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UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

London North West University Healthcare NHS Trust

Visit Date: 14th March 2025

Report Date: 19th June 2025

Contents

Introduction

This report presents the findings of the review of London North West University Healthcare NHS Trust that took place on 14th March 2025.

The purpose of the visit was to review compliance with the Health Service for People with Haemoglobin Disorders Quality Standards Version 5.2, November 2023 which were developed by the Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit were 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:

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

A comprehensive peer review for 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 the report identifies the main issues raised during the course of the visit. Any immediate risks identified will include the Trust and UKFHD/NUCT ML response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in London North West University Healthcare NHS Trust 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:

- London North West University Healthcare NHS Trust
- NHS England London Region
- NHS North West London Integrated Care System

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 approached; 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 NHSE London Region and NHS North West London Integrated Care Board.

About the UKFHD and NHS ML

The UK Forum for 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 UKHFD 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 UKHFD is to, advocate and influence policy, promote and review best practice, share ideas and advise on research, educate health professionals, and support education of patients, whilst influencing and advocating on equitable prevention programmes for sickle cell and thalassaemia disorders.

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

More details about the work of the UKFHD and the NHS ML is available at https://haemoglobin.org.uk and https://www.midlandsandlancashirecsu.nhs.uk/our-expertise/nursing-and-urgent-care/

Acknowledgments

The UKFHD and NHSML would like to thank the staff and service users and carers of the London North West University Healthcare NHS Trust 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 then contributed to this review

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Review Visit Findings

London North West University Healthcare NHS Trust

Trust-wide General Comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders at London North West University Healthcare NHS Trust. During the visit the reviewers attended the Central Middlesex and Northwick Park Hospital sites and visited emergency departments, assessment units and wards. They met with patients and carers, and with staff providing services for the local health economy.

London North West University Healthcare NHS Trust provided care to approximately 850,000 people residing in Brent, Ealing, and Harrow in northwest London which was a diverse and multi ethnic community as well as from other London boroughs including Barnet, West Middlesex, Hillingdon and Hounslow. The children and young people SHT also provided some care for patients residing in Bedfordshire.

The Haemoglobinopathy Service at London North West University Healthcare NHS Trust (LNWH) was jointly commissioned by NHS England's specialised haemoglobinopathy services and the NHS North West London Integrated Care Board. Placed within the Haematology Department under the Clinical Division of Women's, Children's, and Clinical Services, the service operated across three sites. It provided comprehensive care through Haematology and Paediatrics, including inpatient care, day-care, outpatient clinics, newborn screening, and extensive community services via the Brent Sickle Cell and Thalassaemia Centre at Central Middlesex Hospital (CMH). In total the Trust cared for 708 patients living with a haemoglobin disorder.

LNWH was designated by NHS England as a 'Specialist Haemoglobinopathy Team' within the Sickle Cell Disease West London Haemoglobinopathy Coordinating Centre (HCC), in partnership with Imperial College Healthcare NHS Trust and St George's University Hospitals NHS Foundation Trust. Furthermore, it was part of the Thalassaemia HCC for London, South Central, and South West in collaboration with University College London Hospitals NHS Foundation Trust, Imperial College Healthcare NHS Trust, and St George's University Hospitals NHS Foundation Trust. Peer review visits to both HCCs took place before the visit to LNW SHT and the HCC reports once published will be available on the UK Forum for Haemoglobin Disorders website.

West London HCC, Thalassaemia HCC, and National Haemoglobinopathy Panel (NHP) MDT meetings were held monthly. Additionally, the West London HCC and Thalassaemia HCC conducted adverse event MDTs every three months. The LNWH Consultant Psychologist for haemoglobinopathies, was also the Deputy Clinical Director for the West London HCC and represented the West London HCC and LNWH on the NHP MDT.

Some issues in this report relate specifically to the Trust as a whole and have been included in the Trust-wide section of the report. Other issues that were the same for both the adult service and the children and young people service have been repeated in each section of the report.

Trust -wide Good Practice

Trust-wide Good Practice – children and young people

1. The implementation of the Cerner electronic patient record system significantly improved clinical efficiency and communication across SHT hospital sites. This real-time access to essential patient information streamlined decision-making and improved continuity of care.
2. The inpatient ward (Jack's Place) provided a child-friendly and interactive environment catering to all age groups, from infants to teenagers. The ward's facilities and design ensured that children felt comfortable and engaged during their hospital stay, helping to reduce anxiety and improve overall patient experience.

3. A dedicated phlebotomy service operated during the Tuesday clinic, ensuring that haemoglobinopathy patients requiring regular blood tests had timely and efficient access to blood sampling. This service contributed to improved patient flow and reduced waiting times, enhancing patient satisfaction and care delivery.
4. As part of the junior doctor induction programme, sickle cell disease was included as a key area of learning. This ensured that new doctors had early exposure to and awareness of the complexities of managing haemoglobinopathies, promoting better recognition and management of complications such as sickle cell crises.

Trust-wide Good Practice – adults

1. The provision of the emergency call pathway for patients to attend the medical day unit at CMH provided timely management and early escalation. Patients who met with the reviewing team spoke highly of the service.
2. All adult and transition clinics were followed by an MDT discussion about the scheduled patients including those who reviewing any actions needed for those who did not attend.
3. A research fellow in partnership with one of the consultants had developed a 'Sickle Cell Education Series' to improve patient's knowledge and engagement in their care. The sessions had been well received patients and patients continued to be directed to view the sessions on a 'You Tube' channel.

Trust -wide Serious Concerns

1. **Inadequate Care for Patients with Haemoglobinopathies in the Paediatric Emergency Department**

   The reviewers were seriously concerned about the paediatric emergency department pathway for the following reasons: -

   a. Delayed Administration of Analgesia

   The Pain Audit identified significant delays in the administration of analgesia for patients with haemoglobinopathies attending the Paediatric Emergency Department (PED). The average time from arrival to treatment was 1 hour and 40 minutes, with a median time of 36 minutes. Alarmingly, fewer than 25% of patients received analgesia within 30 minutes, despite the recognised urgency of pain management in those patients experiencing a sickle cell vaso-occlusive crises. This delay posed a substantial risk to patient safety and was further corroborated by negative patient feedback regarding their experiences in the emergency setting.

   b. Lack of a Priority Flagging System

   There was no alerting system in place within the Electronic Patient Record (EPR) and no patient passport or 'Act Now' card issued to patients to prioritise and flag patients with sickle cell disease (SCD) upon arrival at the Paediatric Emergency Department. As a result, the service was reliant on families informing staff within the reception area of their child's condition in the event of a sickle cell crisis. This lack of an automatic alert system increases the risk of delayed care and inadequate triage, potentially compromising patient outcomes.

2. **Trust Oversight of the Adult SHT**

   Reviewers were seriously concerned about the level of trust management support available to the SHT. Reviewers were told that there had been many changes to personnel at divisional and trust management level over the last few years and whilst the team reported that their divisional leadership was now supportive, many of the serious concerns in this report have been long-standing issues and escalated to the Trust management by the clinical team on numerous occasions.

   The challenges the adult SHT were facing in terms of patient pathways, the stretched workforce position and governance of the SHT were posing a risk to the viability of the SHT. It was clear to the visiting team, from discussions during the visit, that there was a disconnect between the issues escalated by the SHT and the trust responsibility, accountability and management action needed to address the issues for the SHT. Although workforce issues had been included on the Trust risk register at the time of the visit of particular concern were:

a. The consultant staffing especially for scheduled care and the gap between the available PAs and expected staffing levels.

b. The lack of psychology support and CNS time to care for the number of patients accessing the service as well as access to social and welfare support for this group of patients.

c. The lack of capacity and robust pathway within the SHT to undertake timely and comprehensive annual reviews for all patients living with a haemoglobin disorder and to create care plans for patients.

d. Governance of data especially compliance with the NICE guidance covering sickle cell disease: managing acute painful episodes in hospital as well as access to data and time to undertake the required SHT audits.

See also Serious concerns section of the adult report for more detail

3. **Delays in Progressing the ED Bypass Project**

The reviewers were seriously concerned about the delays to the implementation of the planned ED bypass pathway which would see patients with haemoglobin disorders who would usually attend the ED at NPH seeking emergency care via the ED bypass Unit based at the Hammersmith Hospital (HH). The full implementation of the pathway was dependant on expanding the inpatient bed base at HH for patients attending who would require ongoing care as an inpatient. Reviewers heard conflicting information about the timeframe for implementation and were concerned about the impact that delays were having on patients receiving timely emergency care. Patients who spoke to the visiting team were aware of the planned pathway but did not have any confidence that the bypass model would be operational anytime soon.

