Health Services for People with Haemoglobin Disorders

Barking Havering and Redbridge University Hospitals NHS Trust

Visit Date: 12th September 2025

Report Date: 27th October 2025

Contents

Introduction

This report presents the findings of the review of Barking Havering and Redbridge University Hospitals NHS Trust that took place on 12th September 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 Barking Havering and Redbridge University Hospitals 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:

- Barking Havering and Redbridge University Hospitals NHS Trust
- NHS England, London Region
- NHS North East 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 and North East 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 Barking Havering and Redbridge 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

Barking Havering and Redbridge University Hospitals NHS Trust

Trust-wide General Comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders at Barking Havering and Redbridge University Hospitals NHS Trust (BHRUT).

BHRUT served a population of around 750,000 patients across three London boroughs (Barking Havering and Redbridge) and incorporated two acute hospital Trusts; Queens Hospital in Romford and King Georges Hospital in Goodmayes. Both acute Trusts had emergency departments and the full range of medical, surgical and women's and children's specialties.

The Trust received designation from NHS England as a Specialist Haemoglobinopathy Team (SHT) in 2024, having previously been reviewed as a Local Haemoglobinopathy Team, although the Trust had always been a large local centre providing many functions of an SHT.

In total the Trust served 729 patients living with a Haemoglobin Disorder, mostly sickle cell disorders (SCD). The prevalence in the local catchment area was approximately four to five times the UK prevalence, and the number of people with haemoglobin disorders was increasing year on year, and reviewers were told that the SHT numbers were likely to increase about 10% a year due to a high rate of affected births, migration and transition from other areas.

The adult and paediatric SHT was based at the Queen's Hospital, Romford, and during the visit the reviewers visited emergency departments, assessment units day units and wards, they met with patients and carers, and with staff providing services for the local health economy. The reviewers did not visit the King George Hospital in Goodmayes where patients may attend in an emergency and receive outpatient care and adult inpatient care.

Barking Havering and Redbridge University Hospitals NHS Trust was part of the East London and Essex Haemoglobinopathy Sickle Cell Coordinating Centre and the London and South East Thalassaemia and Rare Inherited Anaemia HCC (both hosted by Barts Health NHS Trust).

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

1. Reviewers were impressed with how the SHT had implemented the transition process across the paediatric and adult services. *For more detail see CYP and Adult sections of the report*

Trust-wide Good Practice – children and young people: - *See CYP section of the report for more detail.*

Trust-wide Good Practice – Adults: - *See Adult section of the report for more detail*

Trust -wide Serious Concerns

1. **Adult Emergency Department Pathway**

   Reviewers were seriously concerned about the emergency pathway for adults to access emergency care via the ED.

   a. The latest audit of compliance with NICE Guidance on Management of Acute Pain showed that only 5% of patients received analgesia within 30 mins of arrival which was suboptimal.

   b. Patient feedback about their experiences in ED were described as very negative and compared to a "battle" or "warfare." Hostility and lack of knowledge from staff about sickle cell protocols were recurring themes. They received delays in pain relief and then subsequent doses were inconsistent. They are constantly moved around the department and also into "corridor ward" for care which they felt led to neglect. Because of these repeated poor experiences, some patients would try to avoid ED entirely, waiting until the infusion unit managed by the SHT team was available, to present.

c. Reviewers were also concerned about the disjointed pathway where patients could experience multiple moves as triage was not streamlined and patients could be sent to SDEC for analgesia, rereferred to RAFT or to 'fit to sit' and then await a decision re admission when they would be transferred to the majors area to await an inpatient bed. Other patients could go to the short stay medical ward or be pulled to the Infusion suite or corridor ward.

d. Staff attitudes were also concerning. Patients described nurses dismissing pain, with comments such as *"you are not the most important person here."* Some patients reported staff becoming irritated or annoyed when patients referenced the NICE guideline standard of 30 minutes for pain relief.

e. Some staff who spoke to the reviewers could not remember when they had last had any training covering the urgent care of people living with a haemoglobin disorder.

2. **Access to Psychology for Patients Living with a Haemoglobin Disorder.**

Reviewers were seriously concerned about the access to psychology for people living with a haemoglobin disorder.

Until June 2025, there had only been 1.0 WTE Clinical Psychologist who served both adults and children and young people (729 patients), who did not have any cover for their absences. This did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of 1 WTE HCPC Senior Psychologist for every 300 patients.

Since June 2025 children, young people and their families had not had access to any psychology unless they were transitioning to adult care, and there was insufficient psychology resource available for adults living with a haemoglobin disorder.

The service had been provided from North East London NHS Foundation Trust via an agreed SLA which had expired in August and reviewers were told that a new contract was in the process of being re-negotiated between the two organisations.

During the visit the reviewers spoke to clinical and management staff about the issue and a range of conflicting reports as to the current state of the service and the reason for this breakdown in communication remained unclear. However, the impact has been significant. It was also not clear what level of service would be reinstated, particularly in view of the numbers of patients across both services. Reviewers noted the issue of only having one full time psychologist providing support for both the adult and children's haemoglobinopathy services had been raised as a concern during the last peer review visit in 2019 and no progress has been seen on this the issue since that time. *See also Children and Adult sections of the report.*

Trust-wide Serious Concern – children and young people: *See CYP section of the report for more detail.*

1. **Access to Paediatric Psychology**

Children, young people and their families did not have access to psychology services. Children and young people requiring neurocognitive assessments were referred to the neuropsychology service based at Kings College Hospital NHS Foundation Trust.

Trust-wide Serious Concern – adults: *See adult section of the report for more detail*

1. **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 scheduled care including regular reviews, and clinics for the patients under their care. At the time of the visit the SHT had three Consultants with a combined total of 4.5 PAs for the care of 396 patients rather than the expected 11.1 PAs needed for scheduled red cell work.

2. **Senior nurse workload**

   The level of Lead Nurse and CNS time was of serious concern.

   a. The Lead Nurse had insufficient time for leadership and service development. The same lead nurse covered both the adults and children's services as well as a significant clinical workload.

   b. The SHT had only 2.8 WTE CNS for the acute and community service, which was insufficient for the 396 registered patients, for whom they provide nurse led clinics, triage to use the infusion unit, support on the acute wards when inpatient and support for haematology ward rounds, as well as cover for the transfusion service on the Infusion Unit.

   c. The range of work being undertaken by the CNS team was impacting on the time they had available to provide outreach and support to patients in the community.

