depending on capacity. Patients living with a sickle cell disorder experiencing a vaso occlusive crisis could also be seen in the Day Case Unit for pain management from Monday to Friday, although this was not always possible due to limitations with capacity.

Top-up transfusion plans were kept in a folder in the Haematology Day Case Unit, while patient exchange transfusion care plans were stored on the apheresis drive. A multidisciplinary team (MDT) review of patients on exchanges was held between apheresis nurses, the Haemoglobinopathy Consultant, and the Haemoglobinopathy CNS three to four times a year.

Outpatient Care

All the haematology clinics were held in the dedicated outpatient suite on the ground floor of the Centre for Clinical Haematology. This suite included its own phlebotomy area and a Sysmex blood count analyser for processing urgent blood counts. The suite featured 11 consulting rooms and a quiet room, providing a conducive environment for patient consultations.

The outpatient clinics for patient living with a sickle cell disorders and thalassaemia were scheduled every Wednesday and Friday afternoon, except for the second Friday of each month when the annual review (AR) clinic was held in Derby. Clinics were led by a consultant haematologist with support from Clinical Nurse Specialists (CNS) or support workers. In the 2022-2023 period, approximately 600 outpatient appointments were offered. The last clinical psychologist in post prior to the current vacancy had an allocated room and saw clients alongside or independently from the clinic on Fridays

CNS clinics included a Hydroxycarbamide monitoring clinic on Thursday afternoons, a nurse follow-up clinic on Friday afternoons, and a transition clinic on Wednesday afternoons. Out-of-hours phlebotomy services were available both in the clinic and the day case unit, as well as in phlebotomy suites at both sites. Additionally, drop-in blood tests were performed in haematology outpatients at the City site on Tuesday mornings and Friday afternoons.

The reviewing team found the outpatient suite environment to be very pleasant and comfortable. They particularly mentioned the comfort of the chairs and appreciated the easy access to the suite, noting it as a significant advantage for patients and staff alike.

Community-Based Care

It was noted that there were no community service available at the time of the visit; however funding had been secured for a CNS to support this community role, and the position was set to go out for recruitment.

Views of Service Users and Carers

On June 11, 2024, a peer review meeting was conducted with 14 adult living with SCD (Sickle Cell Disorder), and on June 21, 2024, a meeting with four adults living with Thalassaemia and carers, was held. Further feedback was also obtained from two patients who were on-site during the visit. The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences.

Sickle Cell Disorder service user feedback

Patients expressed significant concerns and mixed experiences with their treatment and care for their Sickle Cell Disorder (SCD). One patient was very unhappy and highlighted a lack of black nurses and insufficient knowledge about SCD among new nurses, criticizing a new consultant for lacking leadership skills and advocacy. Previous consultants were respected and missed by patients. Reports of stereotyping, racism, and victimization on the wards were common, with patients feeling labelled and not taken seriously, especially when in pain.

Quality of care was inconsistent between different hospitals, with City Hospital often preferred over LHT care such as that received in Kingsmill. Some patients noted positive improvements in care over the years in the East Midlands, particularly at Kingsmill. Pain management was a significant issue, with delays in receiving analgesia and inadequate pain management. Patients called for individualized pain plans and consistent use of PCA machines.

Communication and advocacy needed improvement, with the Red Cell team urged to advocate more strongly for patients. Although patients felt heard, they saw no changes following complaints. Service and training improvements were necessary, with staff training needing to address stereotyping and improve the pain pathway. Patients also called for more visible complaint processes and better coordination between hospitals.

Despite these challenges, some patients praised the seamless care and support from the Specialist Haematology Team (SHT) and specific staff members. Outpatient services also received positive feedback. Additionally, patients requested more support in explaining their condition to employers. The feedback underscored the need for enhanced training, better pain management protocols, more consistent advocacy, and improved racial sensitivity among staff.

Thalassaemia and Rare Inherited anaemias service user feedback

Patients were generally happy with the team and felt the consultants were great. They felt the phlebotomy service needed to be improved as waiting times for their pre transfusion blood tests ranged around 90 mins on average which really affected their quality of life. Patients also expressed concern with the transfusion booking service as they felt they were not being prioritised and often would become extremely symptomatic before transfusions due to the delays in bookings/ or finding appointment times for this. They commented that it would be helpful if the team reviewed this process to ensure they receive their transfusions within the correct time, ensuring their pre-transfusion haemoglobin levels are kept within the UK guidelines. This was also impacting their quality of life and some patients spoke about not being well enough to do the activities they were once able to do or to keep up with their peers.

Additionally, patients commented that outside their haematology consultant and CNS, staff including nurses and doctors (including ED) were not aware of thalassaemia or understood how to treat the condition.