4. **SHT Allocated Funding**

Reviewers were seriously concerned that Trust management arrangements had not ensured transparency relating to specialised commissioning funding being clearly identified and allocated to the SHT. Contracting arrangements should be reviewed to ensure that SHT funding is utilised for the purpose for which it was allocated.

Trust-wide Serious Concern – children and young people

See Trust-wide section above

Trust-wide Serious Concern – adults

See Trust-wide section above and the Serious Concerns section of the adult report for more detail

Trust-wide Concern

1. **Access to Timely Analgesia for Adult Patients**

The trust had identified that the most recent service audit of compliance with the NICE clinical guideline on the management of acute pain for adult patients was incorrect as showing that 98-100% of patients had received analgesia within 30 minutes of arrival to the Emergency department. A recent snapshot audit had shown that this figure was grossly inaccurate. Patients who met with the visiting team also confirmed that when they attended the ED they had not received analgesia within the required timeframe. The reviewing team were told that a number of ED nurses were 'sickle cell link nurses' but they were not allocated any additional time to fulfil this role. The ED team was reliant entirely on the SHT to deliver education on haemoglobin disorders to the ED staff and to conduct the time to analgesia audit, with no active involvement by the ED leadership team in either.

Trust-wide Concern – children and young people

1. **Consultant Staffing**

Reviewers expressed concern regarding insufficient consultant medical staff with the necessary expertise in the care of individuals with haemoglobin disorders. This shortage has led to difficulties in providing adequate staffing for regular reviews, emergency care, and outpatient clinics for the 172 patients under their care. According to UK Forum guidance on consultant staffing, it is recommended that there be 1.5 PAs for every 50 patients for direct clinical

duties. While there has been an increase in staffing capacity since the previous review, a shortfall in consultant numbers remains, impacting the ability to provide timely and comprehensive care.

2. **Lack of Community Support for Ealing and Bedford**

   At the time of the visit there was no community support for patients in Ealing and Bedford. The acute Clinical Nurse Specialist (CNS) had been working to provide essential services, such as neonatal screening support and school care plans or letters of support, in these areas. While her dedication was commendable, the lack of formal community support in these regions placed a significant strain on resources and risks gaps in care.

3. **Unclear Funding and Commissioning Arrangements for Bedford LHT**

   Since the merger of Bedford Hospital with Luton and Dunstable University Hospital, the funding flows and commissioning arrangements for the Bedford Local Haemoglobinopathy Team (LHT) had become unclear. There was a lack of clarity surrounding the financial and operational structures, complicating the ability to secure adequate resources and support for the service. This uncertainty had created difficulties in sustaining and expanding services, negatively impacting patient care.

4. **Inadequate Facilities for Haemoglobinopathy Patients in the Day Unit**

   The day unit lacked a dedicated area for haemoglobinopathy patients, and the available facilities were cramped, with bed spaces in close proximity to each other. The design posed infection risks and reduced patient comfort. A more suitable and spacious environment would enhance both patient safety and overall experience for those receiving treatment

Trust-wide Concern – adults

1. **Access to chronic pain services**

   There was no access to a chronic pain team for patients with complex analgesia needs. Patients did not have access to a community pain service and access an inpatient pain team was limited.

2. **Guidelines**

   Many of the recommended guidelines were not in place. The HCC developed guidance was in the process of being ratified but had not yet been amended and approved for use locally. Reviewers were told that the lack of agreed and implemented guidance was in part due to the lack of clinician time to develop and progress this area of work.

3. **SHT Audit Completion**

   The SHT had not been able to undertake the required audits covering transfusion and acute admissions to other areas Reviewers were told this was due to the Trust IT systems being unable to provide the data and information and the lack of data support but alternative mechanisms for data collection and analysis had not been implemented.

Trust Wide Further Considerations

1. **Haemoglobinopathy alert card/ NHS England 'Act Now' Initiative**

   The NHS England Act Now Initiative aims to improve outcomes and experiences for people with Sickle Cell Disease. The use of Act Now cards or an alternative system for patient identification and priority recognition should be considered. Ensuring that all staff are adequately trained and that patients are issued with and encouraged to use their 'Act Now cards' would help streamline care in emergency settings and reduce delays in treatment.

Views of Service Users and Carers

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

The visiting team held focus groups prior to the visit and during the visit. In total the visiting team met with four adults living with a sickle cell disorder and two adults living with thalassaemia. From the children's perspective we met with two families caring for children and young people living with a Sickle Cell Disorder and two families caring for children and young people 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 those who met with the visiting team for their openness and willingness to share their experiences.

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Specialist Haemoglobinopathy Team (Children and Young People Services)

General Comments and Achievements

The Paediatric Specialist Haemoglobinopathy Team (SHT) at London North West Healthcare NHS Trusts was led by a lead paediatrician, with a deputy lead covering any absences. Specialist haematology support was available from a paediatric haematologist at Imperial College Healthcare NHS Trust. The team included a one WTE Consultant Nurse responsible for both adult and paediatric SHT services, who as part of their role served as the lead for education and training for the WLHCC (0.25 WTE).

Additional clinical support was provided by two WTE Clinical Nurse Specialists (CNSs) covering both acute and community settings and a 0.5 WTE Clinical Psychologist (also the deputy HCC lead).

The SHT conducted a quarterly outreach clinic at Bedfordshire Hospitals NHS Foundation Trust Local Hemoglobinopathy Team (LHT). However, paediatric patients from Bedford requiring inpatient admission were transferred to St Mary's Hospital (SMH) in Paddington, which is part of Imperial College Healthcare NHS Trust. Beford LHT informed reviewers that since their merger with Luton and Dunstable University Hospital, the service structure had been unclear leading to unclear funding flows and support from the SHT, and this had been raised with Bedford, Luton and Milton Keynes ICB.

LNWH paediatric multidisciplinary team (MDT) meetings were generally held on the first Wednesday of every month. These meetings focused on paediatric patients with complex medical or psychosocial needs, severe illnesses such as acute chest syndrome or those requiring high dependency or intensive care admissions. They also included discussions on patients undergoing or being considered for disease-modifying treatments such as hydroxycarbamide, transfusions, and bone marrow transplants. Additionally, patients experiencing frequent admissions, requiring surgery, or those with adverse events, including deaths, were reviewed. Other considerations included safeguarding concerns and social challenges such as housing issues.

Additional safeguarding MDT meetings for paediatric patients were held every three months, bringing together consultant paediatricians, clinical and community nurse specialists, a psychologist, and the LNWH lead consultant and lead nurse for safeguarding.

Growth clinics were also conducted, with referrals to endocrinology made when concerns were identified.

The consultant psychologist (0.5 WTE) carried out neurocognitive assessments, including for patients residing in Bedford. In addition to this role, the consultant psychologist was also the named transition coordinator. Since the last review, four transition clinics per year had been implemented. While patients remained under the paediatric service until the age of 18, transition education and planning typically began at 14 or 15 years of age.

SPECIALIST HAEMOGLOBINOPATHY TEAM- CHILDREN AND YOUNG PEOPLE [1]							
London North West University Healthcare NHS Trust: Northwick Park Hospital and Ealing Hospital		Linked Haemoglobinopathy Coordinating Centres (HCC)					
		The West London Sickle Cell HCC *(hosted in partnership with Imperial College Healthcare NHS Trust)* The Red Cell Network - Thalassaemia and Rare Inherited Anaemia HCC *(hosted in partnership with University College Hospitals London NHS Foundation Trust)*					
		Linked Local Haemoglobinopathy Team LHT			Patient Distribution		
					SCD	Thalassaemia	
		Bedfordshire Hospitals NHS Foundation Trust			31	14	
PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLONOAPTHY TEAM							
Condition		Registered patients	Active patients* [2]	Annual Review **	No. patients long term transfusion	No. of eligible patients on hydroxycarbamide	Inpatient admissions in the last year
Sickle Cell Disorder	CYP	133	84	84	<=5	53	35
Thalassaemia and RIA	CYP	18	14	15	8	<=5	0

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA or WTE (at the time of the visit)
Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies	172	2.9 per week (1.67- NPH clinic 0.64- Ealing clinic 0.14- MDT 0.089- Transition clinic) 0.067- Joint Endocrine clinic). 0.5PA Leadership of SHT
Clinical Nurse Specialist dedicated to work with paediatric patients living with haemoglobinopathies - Acute and Community	172	2 WTE
Clinical Psychologist dedicated to work with paediatric patients living with haemoglobinopathies	172	0.5 WTE

Urgent and Emergency Care

All paediatric emergency care was managed at Northwick Park Hospital. Patients attending the paediatric emergency department were required to register at reception; however, there was no formal system in place to alert reception staff to ensure priority for these patients. Instead, prioritisation relied on parents informing the receptionist of their child's condition and the reception staff informing the ED triage clinicians.