3. **Access to Psychology**

   Access to psychology was insufficient for the 396 people living with a haemoglobin disorder registered with the service with only one WTE senior psychologist who did not have cover for absences.

4. **Infusion Unit/ Ambulatory Service**

   Reviewers were seriously concerned about the suitability of the infusion Unit to provide a safe and comfortable level of care.

Trust -wide Concern

Trust-wide Concern – children and young people: - *See CYP section of the report for more detail.*

1. **CNS Capacity**

   At the time of the visit the SHT had only 2WTE CNS for the paediatric acute and community service which was insufficient for the 333 registered patients under their care.

2. **Transcranial Doppler (TCD) Service**

   The resilience of the TCD service was of concern as the service was dependent on a single specialist doctor to perform all TCDs with no cover for absences.

3. **SHT Leadership Time**

   The designated lead consultant did not have any time allocated for leadership of the SHT.

Trust-wide Concern – adults: *See adult section of the report for more detail*

1. **Access to Elective Automated Red Cell Exchange (aRCE)**

   Staffing for the aRCE service was insufficient for the numbers of patients who required this service. Delays in patients accessing aRCE treatment has the potential to 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.

2. **Inadequate Administrative & Data Support**

   The SHT had no data support for audit or data submissions to the NHR which would enable the NHSE Specialised Services Quality Dashboard (SSQD) returns. At the time of the visit clinical staff only had the capacity to enter registration and patient annual review completion onto NHR. The potential impact of an incomplete picture could impact on the available SHT funding and recognition, as a specialist haemoglobinopathy team and SSQD (Specialised services quality dashboards) returns will be taken automatically from the data the SHT uploads to the NHR.

Trust -wide Further Consideration

1. It may be helpful to review the adult urgent and emergency care pathways with 111 and local ambulance services as patients reported being told to attend their nearest ED which for some was at King George's Hospital. Misdirecting patients to hospitals without expertise in the urgent care of patients with a Sickle Cell Disorder exposes them to delays, fragmented care, and increased risk.
2. Comments were received from adult patients about lack of communication between community teams provided by other organisations and the SHT. As part of the development of the community outreach provision it may be helpful to clarify roles and communication responsibilities between teams and services.

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	N
Thalassaemia – Adults	N

The visiting team held focus groups prior to the visit and during the visit. In total the visiting team met with three adults living with a Sickle Cell Disorder but did not meet with any adults living with Thalassaemia.

The review team did not meet with any children, young people and families living with a haemoglobin disorder as part of the pre visit focus groups but did meet with two families caring for children and young people living with a Sickle Cell Disorder during the visit.

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

This was a small highly committed and enthusiastic team who were very patient centred, providing holistic care and held in high regard by the patients. Most members of the team had only been in post for the last 18 months but had in this time achieved a considerable amount of progress in providing specialist care.

The haemoglobinopathy service was based at Queen's Hospital and comprised of two Paediatric Consultants with special interest in haemoglobinopathies who were part job-planned (8PAs) to deliver haemoglobinopathy care. The team also had a specialty doctor who supported outpatient care. The lead nurse worked across adults and paediatrics 1.0 WTE and the team comprised of two band 7 and one band 6 clinical nurse specialists (covering 2.0 WTE) and one band 4 administrative support.

The SHT cared for 333 children and young people with a haemoglobin disorder made of up of 283 living with a Sickle Cell Disorder and 50 children and young people living with Thalassaemia & RIA. New referrals were via newborn screening, from those moving into the area and from other hospitals. The service had received 27 new referrals in the last year.

The team had good relationships with their colleagues in general paediatrics and other specialties particularly surgical and pain management nurses and consultants.

Pain management pathways were in place and children and young people were issued with an ED passports to expedite access to analgesia which had resulted in a significant increase in the percentage of children and young people receiving timely analgesia from 19.6% in 2023/4 to 56.6% in 2025.

Transition of young people was led by the paediatric team. Joint transition clinics were held 10 -12 times a year and regular workshops took place with representation from the adult team. *See good practice section of the report.*

Newborn screening results were received from the Central Middlesex Hospital by the CNS team within 28 days and the CNS team would then arrange a home visits to discuss the results and provide early support for families.

Transcranial Doppler Scan (TCD) clinics were held weekly and undertaken by a specialty doctor and a business case was in progress to recruit a vascular sonographer to support the TCD service.

Local MDTs were held bi-weekly and attended by the consultant haematologists for haemoglobinopathies and the CNS team. The SHT regularly attended the HCC SCD, Thalassaemia, and Neuroradiology MDTs. The service was also supported by tertiary services including general surgery and paediatric subspecialities as part of the Northeast London Paediatric Network.

SPECIALIST HAEMOGLOBINOPATHY TEAM- CHILDREN AND YOUNG PEOPLE [1]							
Barking Havering and Redbridge University Hospital NHST - Queens Hospital Romford		Linked Haemoglobinopathy Coordinating Centres (HCC)					
		East London and Essex Sickle Cell HCC London and South East Thalassaemia and Rare Inherited Anaemia HCC *(both hosted by Barts Health NHS Trust)*					
		Linked Local Haemoglobinopathy Teams LHT					
		The CYP SHT did not have any linked LHTs					
PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLONOAPTHY TEAM							
Condition		Registered patients	Active patients*[2]	Annual Review **	Long term transfusion	% Eligible patients on hydroxycarbamide	Inpatient admissions in the last year
Sickle Cell Disorder	CYP	283	Data not supplied	213	10	87	92
Thalassaemia and RIA	CYP	50		24	8	<=5	<=5

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	333	8 PAs – two consultants each with 4 PAs
Clinical Nurse Specialist dedicated to work with paediatric patients living with haemoglobinopathies for the acute and community service	333	Lead 1WTE covering adults and CYP 3 CNS = 2WTE
Clinical Psychologist dedicated to work with paediatric patients living with haemoglobinopathies	333	0 No new referrals since June 2025

Urgent and Emergency Care

Patients had passports with brief pain management plans and had individualised care plans on their Universal Care Passport (UCP) which were accessible to the ambulance, ED and hospital staff. Children and young people with haemoglobinopathies were not admitted to the KGH site and parents and carers were given clear instructions to present to Queen’s Hospital ED. However, if they did present to the KGH ED, then they would be transferred and admitted to the Queens site.