With regards to transitioning from paediatric to adult services or from other countries, there were mixed views about the process. The transition experience was better for those who moved from the paediatric service in Nottingham but not so great for those new to the area who described not knowing the process or being given any information on what to expect. Patients felt it would be beneficial if there was more information on the service and also on their condition and if it could also be available in other languages.

Good Practice

1. The Team consistently showcased outstanding dedication. Both the nursing and medical teams demonstrated exceptional enthusiasm and commitment to the service and patients.

2. The introduction of a 24/7 hotline streamlined access for patients, with the SRU allowing patients to bypass ED. Patient feedback on the care received on SRU was positive.

3. Funding had been secured to increase Psychology provision from 0.4 to 1.0 WTE, with the newly appointed recruit set to start in autumn 2024.

4. Funding had been secured to expand the Clinical Nurse Specialist establishment to include a community post.

5. Enhanced training for the CNS team included the Kings Courses, prescribing course, and psychology training.

6. The establishment of a transition pathway and dedicated Nurse improved continuity of care.

7. The establishment of a Red Cell Clinical Fellow post reflected ongoing commitment to specialised care.

8. The development of a community referral pathway for Talking Therapies and the use of complementary therapies (aromatherapy and Reiki) was noted.

9. A dedicated phlebotomy service and point-of-care blood testing in the haematology outpatient clinic enabled tailored care for blood count monitoring.

10. Significant strides were made in the education of staff, as wards had link nurses who attended regular meetings and cascaded information to their colleagues at the ward level. Training in sickle cell disorders management was mandatory for all new starters in the Cancer and Associated Services (CAS) divisional team.

11. The Senior Management team were very engaged and involved in further plans for the service.

12. Specialised funding was ring-fenced for the team to utilise and improve patient outcomes.

Immediate Risk

No immediate risks were identified during the visit.

Serious Concern

1. Consultant staffing

Consultant staffing was a significant concern highlighted by reviewers, who noted insufficient medical staff with appropriate competencies in managing people with haemoglobin disorders to adequately support regular reviews, emergency care, and clinics.

During the visit, the Lead Consultant was allocated a total of 7 PAs for direct clinical care of 224 patients with haemoglobin disorders, in addition to 1 PA for the SHT lead role. According to UK Forum recommendations, the consultant staffing was notably inadequate, impacting their ability to attend network meetings, conduct audits/research, and update policies. A locum consultant was in post at the time of the visit and provided some support to the service. Other consultants within the non- malignant service undertook CPD and attended MDTs to discuss patients

There was a lack of future-proofing evident across the SHT, as the lead consultant had no deputy, and there were no arrangements in place for cover during absences.

Concern

1. Doctors in training development

Registrars were not given the opportunity to attend Red Cell clinics due to schedule clashes and reduced staffing numbers. With difficulties in recruiting at the consultant level, it was deemed prudent to invest in registrar training and exposure to clinics. It is also vital that haematology trainees receive exposure to and education in outpatient haemoglobinopathy management as well as care of inpatients, as part of their training programme.

This concern had been raised previously to the school; however, the situation had not been resolved at the time of the visit.

2.Patient experiences and complaints process

Despite significant efforts and input by the specialist team, including the CNS, to improve patient experiences, feedback from patients has highlighted ongoing concerns regarding attitudes and behaviours at the ward level.

There was a clear need for well-defined guidelines outlining the complaints procedure for patients. Improvements in communication were essential to ensure transparency and visibility in the complaint resolution process. Patients expressed concerns that their complaints were not responded to in a timely manner and that they were unaware of the escalation process when they were dissatisfied with the responses.

Further Considerations

1. **Lack of Thalassaemia information**

   It is recommended that significant efforts be concentrated on improving the dissemination of information and training around Thalassaemia. The notable lack of knowledge and information on Thalassaemia during the visit highlighted the urgent need for enhanced educational initiatives and more written communication for patients and relatives. Addressing this gap is crucial for ensuring that healthcare providers are well-informed and adequately equipped to manage and treat patients living with Thalassaemia effectively; and patients and carers have a better understanding of Thalassaemia.

2. **Information**

   Improvements in the availability of visual information for Thalassemia on the ward are recommended. This should include posters, leaflets, links, or VR codes that provide comprehensive details and important telephone numbers. Additionally, the current information around Sickle Cell Care is very limited, existing only in the form of a display. Efforts should be made to include information about both the Sickle Cell

Society (SCC) and Thalassemia societies to ensure patients and their families have access to vital resources and support networks

3. **Updating Policies to Reflect Current Practices**

   It is recommended that the organisation update its policies and procedures to accurately reflect current practices. The organisation has demonstrated many good practices, which are evident in the high-quality care provided and the positive outcomes achieved. However, aligning policies and procedures with these exemplary practices is crucial to ensure consistency, compliance, and clarity across all operational areas. By bringing policies and procedures up to date, the organisation can improve staff adherence to protocols and provide clear guidance for all team members. This initiative will also support regulatory compliance and contribute to a more efficient and effective workflow, ultimately benefiting both staff and patients.