Following initial triage, children were seen by the paediatric team in the emergency department until the age of 17. The average time from arrival to the administration of analgesia was recorded at 1 hour and 40 minutes, with a median time of 36 minutes. Fewer than 25% of patients received analgesia within 30 minutes.

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

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

There was no documented evidence regarding the competence level of Urgent Care staff in managing paediatric sickle cell crises. However, the Paediatric Emergency Department (PED) sister informed the reviewing team that all staff were aware of the requirement to prioritise these patients. Doctors also received training as part of their induction. Despite this, pain audit data did not support that patients were consistently prioritised, and the Trust acknowledged that an action plan would likely be required to improve this aspect of care as a priority.

A paediatric emergency medicine consultant was available in A&E until 10:00 PM. If an admission was required, the general paediatric team was responsible for patient care. Acutely unwell children requiring high dependency or critical care were transferred to St Mary's Hospital (SMH) via the Children's Acute Transport Service (CATS).

Children and young people from Bedford were seen locally, with open access to a Children's Assessment Unit, where they were managed by the local paediatric team. If necessary, unwell patients were transferred to SMH for further care.

In-patient Care

Children and young people requiring inpatient admission were admitted to the children's ward, Jack's Place, which had a maximum of 28 beds and the service would flex between 24 and 28 beds, depending on acuity.

During the site visit, the reviewing team commended the ward area for its child-friendly and interactive environment, as well as its excellent play facilities designed for both younger children and teenagers.

The attending paediatric team was primarily responsible for patient care, providing daily consultant paediatrician reviews. From Monday to Friday, the lead paediatrician for haemoglobinopathies conducted reviews of all admitted patients with haemoglobinopathy conditions, supported by the paediatric clinical nurse specialist (CNS) and psychologist, as needed. Out-of-hours specialist support was available from a paediatric haematologist based at St Mary's Hospital (SMH).

A dedicated play specialist team was available on the ward Monday to Friday, from 9:00 AM to 5:00 PM.

Day Care

Paediatric patients requiring regular blood transfusions received treatment in the Paediatric Daycare Unit (Rainbow Ward) at Northwick Park Hospital (NPH). This unit also accommodated general elective paediatric patients.

During the review, the parents of an eight-month-old child with Thalassaemia Major expressed satisfaction with the care provided, stating that the team was attentive, accommodating, and responsive to their concerns. They felt well supported and listened to by the staff. While they received extensive verbal information, they noted that written resources were limited.

The reviewing team raised concerns regarding the adequacy of the daycare unit's physical space. Within a four-bed bay, space was limited, and there was only one chair available per patient for a parent, which led to the father sitting on the bed which may have been more challenging for an older child. The family stated that they were concerned about the risk of infection being in such close proximity to the next bedspace.

Outpatients

Weekly adult and paediatric haemoglobinopathy outpatient clinics were conducted by the multidisciplinary team (MDT) in consulting rooms, running simultaneously. These clinics included haematologists, paediatricians, clinical and community specialist nurses, and a psychologist.

Paediatric clinics were held at Northwick Park Hospital (NPH) every Tuesday for the full day, with an additional monthly clinic on Thursdays (usually the fourth Thursday) at Ealing Hospital. A Transition Clinic took place at NPH every three months, typically on a Wednesday afternoon in the paediatric clinic setting. Following all paediatric and transition clinics, MDT discussions were held to review the scheduled patients, including those who did not attend.

The outpatient department environment and facilities were considered adequate. However, there was no designated play specialist for the department. The Head of Nursing informed the reviewing team that play specialists from the ward

provided support to outpatients as needed and stated that securing additional funding for dedicated play specialist support in the outpatient setting was a priority**.**

Community- based care

The Brent Sickle Cell and Thalassaemia Centre formed part of the Specialist Haemoglobinopathy Team (SHT) and was responsible for managing the regional newborn screening programme, preconception and antenatal screening, and community support services. These services included genetic testing and counselling, health monitoring, health promotion, and education for parents and patients, as well as broader community support for patients and their families.

Community support services for Bedford Local Haemoglobinopathy Team (LHT) were severely impacted following the departure of their community nurse, leaving a gap in essential care. In response, the acute CNS for the SHT took on additional duties beyond her role to ensure that critical community functions in Bedford, such as antenatal screening and counselling, and school care plan development or letters of support for families, in these areas were maintained. The result was that this significantly increased pressure on the CNS's already demanding workload.

The Bedford LHT informed reviewers that funding flows for this role were unclear, and they had no budget to recruit a replacement community nurse. The SHT also expressed uncertainty regarding how this post could be funded, despite understanding that the role had previously been filled. Bedford LHT confirmed that they had escalated this issue to Bedfordshire, Luton and Milton Keynes Integrated Care Board (BLMK ICB) for resolution however they appeared disengaged and referred the issue to NHSE specialised commissioning.

Views of Service Users and Carers

The SHT reported that Sickle Cell Society and UKTS patient surveys had recently been undertaken and were in the process of being analysed and actions planned as a result of feedback, however the review team did not see any evidence of this.

The visiting team held focus groups prior to the visit and spoke to patients during the visit. In total we met two families caring for children and young people living with a sickle cell disorder and one family caring for children and young people living with thalassaemia.

Service User Feedback

- Feedback was that the paediatric SHT were very responsive. The team were easily contactable, and they could contact them at any time. Some staff were contactable via WhatsApp.
- They felt the team were extremely knowledgeable about them and their child and knew them well.
- If their child was unwell, they would contact the team first. Out of hours they would have to attend the ED.
- Experience in the ED was 'quite terrible'. If your child was triaged to the urgent care section, then it was terrifying as staff did not understand that about your child's condition and its unpredictability if they were unwell and there was no route back to be seen in the ED as you had been triaged.
- Care in the outpatients was very good and care as an impatient was 'sometimes good and sometimes disappointing'.
- Staff who were experienced in cannulation were not always available and it was a bit of 'trial and error'. They had experience on several occasions blood samples having to be retaken (as clotted) and how this was so traumatic for a child.
- Care protocols and school care plans were in place and they talked about the team visiting their child's school to discuss their child's care plan with school staff.
- Their GPs did have information from the SHT about their child
- Information was accessible and they felt appropriate for parents/families and children and young people.

- Staff on the day unit were attentive and accommodating, and they always felt listened to.
- Ward care was reported to be very positive.
- The daycare unit environment is a concern, with bedspaces being very cramped posing a risk of infection and reduced level of comfort.
- Additionally, families expressed a desire for more information specific to their condition and for events that would allow parents to connect and support each other.
- They also wanted to learn more about ongoing research and potential curative options.

Good Practice

1. A dedicated Growth Clinic was in place for monitoring the growth and development of children with Thalassaemia and Sickle Cell Disease (SCD). This ensured early identification of growth concerns, allowing for timely referral to Endocrinology when necessary. Early intervention was key in managing potential complications related to chronic conditions.
2. The Psychology Clinics played a crucial role in patient care by providing specialist input within routine clinics. This included neuropsychological assessments for children and young people with haemoglobinopathies, helping to identify cognitive or emotional difficulties that may impact education and daily life. The integration of psychology within the clinical setting ensured a holistic approach to patient well-being, supporting both medical and psychological needs.
3. The implementation of the Cerner electronic patient record system significantly improved clinical efficiency and communication across SHT hospitals. This system allowed clinicians, including the paediatric haematologist, to remotely access blood test results and patient notes, eliminating the previous need to request results be sent from Northwick Park Hospital to St Mary's. This real-time access to essential patient information streamlined decision-making and improved continuity of care.
4. As part of the junior doctor induction programme, sickle cell disease was included as a key area of learning. This ensured that new doctors had early exposure to and awareness of the complexities of managing haemoglobinopathies, promoting better recognition and management of complications such as sickle cell crises.
5. Regular teaching sessions were provided for junior doctors and GP trainees, equipping them with the necessary knowledge and skills to manage haemoglobinopathies effectively. These sessions contributed to a more informed workforce, improving patient outcomes through enhanced clinical awareness.
6. The inpatient ward (Jack's Place) provided a child-friendly and interactive environment catering to all age groups, from infants to teenagers. The ward's facilities and design ensured that children felt comfortable and engaged during their hospital stay, helping to reduce anxiety and improve overall patient experience.
7. The strong working relationship between members of the multidisciplinary team (MDT) facilitated coordinated and patient-centred care. Regular MDT meetings and discussions ensured that all aspects of patient care including medical, psychological, and social needs were addressed comprehensively.
8. A dedicated phlebotomy service operated during the Tuesday clinic, ensuring that haemoglobinopathy patients requiring regular blood tests had timely and efficient access to blood sampling. This service contributed to improved patient flow and reduced waiting times, enhancing patient satisfaction and care delivery.
9. A newly developed Deferoxamine patient information leaflet provided up-to-date guidance for patients. The leaflet included details on both types of needles used for treatment, improving patient education and informed decision-making regarding their care.
10. The Community Nurse demonstrated exceptional dedication and commitment by going above and beyond their role to ensure essential community services continued, despite staffing challenges. Thier proactive approach in

maintaining antenatal screening, counselling, and patient support, particularly in Bedford, was recognised as a significant strength of the service.