At Queen’s Hospital they could bypass the standard ED streaming process through the Urgent Care Centre using their paediatric passports and present to the Children’s Emergency Department. They would then be triaged and assessed and given appropriate analgesia and/or management of other acute complications. The CNS team carried a DECT phone Mondays to Fridays during normal working hours, so were accessible to parents and carers to call for advice. If the family had been advised to bring their child to the ED, the staff in the children’s emergency department would be informed by CNS team of their attendance. In the Children’s emergency department, all children living with a Sickle Cell Disorder had an

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[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.

alert on their records so staff were aware their condition. The children's emergency doctors could also contact members of the SHT for advice.

In-patient Care

Patients who required an inpatient stay were admitted to Tropical Lagoon ward which was a 30 bedded paediatric ward with four high dependency (HDU) beds. During working hours, the paediatric team could contact the SHT, out of hours advice was available from the SHT based at the Royal London Hospital.

There was access to 24/7 on-call pain team, play specialists, phlebotomists, dietitians, physiotherapists and teachers for children admitted as inpatients

A team of band 8a senior children's nurses (CSP's) were available 24/7, who were part of the escalation process for any child or young person whose condition deteriorated and required a higher level of care and/or required transfer from ED to another provider.

Day Care

Day care was available on Tropical Bay ward which was a 12 bedded ward. Children and young people could attend for phlebotomy, blood transfusions and for hydroxycarbamide blood monitoring.

The nurse-led hydroxycarbamide telephone clinics were held on Tropical Bay ward and the unit had a play team and a teacher to keep the children occupied during their transfusions.

Outpatients

There were six general haematology clinics a week in which children and young people living with a haemoglobinopathy disorder could be reviewed, Transcranial doppler scans (TCD) clinics were held weekly and their there were two transition clinics held on alternate months. A phlebotomy service was also available attended by the CNS team. Patients who required elective scans (MRI, USS etc) could attend either the Queens or KCH sites.

Community- based care

The CNS team was based at the Trust but provided some community care including newborn screening visits, school care plans and teaching for schools and nurseries. The CNS team would also support families with DLA letters, PIP, housing/immigration support and general guidance and advice. The CNS team also undertook telephone reviews for patients who had been discharged from an inpatient stay. The SHT had plans to develop outreach services when staffing allowed.

Views of Service Users and Carers

The review team did not meet with any children, young people and families living with a haemoglobin disorder as part of the focus groups before the visit but did meet with two families caring for children and young people living with a Sickle Cell Disorder during the visit.

Service User Feedback

- Both families commented on the good experience they had when they had attended the Paediatric Emergency Department. They were seen quickly as they had a 'passport' and received timely analgesia.
- They all knew how to contact the team and were positive about being able to contact their consultant who was caring and understanding. The CNS team were 'excellent' and very responsive which they valued.
- They liked the WhatsApp parent and carer support group.
- Their child had a school care plan and knew how contact the team if any changes were needed.
- One child commented that they liked the 'play team'.

- In general, they found the service easy to access

Good Practice

1. Reviewers were impressed with how the SHT had implemented the transition process, which was based on the national 'Ready Steady Go Hello' programme and led by the Lead Nurse who worked jointly between the paediatric and adult services.

   Young people would be prepared for transition by the paediatric team and would have the chance to discuss transition three times between the ages of 12 to 13 years of age to the age of 16. Joint Transition clinics were held 10 to 12 times a year.

   Young people would also have the opportunity to attend a Transition Workshop which was held three to four times a year and attended by members of both services and patient representatives who would welcome them to the adult service. Activities included party bags, pizza, and opportunities for peer support.

   The Play Specialists also held "graduation days" with cap and gowns for young people to celebrate their transition milestones.

2. The CNS team ran a dedicated WhatsApp support group for parents/carers which families said they found extremely helpful and feedback from users was consistently positive.

3. Clinical Site Practitioner Role was working well often bridging the gap between nursing and medical staff. The practitioners provided 24/7 support in the identification of deteriorating patients, admission coordination, bed flow, and escalation of the sick child.

4. The latest audit of compliance with the NICE Guidance on managing acute painful episodes in hospital, had shown a significant increase in the percentage of children and young people who had received timely analgesia from 19.6% in 2022/3 to 56.8% in 2024/25. Members of the SHT had attributed this increase to targeting patient and staff education.

5. Reviewers were keen to acknowledge the psychology service (prior to its suspension in June '25) which had provided a longstanding and very valuable service from a highly experienced psychologist who was fully embedded in the team. The psychologist had also played a pivotal role in service development. The service constantly received outstanding feedback from children, young people and their families, and staff.

6. The quality board displayed on the ward provided a range of useful condition and performance information.

Immediate Risks

There were no Immediate Risks identified during the course of the visit

Serious Concerns

1. **Access to Paediatric Psychology**

   Children, young people and their families did not have access to psychology. Some access to psychology was still available for young people transitioning to adult care, however referrals to the psychology service for children had ceased in June 2025. Children and young people requiring neurocognitive assessments were referred to the neuropsychology service based at Kings College Hospital NHS Foundation Trust.

   Reviewers were seriously concerned as without sufficient dedicated psychologist support individuals children and young people affected by these disorders will have limited specialist psychological input which may result in increased stress, anxiety, or difficulties in coping with challenges associated with their condition. *See also Trust wide Serious Concern section of the report*

Concerns

1. **CNS Capacity**

   At the time of the visit the SHT had only two WTE CNS for the paediatric acute and community service which was insufficient for the 333 registered patients to provide support to patients and their families, nurse led clinics, MDT meetings and supporting the wards. The range of work being undertaken by the CNS team was impacting on the time being able to provide the level of outreach support to paediatric patients in the community as the SHT had envisaged.

   Reviewers acknowledged that a plan was in place to recruit two Band 6 nurses through the MedTech funding, which potentially would release time to enable to CNS team to refocus on community needs.

2. **Transcranial Doppler (TCD) Service**

   The TCD service was dependent on a single specialist doctor to perform all TCDs with no cover for absences. Reviewers were concerned that this created a significant risk in terms of resilience and sustainability of the TCD provision for children attending the Trust.