Commissioning

The review team had discussions with the regional NHSE specialist commissioner. 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.

The feedback from the NHSE commissioner for HD highlighted significant improvements that had been made with regard to support from the commissioners, particularly in terms of funding new posts and expanding the Apheresis service however at the time of the review the additional funding for the apheresis service had not been approved. The commissioners had prioritised the continuation of improvement work within the Midlands Haemoglobinopathy services. They emphasised the importance of collaborating closely with the HCC, LHT, and SHT to ensure that physical resources were available. Additionally, they underscored the necessity of ensuring that these priorities remained on the agenda for the ICB, recognising their role as the commissioners of care.

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Appendix 1 - Membership of Visiting Team

Visiting Team		
Stephen Boyd	Consultant Haematologist	North Middlesex University Hospital NHS Trust
Indu Thakur	Consultant Paediatric Haematologist	Children's Hospital for Wales, Cardiff and Vale UHB
Hannah Jerman	Clinical Nurse Specialist	Guy's and St Thomas' NHS Foundation Trust
Haidee Nicasio	Clinical Nurse Specialist	Guy's and St Thomas' NHS Foundation Trust
Tracey Bloodworth	Clinical Nurse Specialist	Alder Hey Children's NHS Foundation Trust
Lesley McCarthy	Clinical Nurse Specialist	Oxford University Hospitals NHS Foundation Trust
Kevin Peters	Senior Service Specialist	NHS England
Elizabeth Naamorkor Caulley	User Representative	Manchester Sickle Cell Society
June Okochi	User Representative	
Roanna Maharaj	User Representative	UK Thalassaemia Society

Clinical Leads		
Clare Samuelson	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Sabiha Kausar	Consultant Paediatric Haematologist	Manchester University Hospitals NHS Foundation Trust

NHS Midlands and Lancashire Team		
Rachael Berks	Clinical Lead	NHS Midlands & Lancashire
Sam Singh	Clinical Lead	NHS Midlands & Lancashire

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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
Specialist Haemoglobinopathy Team (SHT) Children and Young People	49	34	71%
Specialist Haemoglobinopathy Team (SHT) Adults	45	24	55%

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** a. Written information should be offered to children, young people and their families, and should be easily available within patient areas, covering at least: b. Brief description of the service, including times of phlebotomy, transfusion and psychological support services c. Clinic times and how to change an appointment d. Ward usually admitted to and its visiting times e. Staff of the service f. Community services and their contact numbers g. Relevant national organisations and local support groups h. Where to go in an emergency i. 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	Y	
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).	Y	
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	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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)	Y	
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	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	Y	
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	Y	SCD questionnaire – 14/194pt responses Thalassaemia questionnaire 3/ 8 pts responses

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	
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.	Y	
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.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	Inadequate consultant time to cover clinics (1.41 PA total for 102 patients) Based on the UK Forum guidance on consultant staffing levels of 1.5 PA for every 50 patients for direct clinical duties staffing, the service is significantly under resourced.
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.	Y	
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	Currently inadequate CNS capacity across the SHT to provide LHT support. There was no formal competence framework in place. The HCC framework had not yet been implemented. No community post however funding had been agreed and recruitment was due to commence.

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	Inadequate psychology capacity to cover the SHT. 0.4wte dedicated Clinical Psychologist working within the broader Psychology team. Good psychology pathway and review questionnaires.
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.	N	Staff providing TCD. Competent with years of experience but not reaching the 40 scan per year standard (due to numbers requiring the service).
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	Inadequate admin support within the service. Consultant PA helps however no direct support for CNS. Network data manager submits NHR data and has honorary contract to ensure all SHT's are up to date with submissions.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	
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	N	No access to automated red cell exchange transfusion; therefore, patients received sub optimal treatment. Machine had been purchased however business case (submitted in March) was still in the process of approval for staffing the service. Plan to commence delivery by end of 2024 if business case is approved.
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.	Y	

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	The joint (Adults and Paeds) transition pathway did not cover 'f'. All other aspects were met.
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	N	No local SOP in place however the national guidance was followed.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	N	Guidelines in place however stated no automated red cell exchange and that they would contact NHSBT to see if transfusion could be provided by them.

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	N	Guidelines in draft form – awaiting ratification
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	N	Draft guideline awaiting ratification.