Immediate Risks

No immediate risks were identified during the visit however please see serious concerns below.

Serious Concerns

1. **Inadequate Care for Patients with Haemoglobinopathies in the Emergency Department:** *see trust wide section of the report*

Concern

1. **Consultant Staffing**

   Reviewers expressed concern regarding insufficient consultant medical staff with the necessary expertise in the care of individuals with haemoglobin disorders. This shortage had led to difficulties in providing adequate staffing for regular reviews, emergency care, and outpatient clinics for the 172 patients under their care. According to UK Forum guidance on consultant staffing, it is recommended that there be 1.5 PAs for every 50 patients for direct clinical duties. While there has been an increase in staffing capacity since the previous review, a shortfall in consultant numbers remains, impacting the ability to provide timely and comprehensive care.

2. **Lack of Community Support for Ealing and Bedford**

   At the time of the visit there was no community support for patients in Ealing and Bedford. The acute Clinical Nurse Specialist (CNS) had been working to provide essential services, such as neonatal screening support and school care plans or letters of support, in these areas. While her dedication was commendable, the lack of formal community support in these regions placed a significant strain on resources and risked gaps in care.

3. **Unclear Funding and Commissioning Arrangements for Bedford LHT**

   Since the merger of Bedford Hospital with Luton and Dunstable University Hospital, the funding flows and commissioning arrangements for the Bedford Local Haemoglobinopathy Team (LHT) had become unclear. There was a lack of clarity surrounding the financial and operational structures, complicating the ability to secure adequate resources and support for the service. This uncertainty had created difficulties in sustaining and expanding services, negatively impacting patient care.

4. **Lack of Data Support for SHT and LHT**

   There was a significant issue with data reporting across the Specialist Haemoglobinopathy Team (SHT) and the Local Haemoglobinopathy Team (LHT). Both teams were facing challenges in maintaining accurate and complete records, as clinicians at the SHT were manually inputting data into the National Haemoglobinopathy Registry (NHR). Meanwhile, the LHT reported that they did not have the capacity to manage this process, leading to inaccuracies and missing data in the registry. The lack of robust data support affected the quality of patient information and the ability to monitor patient outcomes effectively.

5. **Nurse Competences**

   Reviewers were concerned regarding the lack of complete nursing competencies. The RCN competency document for nurses was in the process of being introduced however at the time of the review, the nursing team had not completed these. The acute CNS was new in post and was waiting to start the Kings College London Haemoglobinopathy Course however as a newly appointed member of the team, further on the job training and supervision may be required to ensure they are equipped with the necessary skills and knowledge to handle the complexities of haemoglobinopathy care, particularly in acute settings.

6. **Inadequate Facilities for Haemoglobinopathy Patients in the Day Unit**

   The day unit lacked a dedicated area for haemoglobinopathy patients, and the available facilities were cramped, with bed spaces in close proximity to each other. The design posed an infection risk and reduced patient comfort. A more suitable and spacious environment would enhance both patient safety and overall experience for those receiving treatment

Further Considerations

1. A dedicated patient engagement event focusing on Sickle Cell Disease (SCD) and Thalassaemia would provide an opportunity for patients, families, and caregivers to share their experiences, ask questions, and engage with healthcare professionals. This event could serve as a platform for education, support, and feedback, helping to improve patient satisfaction and service delivery. Additionally, it would allow healthcare providers to gain valuable insights into patient needs and expectations, informing future improvements in care.
2. At the time of the visit there was no out-of-hours transfusion service, which could lead to delays in treatment for patients requiring urgent transfusions outside of standard working hours. Establishing an out-of-hours service locally could help ensure that patients with acute complication, such as those experiencing a sickle cell vaso occlusive crisis or requiring urgent red cell exchange receive timely treatment.
3. There were only two Play Specialists in post, and as a result, there was no dedicated Play Specialist (PS) support for outpatient clinics. Play Specialists play a vital role in reducing anxiety, providing distraction therapy, and enhancing the overall hospital experience for children. The absence of a PS in outpatient settings may have impacted the comfort and engagement of young patients, particularly those undergoing distressing or repeated procedures. Consideration should be given to expanding the Play Specialist team to ensure adequate support across both inpatient and outpatient settings.
4. The NHS England Act Now Initiative aims to improve outcomes and experiences for people with Sickle Cell Disease. The use of Act Now cards or an alternative system for patient identification and priority recognition should be considered. Ensuring that all staff are adequately trained and that patients are issued with and encouraged to use their 'Act Now cards' would help streamline care in emergency settings and reduce delays in treatment.
5. Transition from paediatric to adult care is a critical period for young patients with haemoglobinopathies, requiring structured education and support. The Transition Coordinator role, at the time of the visit, was led by the psychologist with little protected time which is essential in ensuring that adolescents receive adequate preparation for managing their condition independently in the adult healthcare system. To strengthen the transition process, consideration should be given to expanding this role, ensuring a consistent, well-resourced transition pathway for all patients.
6. Despite being fully funded, compliance with Universal Care Plans remained low due to a lack of personnel to implement and maintain the plans. Universal Care Plans are essential for ensuring consistent, high-quality care across different healthcare settings and improving communication between healthcare teams. To enhance compliance, the service must identify resource gaps, allocate dedicated staff, and ensure ongoing training and support for clinicians involved in care plan implementation.
7. At the time of the visit patients were required to attend different sites for Ferriscan and T2 scans*, leading to inconvenience, increased travel burdens, and fragmented care. To enhance the patient experience, consideration should be given to conducting both scans at a single site, reducing travel time, improving coordination, and streamlining the diagnostic process. This would also improve service efficiency and ensure that results were available in a more timely and cohesive manner.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

London North West Healthcare NHS Trust was an Adult Specialist Haemoglobinopathy team (SHT). The team had two substantive consultant haematologists and a locum haematologists who had a total of five PAs for the care of patients living with haemoglobin disorder; one WTE Consultant Nurse responsible for both adult and paediatric SHT services, who as part of their role served as the lead for education and training for the WLHCC (0.25 WTE); two WTE CNSs, one based at NPH and the other at CMH, covering the acute and community service, and 2.6 WTE administrative and data support. The designated lead for the SHT was the head of haematology. The CNS workforce would provide cover for the nurse consultant for clinical workload. At the time of the visit the clinical psychologist post was vacant (0.5WTE).

The Adult SHT did not have any associated linked Local Haemoglobinopathy Teams (LHTs)

Formal LNWH MDT meetings were held monthly on the first Monday for adults. The criteria for discussion of adult patients were complex medical and/or psychosocial needs; severe illness such as acute chest syndrome, high dependency unit and intensive care admissions; those patients on or being considered for disease-modifying treatment e.g. hydroxycarbamide, transfusions, bone marrow transplants; those patients experiencing frequent admissions; patients requiring surgery; adverse events including deaths; safeguarding issues; social issues e.g. housing. However, the MDT also met weekly after each clinic for interim discussions including consideration of clinic patients.

Automated red cell exchange was available 24/7 and provided by the NHS Blood and Transplant Service. Manual exchange transfusions could be provided in accordance with an agreed protocol at the NPH site. The elective red cell exchange programme was delivered two days a week. Patients could attend the NPH site on Thursdays and more recently patients were able to attend the CMH site on Tuesdays.

A transition clinic for adolescents aged 17-18 years was held four times a year and attended by the Consultant Haematologist, Consultant Paediatrician, Consultant Psychologist, and Specialist Nurses and held at NPH. Young people would attend the transition clinic at least once before moving to adult services after their 18th birthday. Transition workshops for 17-18-year-olds to discuss the transition process were also held three times a year led by the consultant psychologist and with representation from the adult and paediatric CNS teams.

The revised RCN competence framework had been adapted for use locally by the SHT. Staff would completed a self-assessment against the framework and once completed the professional development nurses in the various areas would review any training needs that were required.

The SHT was actively participating in the HCC research programme.