3. **SHT Leadership Time**

   The designated lead consultant did not have any time allocated for leadership of the SHT developing which limited capacity for strategic service development, training and audit, and overall responsibility for liaison with other services.

Further Consideration

1. Provision of Nurse Controlled Analgesia (NCA) was not available on the wards and reviewers considered that provision would minimise the delays in analgesia administration and improve patient experience.
2. Children, young people and their families did not have easy access to a welfare and benefits support and the team were spending time supporting families with non-clinical issues. The benefits for patients in improving their quality of life by having this level of support should not be underestimated and would enable the team to focus on their increasing clinical workload whilst ensuring that families gain access to appropriate support.
3. A nurse competency framework covering haemoglobinopathies was not yet in place. Some training was provided by the CNSs' but a competence -based training to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders had not yet been implemented.
4. The SHT had not yet participated in the HCC audit programme and as part of their development should be considering how they can have more involvement in research and clinical trials as expected as a designated SHT.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

This was a small highly committed and enthusiastic team who were very patient centred, providing holistic care and held in high regard by the patients, although they were working under extreme pressures.

The haemoglobinopathy service was based at Queen's Hospital. The team consisted of the Lead Consultant (3PAs) and two other haematology consultants who had some job-planned time to deliver haemoglobinopathy care (making 4.5PAs in total for the SHT), a lead nurse who worked across adults and paediatrics, three band 7 clinical nurse specialists; 2.8 WTE to cover the acute and community service, along with a specialised psychologist, benefits and welfare advisor (shared with oncology) and some administrative support. The SHT did not have any support for data management.

Local multidisciplinary meetings were held monthly and representatives from the SHT regularly attended the HCC SCD, and Thalassaemia MDTs

The SHT had good relationships with other specialists particularly obstetrics, surgery and the pain team. Monthly joint obstetric clinics were held, the consultant from the pain team attended the teams MDTs on a regular basis to advise on complex pain issues. The team had a link Consultant in the ED and were working with them to improve timely access to acute pain management for patients attending in an emergency.

Patients requiring regular transfusions were able to attend the Infusion Suite for their transfusions on weekdays and attend the Sunflower Suite on Saturdays. Patients living with a Sickle Cell Disorder experiencing an uncomplicated crisis, could also attend the Infusion Suite for pain management.

Transition of young people was undertaken in conjunction with the paediatrics team to facilitate seamless transition of care and shared educational and multidisciplinary team approaches. Joint transition clinics were held 10 to 12 times a year. The lead nurse ran transition workshops with the Paediatric team. *See also Good Practice section of the report.*

Patients also had access to the Welfare Benefits Advisor and patients who met with the visiting team were highly appreciative of the support they had received from the advisor.

Nurse-led hydroxycarbamide clinics were in operation and once capacity allowed the team were planning to improve the provision of more nurse led services and develop the community outreach service.

Members of the SHT provided regular training for medical staff and a competence framework adapted from the RCN Competence Framework: Caring for People with Sickle Cell Disease had been developed and had been implemented in key areas.

The SHT had been successful obtaining MedTech funding for an apheresis machine, which included an additional band 6 post in order to increase the capacity of their automated red cell exchange service. The SHT hoped to be able to double the capacity from 33 patient to 60 patients on the programme. At the time of the visit recruitment to the band 6 nurse post was progress.

The SHT were planning to develop patient-led advisory, advocacy and education groups. The patients who met with the visiting team commented that they would value a forum for education and support.

The SHT were very aware of the challenges they faced in terms of the appropriate multidisciplinary workforce and required infrastructure to provide specialist care for their existing and ever expanding population of people living with a haemoglobin disorder in the area.

SPECIALIST HAEMOGLOBINOPATHY TEAM- ADULT [3]	
Barking Havering and Redbridge University Hospital NHST - Queens Hospital Romford	Linked Haemoglobinopathy Coordinating Centres (HCC)
	East London and Essex Sickle Cell HCC London and South East Thalassaemia and Rare Inherited Anaemia HCC *(both hosted by Barts Health NHS Trust)*
	Linked Local Haemoglobinopathy Teams LHT
	The Adult SHT did not have any linked LHTs

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLONOAPTHY TEAM

Condition		Registered patients	Active patients*[4]	Annual Review **	Long term transfusion	% Eligible patients on hydroxycarbamide	Inpatient admissions in the last year
Sickle Cell Disorder	Adults	365	389	242	45	108	190
Thalassaemia and RIA	Adults	31		31	17	None	<=5

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	396	4.5 PAs in total – 3 consultants.
Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies – Acute	396	Lead – 1WTE 1.8 WTE CNS
Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies in the community	396	1WTE
Clinical Psychologist dedicated to work with patients living with haemoglobinopathies	396	1 WTE

Urgent and Emergency Care

Patients were provided with passports which included a brief pain management plan and instruction to fast-track to appropriate acute clinical areas. Patients also had Universal Care Plans (UCP). Patients were encouraged to present to the Emergency Department (ED) at Queen's Hospital where the haemoglobinopathy team were based rather than King George's ED. Walk-in patients would bypass the standard streaming processes through the Urgent Care Centre using the passport and access the Rapid Assessment areas (RAFT) directly where they would access triage and appropriate nursing and medical review to enable access to analgesia, or management of other acute complications.

Patients who attended the ED overnight were reviewed by the outlying haematology team/CNS the following morning and if suitable, and the unit was open, were transferred to the Infusion Suite for further management.

People living with a Sickle Cell Disorder experiencing an uncomplicated painful crisis, and who met the admission criteria could also avoid attending the ED and access the Infusion Suite for pain management by calling the Infusion Suite between 09:00-10:00 am Monday to Friday.

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[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.

A consultant haematologist was on call 24/7 and during normal working hours a specialist trainee resident and nurse specialists were available for patients to contact for advice.

In-patient Care

Patients requiring and inpatient admission could be admitted to any area but most inpatients were accommodated on Sky A or Sky B. Sky B ward was the designated haematology / oncology ward and reviewers were told that the ward generally ran at 90% occupancy with patients who had a haematological disorder. Patients had access to patient controlled analgesia (PCA) on Sky B and patients admitted to other wards who required a PCA would be prioritised for transfer to the ward. Sky B ward had 13 side rooms with an ensuite bathroom; two side rooms with a shared bathroom; one four-bedded bay with a shared bathroom.