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	The guidance did not cover 'l' dental
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	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	Available on Trust Intranet
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	Y	

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 yet in place however there were plans to progress with the 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).	Y	
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	Integrated acute and community service.
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	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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.	N	No evidence of meetings taking place
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	Y	
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS HC-702d).	Y	
HC-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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.	Y	
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'.	Y	
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.	Y	

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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 HC-199)	N	'a' Information was not very clear on what information patients received as opposed to what information was for staff 'b' Not provided 'c' Ward visiting times was not clearly documented. 'f' No clear evidence that information was shared with patients or relatives – no posters or leaflets available. 'h' Information was not clearly displayed and there was no written communication, such as leaflets or contact details, for patients to take away and refer to. Staff commented that patients were given verbal information and/or emails, but the reviewers remained unclear about when this occurred in the care pathway. Staff also expressed that patients were given contact numbers on cards and a new patient contacts letter.

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**	'a' Information was very basic covering inheritance 'c' No clear information on emergency advice 'g' No clear health promotion; complication advice
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 c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	**Y**	
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)	**Y**	

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.	Y	
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	A lot of good work had gone into reviewing the service, and the improvements made were notable. However, there was no evidence of operational policies, and no Thalassemia transition passport was available. The presentation given as evidence appeared to be intended for staff rather than young person. No written information was seen around the facility; however, a Transition leaflet was subsequently shared with the reviewing team. The visit revealed that many practices are being carried out, but now the necessary paperwork, documentation, and evidence need to be secured to verify these good practices.

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	No questionnaire for Thalassemia patients seen. The UKTS survey was not completed but noted was in progress.
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	N	No evidence of this was seen or provided before the visit. A plan to set up a patient representation group was discussed and in progress; however, this was not in practice at the time of the visit.
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	They had a lead consultant with 1 PA; however, there was no named deputy, which meant there was no evident cover when not on duty or for absences. Due to the substantive consultant post remaining vacant, despite numerous attempts to recruit, the lead consultant's workload was unsustainable. Support was offered in part by a locum.
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	The consultant time allocated for the service was inadequate. The Lead Consultant was allocated a total of 7 PAs for direct clinical care of 224 patients with haemoglobin disorders, in addition to 1 PA for the SHT lead role. 1.5 PA of SPA
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.	N	The registrar did not attend the Red Cell clinic as it clashed with their schedule. This issue was raised with the deanery but remained an ongoing problem.
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	Competences were not available in all areas, especially the wards. It was being developed with the view that all staff within the division would be required to undergo training as part of their mandatory training, starting with all new starters from August 2024. Competencies, however, were provided as evidence and were individualised to meet the needs of each area.

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	1.0 WTE was funded (post was vacant) and recruit begins in Autumn 2024. There was good practice available to support patients in the interim; in the form of a community referral pathway developed by Psychology services, including a dedicated pathway for talking therapies and complementary therapies (aromatherapy and Reiki) on site. The CNS team had also completed psychology training.
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.	Y	
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	At QMC, there was no automated red cell service, requiring patients to be transferred to City Hospital. The gap was recognised, and plans were in progress to improve this situation.

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.	Y	
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	There was a pathway document in place, but it lacked detailed guidelines. Regarding section G, there were no established arrangements between different centres, particularly concerning the transition pathway with Derby (LHT's).
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	

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	d. Information was not provided; patient feedback indicated that the nurses had two attempts. e. This standard asks that the patient pathway includes expected timescales, OOH services, waiting times etc - this was not covered in either guideline. f. was not covered in either guideline. Trust wide policy on central IV access is in development therefore cannot be counted as present at time of review
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	Y	

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	There was good RCT evidence for escalation to MDT as per the recommendation of the BSH guideline as a standard option. The BSH guideline also recommends offering to all patients with HbSS / SB0 genotypes due to improved life expectancy and this differs from the NUH guideline. The guidelines did not recommend hydroxycarbamide as standard for patients with HbSS / $HbSB^0$ thalassaemia, or that dosing should be escalated to maximum tolerated dose. In practice both were reported as implemented by the clinical team, but this was not reflected in the guidelines.
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	Y	

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 iv. 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 v. For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine	**N**	a. The acute pain guidelines were in draft locally to the department; approved guidelines were available within the trust. b. The Sickle Cell Crisis (SCC) guideline was out of date. c. The Thalassemia guidelines were good. d. The Sickle Cell Crisis (SCC) Emergency Department guideline was good.

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**	'i'. There were no chronic pain guidelines for Thalassemia. 'I'. There was no recommendation on dental care for SCC and Thalassemia.
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.	**Y**	

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	Y	
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	There were no service organisation polices or guidelines available covering the organisation of the service.
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	The SLA with Derby had no start or finish date

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	There was no community service available at the time of the visit; however, this was in the process of been looked at as recruitment to a CNS post was in process
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	
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	b. An audit covering acute admissions to inappropriate settings had not been completed, which included patient and clinical feedback on these admissions.
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
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.	Y	
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 Documents were out of date. On some policies it was noted; were adopted from different trust and the original trust (GSTT) information was not removed.

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