The NHSE funded pilot quality improvement programme for sickle cell disease within the region included the North West London Community Improvement Project which would include, amongst a wider community provision, a social prescriber post. The Universal Care Plan (UCP) enabling every Londoner to have their care and support wishes digitally shared with healthcare professionals across the capital was in the process of being implemented at the Trust. As part of this project the SHT had developed guidance for staff on the completion of care plans for those with haemoglobin disorders. Once patients had a UCP these plans would be accessible on the London Care Record Portal.

The Trust was working to improve the experience of patients attending the ED in an emergency. A rolling monthly ED training programme was delivered for ED staff and the SHT were planning to implement the 'ACT NOW' initiative to enable rapid and effective clinical responses to patients experiencing a Sickle Cell crisis. A Darzi Fellow based at LNW had undertaken work looking at clinical leadership and had instigated sickle cell simulation training as part of this project to improve care in the ED and inpatient pathway at the Trust. At the time of the visit discussions were ongoing to centralise emergency admissions for patients residing in the LNW area to be assessed at the Renal and Haematology Trage Unit (RHTU) based at the Hammersmith Hospital (HH) and then if required receive inpatient care at the HH but this pathway had not yet been implemented.

In partnership with one of the consultants, the clinical fellow had also developed a 'Sickle Cell Education Series' to improve patient's knowledge and engagement in their care. These sessions had been recorded and were available for patients to access on 'You Tube'.

A support group was active for patients residing in the local area.

SPECIALIST HAEMOGLOBINOPATHY TEAM- ADULT [3]							
London North West University Healthcare NHS Trust: Central Middlesex Hospital and Northwick Park Hospital		Linked Haemoglobinopathy Coordinating Centres (HCC) The West London Sickle Cell HCC *(hosted in partnership with Imperial College Healthcare NHS Trust)* The Red Cell Network - Thalassaemia and Rare Inherited Anaemia HCC *(hosted in partnership with University College Hospitals London NHS Foundation Trust)* The Adult SHT had no linked Local Haemoglobinopathy Teams LHT					
PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLONOAPTHY TEAM							
Condition		Registered patients	Active patients*[4]	Annual Review **	No. of patients on long term transfusion	No. of eligible patients on hydroxycarbamide	Inpatient admissions in the last year
Sickle Cell Disorder	Adults	428	312	330	41	75	265
Thalassaemia and RIA	Adults	108	58	41	6	0	0

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA or WTE (at the time of the visit)
Consultant Haematologist dedicated to work with patients with haemoglobinopathies	536	5PAs
Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies in the acute trust	536	1 WTE
Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies in the community	536	1WTE
Clinical Psychologist dedicated to work with patients living with haemoglobinopathies	536	0.5 WTE post vacant

Urgent and Emergency Care

All patients were asked to attend the ED at NPH. After initial triage, patients were reviewed by the ED medical team.

The haematology team primarily managed patient care, with support from general medical teams.

The shared haematology/ medical doctor in training would review the patient in the first instance and discuss with the haematology StR/ attending Consultant. There was a haematology speciality registrar, on site until 6pm, to assess and

[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.

admit patients as required. After 6pm, the on-call medical team would conduct the initial patient review and liaise with the on-call haematology registrar for advice and further review if necessary.

Patients were advised not to present at Ealing Hospital but in exceptional cases patients presenting would be assessed and given a first dose of analgesia before being transferred to the ED at NPH.

In-patient Care

Patients with a haemoglobinopathy condition requiring an inpatient admission were admitted to one of three wards at NPH: the haematology ward (Drake), an acute medical ward (James), or the high dependency unit (Dryden). Drake ward had 23 beds, including four beds specifically for patients with haemoglobinopathies, with flexibility for an additional two beds. James and Dryden wards had 34 beds and 24 beds respectively, with two beds dedicated for haemoglobinopathy patients with flexibility for an additional two beds. Patients had a more variable experience on James than Drake ward.

There was an attending haematology consultant available 24/7 covering the inpatient service on a 1:6 rota. The service was supported by resident doctors; Speciality Registrars (StRs), Internal Medicine Trainees (IMTS). Local MDT and, daily inpatient ward rounds included resident doctors and one of the clinical nurse specialists. Wednesday morning, ward rounds were followed by a virtual MDT meeting, involving consultants, community nurses, and the attending team. A Senior Haematology Nurse was also involved along with the acute CNS in the management of admissions and day care facilities at NPH. In addition, joint haemoglobinopathy handover meetings were held with Hammersmith Hospital (Imperial College Healthcare NHS Trust) red cell team on Monday mornings and Friday afternoons.

Out-of-hours support was provided by the haematology StR 24/7, and haematology consultants on a red cell haematology 1:6 on-call rota.

Day Care

The Medical Daycare Unit at CMH offered a walk-in service (following telephone triage) for managing uncomplicated sickle cell vaso-occlusive crises in adults and was open from 9am to 5pm on weekdays. Adult patients requiring regular blood transfusions were treated in the CMH Medical Daycare Unit or Haematology Daycare Unit at NPH. An apheresis service was provided by NHS Blood and Transplant on both sites.

Outpatients

Adult and paediatric haemoglobinopathy weekly outpatient clinics were conducted by the multidisciplinary team (MDT) in consulting rooms, running simultaneously, and included haematologists, clinical and community specialist nurses, and the psychologist. The adult clinics were held at CMH every Tuesday from 9:00am to 1:00pm and a transition clinic held at NPH (Paediatric clinic setting) every three months, on a Wednesday afternoon.

All adult and transition clinics were followed by MDT discussions about the scheduled patients including those who did not attend.

Community-based care

Community services were provided by Central London Community Healthcare NHS Trust (CLCH) and Central and North West London NHS Foundation Trust (CNWL).

Brent Sickle Cell and Thalassemia Centre, which had been in operation since 1979 managed the regional newborn screening programme, preconception and antenatal screening, and community support services including genetic testing and counselling, health monitoring and health promotion for individuals including parental and patient education, community support for patients and their families.

Views of Service Users and Carers

A patient support group was available locally and the groups was in the process of discussing how they may increase patient engagement within the SHT. The Sickle Cell Society patient survey had recently been undertaken and responses

were in the process of being analysed but results were not available at the time of the visit. The UKTS patient survey had not been undertaken but was planned.

The visiting team held patient focus groups prior to the visit. In total the visiting team met with four adults living with a sickle cell disorder and two adults living with thalassaemia. Their views are summarised below.

Patient meeting: Adults living with a Sickle Cell Disorder

- The SHT members were supportive and the CNSs were easily contactable and helpful.
- Arrangements were in place to attend the adult day unit at CMH for a clinical assessment and treatment if unwell and this process worked well. There was unanimous agreement that the care they received on the adult day unit at CMH was very good.
- They did consider that the parameters for being seen on day unit at CMH were too restrictive and they dreaded being asked to attend the ED at NPH instead.
- Face to face appointments were helpful and they commented that they did receive updates about their condition during these appointments with the team. Other talked about accessing information via a local website.
- There were mixed view about the care from GPs with some citing that their GP was not aware of their condition.
- Not all we spoke to had care plans; some had recently had a Universal Care Plan created.

Emergency Department and Ward Care

It was disconcerting to hear that issues for patients attending the ED at NPH had not improved since the last visit undertaken in 2019.

- They all commented that they would rather delay attending the ED and stay at home.
- None of the patients had confidence in the staff in the ED at NPH, commenting that some staff had limited knowledge of haemoglobin disorders.
- They would wait for a long time to be seen and to receive analgesia as they were not prioritised for pain relief. Several commented that they were not always listened to or believed to be in pain. When asked about being identified 'flagged' when they first attended the ED, the view was that this did not make a difference. 'You don't get seen earlier. In theory you should, but it doesn't happen'
- One patient had been admitted to a ward in the ED area for several days and although they had been reviewed by the haematology team in the ED, for the majority of time, staff were too busy to provide care and they felt they had no option other than to discharge themselves.
- The view of care on the wards was mixed. Experiences depended on where they were admitted and often which staff were on duty. Some staff were understanding and knowledgeable about their condition whereas others were less so and were not so compassionate.

Other aspects

- Some who spoke to the visiting team had been on various groups particularly for the local ED Bypass project but did not have any confidence that this model would be operational anytime soon for patients linked to LNWUH. In view of this they all wanted direct access via the medical day care unit at CMH to be extended to 24hrs/ 7 days a week.
- Some had taken part in service reviews previously. They were sceptical about providing feedback on this occasion as 'absolutely nothing has changed' and they were 'tired of giving views as nothing changes'. ' We want to see some real change rather than going over and over this all again.'