Day Care

The SHT had recently acquired the Infusion Suite as a dedicated space for their haemoglobinopathy service. The infusion suite had two bed spaces for automated red cell exchanges and two reclining chairs where they could offer ambulatory pain management for patients experiencing an uncomplicated vaso-occlusive crisis. There were an additional two reclining chairs for patients to attend for blood transfusions.

At the time of the visit the SHT were actively recruiting to two Band 6 nurses who will deliver direct care for patients receiving exchange transfusions, patients attending for top up blood transfusions and for those attending for ambulatory pain management. At the time of the visit the CNS team were based on the infusion suite and were supporting the delivery of care on the unit as well as providing the triage for ambulatory care.

Due to the piloting of the new unit and staffing, the criteria for attending was limited. Patients could self-refer by phoning the Infusion Suite between 09:00 and 10:00 Monday to Friday and be triaged by a member of the CNS team. Patients already in ED or in SDEC who met the Infusion Suite inclusion criteria and had been reviewed by the Haematology Outliers team could be accepted and transferred to the unit on weekdays before 10am.

Outpatients

Dedicated haemoglobinopathy clinics were held on Wednesday afternoons for follow up and annual review with 15 appointment slots and attended by two consultants, specialist trainee doctor and other members of the multidisciplinary team. The CNS, psychologist and welfare & benefits advisor were also available in clinic but not always on a regular basis. New patients were seen in the general haematology new patient clinics by any of the three haemoglobinopathy specialist consultants. Monthly joint obstetric clinics were held, as well as a monthly transition clinic. Patients did have access to a complex pain clinic although there was no dedicated service for those with complex pain.

Community- based care

The haemoglobinopathy service was an integrated community and acute care service which enabled the specialist nurses to develop their skills in both aspects of the service. At the time of the visit due to capacity issues in the acute trust the majority of community care was provided virtually although it was planned that they would develop the outreach service further. The CNSs would follow up of patients post discharge from hospital, follow up patients who had DNA their clinic appointments and for patients and students going off to university, provide letters of support so that they could apply for additional student finance support.

Views of Service Users and Carers

The SHT had undertaken patient surveys in July 2025 Sickle Cell. The responses had been analysed and were consistent with the views of the patients who met with the reviewers before the visit.

Service User Feedback

The visiting team held focus groups prior to the visit during the visit, and in total met with three adults living with a Sickle Cell Disorder but did not meet with any adults living with Thalassaemia.

General Experience & Support

- Patients described the SHT team as "really helpful" and providing holistic, person-centred care. They were valued for being supportive, approachable, and genuinely caring. They were "like family" and a "privilege to have them", highlighting their compassion, advocacy, and deep understanding of Sickle Cell disorders.
- Previously, information about medical trials and research was shared more openly but they commented that this was only accessible if attending medical conferences. Patients commented that they would value more updates on new developments and trials.
- All had regular check-ups every three months with their medical consultants, and they commented this also provided opportunities to discuss treatment options.
- CNSs organised support groups to encourage peer communication and also run education sessions (e.g., family planning, conception advice). However, there was no single structured running support group, although they commented that one was due to restart.
- Transition support for young people was seen as well managed, with education sessions available. Those who spoke to the review team had attended the workshops to speak to young people and welcome them to the adult service.
- They were aware of their care plans and commented that they were meant to be up to date and accessible at the hospital, but:
    - Different data systems between A&E and medical wards sometimes mean care plans were hard to find.
    - Patients had to rely on yellow cards with care plan details to mitigate this.
    - Care plans were also available on the NHS App but it didn't appear that they were accessed.
- GPs usually received copies of their clinical letters, which helped with continuity of their care.
- All who spoke to the visiting team valued the holistic and compassionate approach of the haematology team, describing them as advocates who resolve issues when situations escalate in ED and on the inpatient wards.
- There was good welfare and psychological support, but capacity was limited, leading to longer wating times. Some patients were unaware that complementary services (dietitian, benefits support, etc.) were also available to them, thinking they were for oncology patients only.
- Patients considered that staff genuinely cared but budget constraints limited service expansion for example the outreach work had been delayed which they considered had the potential to reduce admissions and support earlier discharge.

Emergency Department (ED) Pathway

- Experiences in ED were described as very negative and compared to a "battle" or "warfare." Hostility and lack of knowledge from staff about sickle cell protocols were recurring themes.
- Delays in pain relief:
    - If admitted directly to majors (often via ambulance), pain relief was timelier.
    - However, the first dose was often delayed, and subsequent doses were inconsistent.
    - Being moved into corridors they felt led to neglect, with patients waiting hours for pain relief and sometimes being forgotten.
    - One patient reported waiting 14 hours, being moved from chair to chair.

    - One patient had their family member with them in corridor care as they could not access a member of staff, a bell to alert the staff and couldn't shout either. Patient emphasised that if the relative was not with them, it could have been worse that night.

- Patients described nurses dismissing pain, with comments such as "*you are not the most important person here.*"

- Some reported staff becoming irritated or annoyed when patients referenced the NICE guideline standard of 30 minutes for pain relief.

- The environment in the ED they felt was unsuitable: no buzzers in corridors, patients having to shout for help, noise exacerbating pain and with their families often staying overnight to advocate for them.

- Because of repeated poor experiences, some patients would try to avoid ED entirely, waiting until SHT were available (e.g., weekdays) or relying on MDU/day unit instead.

Unclear Emergency Pathway

- All were aware of the urgent care pathway however one patient described being advised by 111 to attend King George's Hospital (KGH) during an acute episode, even though they knew they should attend Queens ED. On arrival, they were asked to provide evidence that they had a Sickle Cell Disorder and required fast-track access. Although triaged within 20 minutes, they soon discovered there were no haematology doctors available at KGH. This created a barrier to appropriate specialist input and resulted in delays to their care pathway, as KGH does not provide dedicated sickle cell services in their Emergency Department. The patient reported feeling that they had to advocate for themselves to be taken seriously, which added further stress during a crisis episode.

- The patients considered that the lack of clarity within urgent care pathways (111 referrals) can misdirect patients to hospitals without sickle cell expertise, exposing them to delays, fragmented care, and increased risk and highlighted the need for better coordination between 111, ambulance services, and specialist sickle cell centres, ensuring patients were always directed to appropriate hospitals with the right expertise.