Patient meeting: Adults living with Thalassaemia

- Patients highly praised the care and support they received from the SHT team.
- The patient representatives were also highly complementary about the day unit staff who they considered were 'amazing' , were always helpful, personable and approachable.
- All considered that they had sufficient information. If they had any issues they would call the medical day unit or speak to a member of the team when attending clinics appointments. They had received information about gene therapy. Notice boards in the medical day unit at CMH had useful information.
- SHT will liaise with other specialties when required.
- They were not sure if they had annual reviews but considered that they were always reviewed at each clinic appointment. They all received copies of their letters after follow-up appointments and if they contacted their GPs they would have up to date communication from the team.
- Patients could have face to face consultations or virtually. They preferred face to face consultations as they could have more in depth discussions, though accepted that virtual clinic appointments were useful if they were working.
- They talked about consultations often being changed from face to face to virtual at short notice.
- They were aware of requiring endocrinology , ophthalmic and audiology reviews and these were panned and happened regularly. Blood glucose monitoring had to be via the GP and none had a recent glucose tolerance test performed.
- One patient had transitioned in the last five years and had relied on an older sibling to share their experience. Discussions had not commenced about transition until they were 17 years of age and then they moved to adult services when 18 years old.
- They were not aware of any local support groups.

Transfusion

- Patients could attend for their transfusion Tuesday to Thursday; the unit was open 9am-4pm. They commented that they would like more flexibility to attend at other times.
- Day unit staff were 'great' and knowledgeable about their condition.
- When attending for transfusion they could receive their test results
- All those who met with the visiting team said that when attending, transfusions were generally commenced quickly, although could be delayed if the unit was busy. If this was the case they would have to let staff know to that their blood units had completed and needed changing.
- There were a limited number of beds and chairs and they talked about sitting in the waiting room as there was not enough space for them when they attended.
- No patients had issues about cannulation if undertaken by existing staff. Temporary staff were not so understanding and also not as experienced at cannulation which did cause them some anxiety.
- Often medication would be available for collection on the unit when they attended which saved them time.

ED and inpatient care

- The patients were aware to access the ED in an emergency but had not had the need to do so for some time.
- They were aware that they could contact the team if they were unwell and could attend the Day Unit at CMH. None of the patients who provided feedback to the visiting had required any inpatient admissions.

Feedback

- They had been asked for feedback on the service and completed surveys usually when attending for their transfusions. They all said if they had any issues/complaints, the day unit team would listen and address these.

When asked what could be better the following comments were provided

- Refresher information and training on equipment for iron chelation would be appreciated.
- Access to Out of hours /weekend transfusions was requested, as the opening times of the day unit were limited and not flexible.
- Use of an ultrasound machine for identifying good venous access
- The representatives had not had experience of any other services so were not sure how services could be improved and wondered how they could find out about best practice and what happens at other hospitals.
- They considered that there were too many IT systems and they received multiple communications, some digital and others sent by post.
- The medical day unit and haematology clinic used to be collocated but this had changed during the time of the Covid-19 pandemic and they sometimes found it difficult to work out where they needed to be to see the right person.

Good Practice

1. Reviewers were impressed by the SHT team who were clear about their vision for the service and the challenges they faced. Patients who met with the visiting team held them in high regard and were extremely appreciative of the care and support they received from the team.
2. The provision of the emergency care pathway for patients to attend the medical day unit at CMH provided timely management and early escalation. Patients who met with the reviewing team spoke highly of the service.
3. All adult and transition clinics were followed by an MDT discussion about the scheduled patients including those reviewed and any actions needed for those who did not attend.
4. In preparation for the peer review visit the SHT had implemented a working group to identify areas that were working well and where action was required. Reviewers were impressed that they had decided to continue with the working group after the visit as a mechanism for progressing their work programme.
5. A research fellow in partnership with one of the consultants had developed a 'Sickle Cell Education Series' to improve patient's knowledge and engagement in their care. These sessions had been well received by patients and patients continued to be directed to view the sessions on a 'You Tube' channel.

Immediate Risk

No immediate risks were identified during the course of the visit. *However, see serious concerns section of the report.*

Serious Concern

1. **Lack of SHT Lead with Haemoglobinopathy Expertise**

   The designated clinical lead for the SHT did not have expertise in haemoglobinopathies or undertake any regular clinical activity relating to haemoglobin disorders. The lead did not demonstrate specific responsibility for guidelines, protocols, training, audits or data relating to haemoglobin disorders, or overall responsibility for liaison with other services. These areas being led by the already overstretched medical and nurse consultant SHT workforce.

2. **Consultant Staffing**

Reviewers were seriously concerned that the service had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care and clinics for the 536 patients under their care. This would have been considered an immediate risk but consultant medical staff were working far beyond their expected hours and workload to ensure that patients were not at risk.

a. At the time of the visit, there were two substantive consultant haematologists and one locum who had a total of five programmed activities (PAs) rather than the recommended 19 PAs for the number of the patients. The three consultants also had general haematology and on call clinical commitments.

b. The consultant attending rota was 1:6 and as they were released from other commitments whilst attending, routine clinics were regularly cancelled which significantly reduced the overall clinic capacity for routine and scheduled care for patients with haemoglobin disorders.

c. The lack of available time outside of clinical duties had impacted in the time available to be proactive in developing the SHT and to engage fully with both the WL Sickle Cell HCC and TRCN Thalassaemia HCC.

d. Whilst the Trust acknowledged the need to increase medical staffing capacity and a business case for an additional consultant haematologist with red cell expertise was being developed at the time of the visit the timeframe for achieving this was not clear. Even if this post were to be recruited to with a further full-time consultant, this would still be inadequate to bridge the gap between the amount of consultant time required for the service and that which is available. Reviewers were also concerned that should recruitment of an additional haematologist for the haemoglobin disorder service not be successful then the service viability would be at risk.

3. **CNS Workload**

The SHT had only one WTE CNS for the acute service which was insufficient for the 536 registered patients under SHT care and for the care of acute inpatient admissions (265 in the year before the visit), which was having an impact on the CNS being able to provide the level of support to patients, undertake audits and staff education as required by a specialist haemoglobinopathy team. The absence of a psychology service for patients with haemoglobin disorders and access to social care and welfare support had also resulted in the trust CNS trying to cover these requirements supporting patients wellbeing, social and financial needs. Reviewers were seriously concerned that the CNS workload was not sustainable and that CNS staffing for the future would also need to take account of increasing patient numbers, longevity and complexity.

4. **Access to Psychology**

Patients did not have access to a psychologist with relevant experience in caring for patients and families with haemoglobin disorders. The SHT cared for 536 patients and reviewers were concerned as without a dedicated psychological practitioner individuals affected by these disorders will have limited specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition.

The SHT had a 0.5WTE vacancy for a psychologist but even if successful in recruitment, this would still not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE clinical health Psychologist for 300 patients.

5. **Access to Timely Analgesia:** *see Trust-wide section of the report*

6. **Access to Welfare and Benefits Support**

Reviewers were concerned that patients did not have access to welfare and benefits and staff were spending clinical time supporting patients with social and welfare issues. The benefits for patients in improving their quality of life by having this level of support should not be underestimated and although there was a plan to recruit a social prescriber

as part of the NHSE regional community project work, they would not be able to provide the level and range of support which a benefits advisor or social worker could do. In addition, the community pilot was also only funded for a period of for two years; it was not clear if the service would be continued after this time.

7. **Care Planning and Annual Review Pathway**

   The proportion of patients who had care plans in place was only 44% (UCPs) and only 63% of patients had received a formal annual review. Reviewers were seriously concerned as patient annual reviews and care plans are crucial for ensuring that patients are managed effectively, identifying potential problems early, and promoting patient confidence in managing their health.

   The low compliance was as a result of no formal time allocated to undertake annual reviews and implement UCPs. In practice they were undertaken within the existing clinic capacity when time allowed. However, reviewers were told that clinic appointment times were only 20 mins, which was insufficient time to undertake a patient annual review or develop a care plan with the patient. Reviewers were informed that requests to have extended clinic appointments to 40 mins to enable sufficient time for annual reviews had been declined by the Trust.

8. **Governance and Oversight of SHT Data**

   Reviewers were seriously concerned about the lack of governance and oversight of clinical data. The audit of compliance with NICE guidance on timeliness of analgesia data submitted to the HCC was inaccurate (see also Trust Serious Concern section of the report).

   There were also anomalies with the data provided before the visit as the data suggested that more patient had received an annual review than were active and the percentage completion rate of annual reviews submitted in the background report was 63% (whereas the data on the National Haemoglobinopathy Registry suggested 100%).

9. **Patient Feedback**

   Patient's reported poor experiences when attending the ED and their experiences had not improved since the last visit undertaken in 2019 with a number of patients commenting that some staff had limited knowledge of haemoglobin disorders, they waited long times to be seen and were not always listened to or believed to be in pain.