Day Unit / Infusion Suite

- Day unit haematology staff were described as caring, compassionate, and attentive, constantly monitoring and talking with patients.

- Available Monday to Friday, 9am to 5pm. Services included pain management, transfusions, and exchange transfusions. The patients felt that the service was limited as it was not suitable for patients with complex vaso-occlusive crisis e.g. chest pain, cardiovascular problems and other major complications. There were limited beds (mostly reclining chairs, only one bed prioritised for blood exchanges).

- Patients also commented about the limited capacity of the service to access the exchange transfusion programme.

    - Exchange transfusions every 6 weeks required a blood test 72 hours prior and booking could be inconsistent and sometimes the patient would have to arrange this themselves

    - Some had a 'port-a-cath' to assist with line access, for other patients with complex access they may have to attend other areas for access (e.g. theatre).

- Patients appreciated being involved in decision-making especially around hydroxyurea and transfusion scheduling.

- Some issues with accessing veins and slow cannulation were raised, but overall, the team were described as experienced, kind and professional. Once transfusions were running, the process was smooth, with appointments made during treatment to reduce delays.

- Patients valued the choice of appointment times (e.g., Swiftqueue system).

- Those who were on Hydroxyurea were monitored every three months and bloods were often arranged via the GP.

- Patients were complimentary of medical team in day unit, noting that new checks were introduced pre and post transfusion such as leg swelling or reviewing results before discharge and this gave them confidence in the service.

Inpatient Care

- Experiences were described as mixed “hit and miss” and ‘luck of the draw’:
    - On MRU (Medical Receiving Unit), one patient was placed with a patient with diarrhoea & vomiting, in poor conditions (dirty toilets).
    - Complaints about care and hygiene of the ward led to medication delays and feelings of neglect (buzzers not answered, nurses ignoring requests).
    - Reports of being treated with suspicion or hostility, e.g., “Why is this patient here?” and staff being annoyed about bed use. This was a patient who had been discharged on the system from the day unit following a transfusion but developed suspected sepsis and became very unwell and had to go to the ED. The system picked them up as a discharged patient and there was confusion regarding their episode of care.
- General lack of care was experienced. Some patients felt better supported on dedicated wards (e.g., Sickle Cell Ward, Sky A/B), where staff had more knowledge and showed greater understanding. However, access to these wards was inconsistent due to bed shortages. Staff on Sky B were reported to be more understanding and they would receive timely analgesia.
- Instances where patients had been discharged on the IT system while still receiving treatment were noted.
- When the SHT was involved, care improved significantly: ‘they advocate, resolve issues, and ensure patients are treated properly’.
- Some patients said they would try not being admitted, preferring to manage at home or delay admission until the haematology team was present.

Care in the community

- Comments were received about lack of communication between community teams and the SHT.
    - One patient described how recurrent leg ulcers were managed in the community by an outsourced team, but there was no communication with the hospital haematology team, leading to fragmented care.
    - Patients receiving oxygen at home found that the community oxygen service did not coordinate with the hospital team, again leaving gaps in joined-up care.
- Patients felt they could benefit from a home service that supports admission avoidance e.g. pain relief administration for mild to moderate pain.

Good Practice

1. The feedback from patients who met with the visiting team was overwhelming in their praise of the SHT team whom they knew by name saying that all members of the team treated them as “human beings” and with respect. They considered that their care was holistically managed and that team members would listen, problem solve and ensure they had sufficient knowledge to make decisions about their care.
2. Reviewers were impressed with how the SHT had implemented the transition process, which was based on the national ‘Ready Steady Go Hello’ programme and led by the Lead Nurse who worked jointly between the paediatric and adult services. Joint Transition clinics were held 10 – 12 times a year. Young people would also have the opportunity to attend a Transition Workshop which was held three to four times a year and attended by members of both the adult team and patient representatives who would welcome them to the adult service. Activities included party bags, pizza, and opportunities for peer support.

3. The SHT were in process of mandating training covering Sickle Cell Disorders and pain for the relevant staff groups across the Trust. Work was also being undertaken to develop an online resource covering key aspects about haemoglobin disorders for staff.
4. The service provided by the Psychologist was impressive in terms of their dedication and excellent knowledge of the local mental health services and pathways (as a result of their long standing service in the region). They were a highly valued member of the SHT and their work consistently received good feedback from patients and families.
5. The team had good links with the pain team who had a special interest in supporting patients experiencing a vaso occlusive crisis and those who required complex pain management. The Consultant also attended the SHT MDTs.
6. The Lead Nurse role that provided overarching leadership across both the adults and paediatric services fostered collaborative and cohesive working and promoted whole life care for this group of patients.
7. Ward staff who met with the reviewing team were very complimentary about the CNS team who they found were always responsive when contacted, would make themselves available and were helpful in providing advice and support.

Immediate Risks

No immediate risks were identified during the course of the visit.

Serious Concerns

1. **Consultant Staffing**
    a. 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 scheduled care including regular reviews, and clinics for the patients under their care. At the time of the visit the SHT had three Consultant Haematologists with a combined total of 4.5 PAs for the care of 396 patients rather than the expected 11.1 PAs needed for red cell work. None of the consultants had time allocated for hemoglobinopathy CPD and were spending time on administrative work due to the lack of available administrative and data support.
    b. Reviewers were told that work was being undertaken to review consultant job plans and there was funding to increase the available PAs for red cell work. However, reviewers were concerned the existing workload was not sustainable and that consultant staffing for the future would also need to take account of the increasing patient numbers, longevity and complexity.
2. **Senior Nurse Workload**

    The level of senior nurse time was of a serious concern for the following reasons:

    a. The Lead Nurse had insufficient time for leadership and service development. The Lead Nurse covered both the adult and paediatric services as well as their own clinical workload and was the lead for children transitioning to adult care.
    b. The SHT had only 2.8 WTE CNS for the acute and community service which was insufficient for the 396 registered patients to provide nurse led clinics, supporting the wards and ward rounds, providing triage and covering the transfusion service on the Infusion Unit.
    c. The range of work being undertaken by the CNS team was impacting on the time to provide the level of outreach support to patients in the community as envisaged, and at the time of the visit only virtual support was provided for those who had been discharged from acute care.
    d. The senior nursing team had little time to undertake audits and staff education and had no time available for professional development in their speciality.

3. **Access to Psychology**

   Access to psychology was insufficient for the 396 people living with a haemoglobin disorder registered with the service and at the time of the visit the waiting time to see the psychologist was six months. There was only 1 WTE senior psychologist who did not have cover for absences, which did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE HCPC Senior Psychologist for every 300 patients. Reviewers were concerned as without sufficient dedicated psychologist support individuals affected by these disorders will have limited specialist psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition. *See also Trust wide Serious Concern section of the report*

4. **Infusion Unit/ Ambulatory Service**

   Reviewers were seriously concerned about the suitability of the infusion Unit to provide a safe and confutable level of care.

   a. The unit was cramped with two beds for patients undergoing aRCE and patients attending unwell or for transfusions only had access to recliner chairs, which are not comfortable for all patients for prolonged periods of time.

   b. There was no piped O_2 and staff were reliant on access to a small portable O_2 cylinder which reviewers considered posed a safety issue as patients attending could experience a highly reactive episode during their transfusion, and there may be other patients on the unit at same time experiencing a vaso occlusive crisis who would require O_2 therapy.

   c. The unit was only open 9am to 5pm, Monday to Friday and at the time of the visit did not have an appropriate number of staff to provide the transfusion service and the direct access ambulatory pain management service. The transfusion service was therefore reliant on the CNS team to provide the clinical service whilst recruitment took place which was impacting on the CNSs being able to fulfil their specialist roles.

   d. The lack of staff and space had also impacted level of ambulatory care that could be provided resulting in their being a restrictive criteria for access and reducing the impact an ambulatory service could have on the urgent care pathway.

   e. The unit was also used as an office space for the CNS team and there was no space available for any private consultations/ conversations with patients attending, for patients contacting the unit for triage, or for general advice and support.

5. **Adult Emergency Department Pathway:** *See Trust wide Serious Concern section of the report*

Concern

1. **Access to Elective Automated Red Cell Exchange (aRCE)**

   Staffing for the aRCE service was insufficient for the numbers of patients who required this service and despite the MedTech funding and improved tariff, the service had a waiting list of 15 patients. Delays in patients accessing aRCE treatment has the potential to 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.

   Reviewers were concerned that as part of the MedTech bid only one Band 6 nurse had been included which reviewers considered was unlikely to improve the staffing of the service sufficiently to reduce the existing waiting list and address any future growth in patient demand.

2. **Inadequate Administrative and Data Support**

   The SHT had limited administrative support with clinical staff spending time on administrative activity which was often undertaken outside of normal working hours so as not to impact on clinical activity.

The SHT had no data support for audit or data submissions to the NHR which enable the NHSE Specialised Services Quality Dashboard (SSQD) returns. At the time of the visit clinical staff only had the capacity to enter registration and patient annual review completion onto NHR. Completion of the SSQD is a requirement within the NHSE SHT specification as submission provides assurance on the quality of care and patient outcomes by commissioners. Reviewers were concerned that the potential impact of an incomplete picture could impact on future available SHT funding and recognition as a specialist haemoglobinopathy team.

Further Consideration

1. 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. The patients who spoke to the reviewing team had a number of areas where they considered improvements could be made: -
    - Care when attending the emergency department: *see Trust wide section of the report.*
    - Widening of the criteria for admission to the Infusion Suite so that they could bypass the ED.
    - Improvement of care and staff knowledge on other wards. They wondered whether more could be done to reduce the number of outlying wards to where patients were admitted. The reduction would streamline patient management, allow for more focussed and specialist care and enable more targeted training for staff covering the urgent care need of patients with a haemoglobin disorder.
    - Patient support group/ forum where they could receive updated information and be signposted to the right places.
2. As part of the strategy to make the service more nurse led the team would require some additional resource to enable the benefit of nurse led clinics to be fully realised. At the time of the visit only one of the three CNSs was a nurse prescriber which meant that the hydroxycarbamide clinics were not fully nurse led as they were dependant on the medical team to review and prescribe medication.
3. An audit of acute admissions to inappropriate settings including patient and clinical feedback on these admissions had not been completed which, if undertaken would help with identifying pathway issues and identifying educational needs in these areas, planning patient management and support to areas, as well as identifying if there were any specific training needs for staff. An audit would also enable a review of the patients length of stay in these areas and targeting of any actions to ensure timely assessment, treatment, and discharge of patients.
4. The SHT did not have the workforce capacity to fully engage in clinical trials and research as expected as a designated SHT. The team were keen to engage with clinical trials but acknowledged that they did not have sufficient time and would require additional support from the Trust clinical trials department.

Commissioning

The review team had discussions with specialist services representatives from the regional NHS England London and North East London ICB. Several issues in this report will require the active involvement of the Trust leadership team and commissioners to ensure timely progress is made.

Concern

1. From discussions during the visit the review team identified that further work would be required with the Trust and their local and specialist commissioners to progress meeting the local population health needs in terms of ensuring that the SHT are able to meet the NHSE specification for a designated Specialist Haemoglobinopathy Team.

Appendix 1 Membership of Visiting Team

Visiting Team		
Srinivasan Narayanan	Consultant Haematologist	University Hospital Southampton NHS Foundation Trust
Afoke Arigbe	Clinical Nurse Specialist	Imperial College Healthcare NHS Trust
Hannah Jerman	Clinical Nurse Specialist	Guys and St Thomas NHS Foundation Trust
Chifundo Tsaka-Stubbs	HCC Practice Development Nurse	Guys and St Thomas NHS Foundation Trust
Heather Rawle	Consultant Clinical & Health Psychologist	Guys and St Thomas NHS Foundation Trust
Sarah Wilkinson	Consultant Haematologist	Lewisham and Greenwich NHS Trust
Clare Clark	Paediatric Haematology Clinical Nurse Specialist (CANP)	Cambridge University Hospital NHS Foundation Trust
Giselle Padmore-Payne	Sickle Cell Society UK Paediatric Nurse Advisor	The Royal Wolverhampton Trust
June Okochi	User Representative	
Gabriel Theophanous	User Representative	UK Thalassaemia Society
Charity Mutiti	Dep Director of Quality and Patient Safety Specialist	South West London ICB

Clinical Leads		
Rachel Kesse-Adu	Consultant Haematologist - Adults	Guys and St Thomas NHS Foundation Trust
Mark Velangi	Consultant Haematologist – Children	Birmingham Women and Children’s Hospital NHS Trust

NHS Midlands and Lancashire		
Sarah Broomhead	Professional Lead	NHS Midlands and Lancashire
Rachael Berks	Clinical 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	33	70%
Specialist Haemoglobinopathy Team (SHT) Adults	45	26	59%

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	Reviewers commented that it may be helpful for children, young people and families if some of the information was also available in the PED.