   Some of the patients who met with the visiting team had taken part in service reviews and listening events in the last few years and were sceptical about providing feedback on this occasion as 'absolutely nothing has changed' and they were 'tired of giving views as nothing changes'.

10. **Access to Elective Automated Red Cell Exchange**

    Reviewers were seriously concerned about the capacity to provide elective apheresis due to the facilities, operational times of the day unit and the number of apheresis machines available. At the time of the visit elective apheresis was available on Tuesdays only in the day unit at CMH and on Thursdays only at NPH and there were six patients on the waiting list to join the programme. It is foreseeable that this delay in treatment would increase the risk of these patients developing additional complications of their condition in the interim, some of which could be life threatening or life changing**.**

Concern

1. **Access to chronic pain services**

   There was no access to a chronic pain team for patients with complex analgesia needs. Patients did not have access to a community pain service and access an inpatient pain team was limited.

2. **Guidelines**

   Many of the recommended guidelines were not in place. The HCC developed guidance was in the process of being ratified but had not yet been amended and approved for use locally. Reviewers were told that the lack of agreed and implemented guidance was in part due to the lack of clinician time to develop and progress this area of work.

3. **SHT Audit Completion**

   The SHT had not been able to undertake the required audits covering transfusion and acute admissions to other areas (Quality Standard HA-604). Reviewers were told this was due to the Trust IT sysytems being unable to provide the data and information and the lack of data support and alternative mechanisms for data collection and analysis had not been implemented.

Further Consideration

1. Capacity to see patients requiring an acute assessment and pain relief on the day case unit at CMH was limited to patients contacting the unit by 11am and limited to two patients per day, and those attending for transfusions were limited to attending on a limited number of days in the week. With the changes in demographics and the increasing numbers of patients being cared for at the trust, extending the capacity and opening hours of the medical day unit at CMH should be considered.
2. The ED bypass unit once in operation will addressing emergency care access for some patients, however it is likely that patients requiring emergency care will still attend the trust or be transferred to NPH from the medical day unit at CMH. It will be important that future emergency care provision pathways are reviewed to ensure that patients attending the trust receive safe and timely care including assurances that medical and nursing staff have appropriate competences in the care of patients with haemoglobin disorders.
3. Patient feedback was insightful about care at the trust and it will be important for the trust to take account of the positive patient views but also act on and build confidence with this patient group around the areas that are causing them concern.

Commissioning

The review team had discussions from representatives from NHS England London and a local commissioner from North West London ICB. There are a number of serious issues identified in this report which will require the active involvement of the Trust leadership team and commissioners to ensure timely progress is made.

Appendix 1 Membership of Visiting Team

Visiting Team		
Marta de Almeida	HCC Network Manager	Oxford University Hospitals NHS Foundation Trust
Nazma Chowdury	Consultant Paediatrician	Croydon Health Services NHS Trust
John James	Chief Executive	Sickle Cell Society
Roanna Maharaj	User representative	
Dede-Kossi Osakonor	Lead Psychologist	East London NHS Foundation Trust
Sharon Ndoro	Specialist Nurse	Guys and St Thomas NHS Foundation Trust
Olushola Taiwo	Advanced Nurse Practitioner and Adult Lead Nurse for Haemoglobinopathies	Guys and St Thomas NHS Foundation Trust

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

NHS Midlands and Lancashire		
Rachael Berks	Clinical Lead	NHS Midlands and Lancashire
Sarah Broomhead	Professional Lead	NHS Midlands and Lancashire

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Appendix 2 – Compliance with the Quality Standards

Analyses if 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	28	58%
Specialist Haemoglobinopathy Team (SHT) Adults	45	12	28%

Quality Standards – Care of Children and Young People

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

Ref	Standard	Met Y/N	Reviewer comment
HC-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	N	Funding for implementation of universal care plans has been received by the SHT however there was poor compliance with completion due to capacity of staff to complete these.
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)	N	There was no evidence covering 'b'
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: Immunisations 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	

Ref	Standard	Met Y/N	Reviewer comment
HC-106	**Information about Transcranial Doppler Ultrasound** Written information should be offered to children, young people and their families covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	Y	
HC-107	**School or College Care Plan** A School or College Care Plan should be agreed for each child or young person covering at least: a. School or college attended b. Medication, including arrangements for giving/supervising medication by school or college staff c. What to do in an emergency whilst in school or college d. Arrangements for liaison with the school or college e. Specific health or education need (if any)	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.	N	There was inadequate space in the day unit area to deliver blood transfusions.

Ref	Standard	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	N	The SHT advised that the survey results were in progress.
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	N	It was not clear about the mechanisms for 'a -'c.'

Ref	Standard	Met Y/N	Reviewer comment
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session(s) identified for the role within their job plan and cover for absences should be available.	N	The Lead Consultant had 0.5Pas dedicated for their leadership role which was inadequate according to the UK Forum guidance which states that 1PA should be provided for leadership of the geographical area.
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	
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	Lead Consultant had 2.9 PAs (including leadership time) plus the deputy had 1.3 PA's which was inadequate according to the UK Forum recommendations of 1.5 PA's per 50 patients for direct clinical care.
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	

Ref	Standard	Met Y/N	Reviewer comment
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	The RCN Competency document was in place however no evidence of its use in practice. The SHT had 1 WTE acute CNS plus 1WTE community CNS. The acute CNS was new in post and had recently commenced Kings College London Haemoglobinopathies Course.
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	There was 0.5 WTE Clinical Psychologist dedicated to work with CYP including support for the LHT, which was insufficient for number of patients served.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	Y	
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	The SHT did not have data support. *See main report.*

Ref	Standard	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	N	At the time of the visit, the service had no access to a Social Worker/Benefits advisor however a post was being advertised following funding approval. Standards 'b-f' were met.
HC-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	Y	
HC-303	**Laboratory Services** UKAS/CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	North West London Pathology (NWLP)
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders.	N	No evidence of Urgent Care staff competencies The average time from Arrival to Analgesia was 1hr 40 mins. Median time 36 minutes. Less than 25% of patients received analgesia within 30 minutes.

Ref	Standard	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)	Y	
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	Standard	Met Y/N	Reviewer comment
HC-504	**Transcranial Doppler Ultrasound Standard Operating Procedure** A Standard Operating Procedure for Transcranial Doppler ultrasound should be in use covering at least: a. Transcranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Transcranial Doppler ultrasound (QS HC-209) d. Arrangements for ensuring staff performing Transcranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	Y	The Sickle Cell and Thalassaemia SOP and TCD protocol 2025
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	The WLHCC guidance and local SOP were not clear on 'f' patient pathway for Central Venous Access Device insertion, management and removal.

Ref	Standard	Met Y/N	Reviewer comment
HC-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 family involvement in monitoring wherever possible	Y	
HC-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring complications Indications for discontinuation	Y	
HC-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	

Ref	Standard	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	Standard	Met Y/N	Reviewer comment
HC-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. 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	l' Dental was not covered in the WLHCC sickle cell guidance or the Sickle Cell and Thalassaemia SOP.
HC-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of children and young people with sickle cell disorder and thalassaemia during anaesthesia and surgery.	Y	
HC-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HC-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by an HCC / SHT b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission c. Patient discussion at local multidisciplinary team meetings (QS HC-604) d. Referral of children for TCD screening if not provided locally e. 'Fail-safe' arrangements for ensuring all children and young people have TCD ultrasound when indicated f. Arrangements for liaison with community paediatricians and with schools or colleges g. Follow up of patients who 'were not brought' h. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care i. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together j. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	Y	
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	There was no evidence of a shared care agreement with LHT's seen by reviewers. The LHT reported unclear structures and funding flows.

Ref	Standard	Met Y/N	Reviewer comment
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 Trust
HC-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each HCC Business Meeting (QS HC-702).	Y	
HC-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each HCC Business Meeting (QS HC-702).	Y	
HC-608	**Neonatal Screening Programme Review Meetings** The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results, identify issues of mutual concern and agree action.	Y	
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.	N	Clinicians reported that NHR data was inaccurate as not updated in a timely manner due to lack of admin/data inputting support. HCC data manager post once recruited to would support with this in future.
HC-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions	N	The transfusion audit ‘a’ had not been undertaken. Patients were only admitted to Jack’s Place or transferred to St Marys Hospital ‘b’.

Ref	Standard	Met Y/N	Reviewer comment
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	N	It was not evidenced that the SHT had participated in the HCC specific audits.
HC-707	**Research** The service should actively participate in HCC-agreed research trials	N	At the time of the visit there were no patients engaged with clinical trials.
HC-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HC-197) compared with other services c. Results of audits (QS HC-705): I. Timescales and pathway for regular transfusions II. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	b' Results and themes of LNW patient surveys had only just been undertaken in February 2025 had not yet been processed for a comparison with other services and discussed as per the QS. Results of audits as defined in HA- 705 had not been undertaken.
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	

Quality Standards – Care of Adults

Ref	Standard	Met Y/N	Reviewer comment
HA-101	**Haemoglobin Disorder Service Information** Written information should be offered to patients and their carers, and should be easily available within patient areas, covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HA-199)	N	Written information on the day unit tended to be given to patients on request. There was no information covering 'h ii, iii, v, or vi '. The information for psychology had a contact number but there was no service for adults. Some information could be accessed via the HCC website hub but it was unclear whether patients were routinely made aware of this.
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	The information seen for those living with Thalassaemia was limited to 'e' -iron chelation 'h' and 'I' only for Desferal. Information covering sickle cell disorders was not available for 'e' apart from red cell exchange or 'f' covering transfusion and iron chelation.

Ref	Standard	Met Y/N	Reviewer comment
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	N	The Trust were in the process of implementing the SCD universal care plan (UCP). Data showed that 44% of patients living with a sickle cell disorder had a UCP created and some of the patients who met with the reviewing team commented about having new care plans. Patients living with thalassaemia did not have care plans.
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	N	Patients who did have care plans did not have information covering 'b'.
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: Immunisations Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	Patients who met with the reviewing team commented that their GPs did get copies of their clinical letters.
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	N	The medical day unit did not have sufficient capacity for apheresis. The SHT did not have sufficient clinic space for the nurse led clinics.

Ref	Standard	Met Y/N	Reviewer comment
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	The transition patient information seen did not cover 'c' or 'e' and did not cover those young people living with thalassaemia transitioning to adult care. Transition clinics were held four times a year and young people could also attend a workshop which was held three times a year.
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	N	The UKTS patient survey had not yet been undertaken. The QS was met for SCD as patient survey had been undertaken in February 2025 and 78 responses had been received.
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	There was an active WLHCC PPV group but this group discussed strategic regional issues and was not in place to discuss specific issues about local services.

Ref	Standard	Met Y/N	Reviewer comment
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	Designated Lead Consultant had been allocated 1 PA for leadership of the SHT but did not demonstrate engagement with responsibilities as required by the QS and did not undertake any haemoglobin disorders clinical activity.
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	The designated lead nurse (0.75 WTE) was also the HCC lead for education and training (0.25WTE).

Ref	Standard	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. *Notes:* *1. 'Caring for haemoglobinopathy patients: Report of a national workforce survey' (2015), UK Forum on Haemoglobin Disorders, gives guidance on consultant staffing levels, which should be reflected in job plans, in particular: "For calculating consultant requirements it is suggested that consultant PAs are allocated as follows:* *a. 0.25 PA CPD per consultant* *b. 1.5 PA for every 50 patients for direct clinical duties* made up as:* *i. Clinics including specialist annual review (2.0 hours/week)* *ii. Ward rounds (1.5 hours/week)* *iii. Day unit attendance and ad hoc consultations, on call (1.0 hour/week)* *iv. Clinical administration and MDT meetings (1.5 hours/week)* *c. 0.25 PA for every 50 patients for supporting activities (NHR and data collection, audit, teaching, patient liaison, network participation)* *d. 1 PA for geographical area clinical lead* *e. Additional PAs as required (e.g. for specialist training, laboratory work, research, outreach clinics)* **Some of these duties may be delegated to clinical nurse specialists, [ANP] or specialty doctors, with the appropriate training: this must be recognised in their job plans."*	N	The two substantive consultants and one locum consultant had a total of 5 PAs for the care of people with haemoglobin disorders for the care of 536 patients. The SHT should have a total of 19.510PAs for the size of the service. None of the Consultant staff had CPD time specifically for haemoglobin disorders.
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	Cover for unscheduled care was covered by the on call haematology team.

Ref	Standard	Met Y/N	Reviewer comment
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	Doctors in training did have not have formal training in the care of people with haemoglobin disorders.
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	There was insufficient CNS time to care for 550 patients. At the time of the visit there were only two WTE CNS, one with responsibility for acute care and one for community care. The SHT also had a Nurse Consultant 0.75WTE (0.25 HCC). Ward and ED staff received updates annually. Staff were in the process of self-assessing against the latest RCN competence framework and any training issues would be identified by the practice development nurses in the respective areas. Staff did have competences in the care of patients requiring a PCA.
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	Patients did not have access to a psychologist. The SHT had a 0.5 WTE vacancy for a psychologist but this would still not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE clinical health psychologist for 300 patients.
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	The SHT had 2.6WTE admin support for the whole of haematology and limited support for data collection.

Ref	Standard	Met Y/N	Reviewer comment
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	N	Patients did not have access to a social worker or benefits advice through the trust. In practice patients would be directed to contact the citizens advice service. All other support services were available.
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	There was no access to a chronic pain team for patients with complex analgesia needs 'g'.
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	North West London Pathology (NWLP).
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. *Notes:* 1. *This QS applies to Emergency Departments, Paediatric Admissions Units and any other areas to which children and young people with haemoglobin disorders are normally admitted.* 2. *Documentation of training undertaken and discussion of audits of compliance with NICE Clinical Guideline on the management of acute pain could be used to demonstrate compliance with this QS.*	N	Patients who met with the reviewing team commented that they did not receive timely analgesia when attending the ED. The audit data covering NICE guidance on the timeliness of analgesia within 30 mins of presentation was incorrect. A rolling monthly ED training programme was provided to ED staff and the SHT were planning to implement the Act Now initiative. Nursing staff did have competences in PCA delivery.

Ref	Standard	Met Y/N	Reviewer comment
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)	Y	The Consultant Psychologist was the named coordintor/lead for young people transtioning to adult care.
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	Adult Haemoglobinopathy Clinic Standard Operational Procedure included 'a' and 'b'
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	Trust transfusion documents, Red Blood Cell and the Haemoglobinopathy Clinic SOP guidance were not clear about 'e' timescales and detail of the pathway and OOH services, and 'f' Patient pathway for Central Venous Access Device insertion, management and removal. TRCN HCC guidance would cover Thalassaemia for all guidance once ratified and amended for use locally.

Ref	Standard	Met Y/N	Reviewer comment
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug(s), dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	N	Self-administration of medications and infusions – 'f' was not included in the SOP OPD guidelines or HCC guidance. All other aspects were met.
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	Y	
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	N	The TRCN guidelines had not had Appendix 2 amended for use locally.

Ref	Standard	Met Y/N	Reviewer comment
HA-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC/SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred For patients with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation	N	The TRCN guidelines had not had Appendix 2 amended for use locally. The WLSCD HCC Sickle Cell guidance did meet the requirements of the QS.

Ref	Standard	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	'l' Dental was not covered in the WLHCC guidance. TRCN guidelines were in the process of being ratified by the Trust and appendix 2 had not yet been amended for use locally
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	Standard	Met Y/N	Reviewer comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	N	The guidance seen did not consider arrangements for the care of pregnant women under 18. The LNW pathway was not clear about referral to other services and the arrangements for shared care.
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	
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	The SHT did not have a service organisation policy that covered the requirements of the Quality Standard.

Ref	Standard	Met Y/N	Reviewer comment
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/A	The adult SHT did not have any linked LHTs.
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	SCD MDTs were held first Monday of each month and Thalassaemia MDTs twice a year and short MDTs were held after each clinic.
HA-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A	Integrated service for Haemoglobin disorders.
HA-607 S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each HCC Business Meeting (QS HA-702).	N	WL SCD HCC attendance was not clear as only the attendance for the last two meetings was seen.
HA-607 T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each HCC Business Meeting (QS HA-702).	N	Representatives from the SHT were unable to attend The Red Cell Network – Thalassaemia HCC meetings due to clinical commitments.

Ref	Standard	Met Y/N	Reviewer comment
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.	N	Clinicians reported that NHR data was inaccurate as not updated in a timely manner currently due to lack of admin/data inputting support. HCC data manager post once recruited to would support with this in future.
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	Background report stated that the Trust IT systems did not enable the SHT to undertake the audits as defined by the QS.
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	N	The SHT had not participated in the HCC agreed audit programme due to capacity.
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	
HA-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HA-197) compared with other services c. Results of audits (QS HA-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	'b' Results and themes of LNW patient surveys undertaken had only just been undertaken in February 2025 had not yet been processed for a comparison with other services and discussed as per the QS. Results of audits as defined in HA- 705 had not been undertaken.
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	

Ref	Standard	Met Y/N	Reviewer comment
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Some of the guidance had been ratified but not amended for use locally. Other documents were controlled.