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).	Y	For those living with SCD they had a Universal Care Plan. Care plans were in place for those living with Thalassaemia.
HC-104	**What to Do in an Emergency?** All children and young people should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	Covered in service leaflet - 'when to go to ED' UCP Care Plan template included reference to 'b' Feedback from families was that they were aware of where to go in an Emergency.
HC-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents [SCD and Th] c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health (if appropriate) d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	N	The new diagnosis GP New Birth letter example for a baby with SCD was met apart from 'b' side effects of medication including chelator agents. Information was not seen for those living with Thalassaemia.

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.	Y	All the areas visited were bright, welcoming and interactive child friendly. The facilities seen in the ward area, day unit and outpatients were excellent. The areas all had Play Specialists.

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	'Ready steady go hello' was used. Transition workshops were held on a regular basis which were fun as well as being educational. The Play Specialists also led on a 'graduation day' for those about to transition to adult services. *See also Good Practice section of the report.*
HC-197	**Gathering Views of Children, Young People and their Families** The service should gather the views of children, young people and their families at least every three years using: a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder' b. UKTS Survey for Parents of Children with Thalassaemia	Y	
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	Y	A patient forum was in operation as well as transition workshops.

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 designated Lead Consultant did not have anytime allocated for leadership of the SHT. There was a named deputy.
HC-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The designated Lead Nurse (1.0WTE) worked across the SHT (adults and paediatrics) and had insufficient time for SHT leadership, service development and their clinical commitments.
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	The SHT had a total of 8 PA allocated for all haemoglobinopathy work (4PAs per two consultants) which was insufficient to provide scheduled care for the 333 patients under their 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	Onsite cover from a paediatric consultant and a networkwide SLA was in place for out of hours advice from a consultant paediatric haematologist based at Barts Health NHS Trust.
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	There were only CNSs 2.0 WTE for HBO and one B6 to provide acute and community care which was insufficient for the number of CYP and scope of their roles. A competency framework for nursing staff working in key areas had not yet been implemented. Staff did have competences in cannulation and transfusion.
HC-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. An appropriate number of regular clinical session(s) for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	At the time of the visit there was no psychology provision for children, young people and their families. Access to neuropsychology was via the team based at Kings College NHSFT.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N	There was only one TCD practitioner which meant the service was dependant on one individual who had no cover for any absence.
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.	Y	The team had 0.8 band 4 data manager and there was plans to increase the administrative support as part of the provision of the apheresis service.

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	Y	
HC-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	CYP requiring aRCE (f) were transferred to the SHT based at RLH. Funding had been agreed to provide an onsite apheresis service by the end of the financial year. Reviewers were told that recruitment was about to commence for this service.
HC-303	**Laboratory Services** UKAS/CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders. *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.*	Y	Training on hemoglobinopathies had been provided as part of an ED training day (KIT day) The latest audit covering compliance with the NICE audit on access to analgesia within 30 mins of arrival to the ED had shown a significant improvement.

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	The transition process was very good. *See good practice section of the report.*
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	
HC-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: I. Emergency and regular transfusion II. Use of simple or exchange transfusion III. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: I. Manual exchange transfusion II. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Arrangements for accessing staff with cannulation competences f. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion g. Patient pathway for Central Venous Access Device insertion, management and removal	Y	

Ref	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	Covered in separate SCD and Thalassaemia guidelines.
HC-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring complications e. Indications for discontinuation	Y	Covered in separate SCD and Thalassaemia guidelines.
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	Covered in separate SCD and Thalassaemia guidelines.

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	Covered in separate SCD and Thalassaemia guidelines.

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	Y	Covered in separate SCD and Thalassaemia guidelines.
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	Covered in separate SCD and Thalassaemia guidelines.
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	Staff accessed guidance via the intranet and paper copies in a folder.

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	N	The SHT did not have an SOP covering the requirements of the QS.
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/A	The SHT had no linked LHTs

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	Weekly MDTs were held and a weekly HCC meeting.
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	BHRUT provided community support as an outreach model.
HC-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each HCC Business Meeting (QS HC-702).	N	A representative had only been able to attend one of the two business meetings held in 2024. At the time of the visit no meetings had been held in 2025.
HC-607T	**HCC Business Meeting Attendance -Th)** At least one representative of the team should attend each HCC Business Meeting (QS HC-702).	Y	A representative of the SHT had attended both of the HCC meetings held in 2024.
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.	Y	
HC-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions	N	Audits covering ‘a’ and ‘b’ had not been undertaken. The team had undertaken a local audit to assess the number of children with SCD on Hydroxycarbamide.

Ref	Standard	Met Y/N	Reviewer comment
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	N	No evidence of HCC audits having been completed A local audit of compliance with the NICE Guidance covering analgesia within 30 mins of presentation had been undertaken.
HC-707	**Research** The service should actively participate in HCC-agreed research trials	N	The team was relatively new and had not participated in any research. Reviewers were told that they would consider undertaking research in the future.
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	The team had not yet reviewed 'a-c' with patient representatives as defined by the QS. Some work had been undertaken to gather feedback about psychology support and for those with SCD and a patient conference had been held in April 2024.
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)	Y	
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 iii. National Haemoglobinopathy Registry, its purpose and benefits iv. Self-administration of medications and infusions	Y	Information was seen covering all aspects of the QS for those living with a Sickle Cell Disorder and Thalassaemia.

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).	Y	
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	Patients had ED passports which also directed clinicians to their individualised care plans on EPS.
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	N	The environment on the Infusion Suite was cramped. *See main report.* This QS was met for the ward area visited.

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	Y	
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: 'Patient Survey for Adults with a Sickle Cell Disorder' UKTS Survey for Adults living with Thalassaemia	Y	Surveys had been undertaken in July 2025 and results analysed.
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	'a' and 'b' was met and team were planning to do 'c' Patient advocates had been invited to join quarterly service development and community support meetings and the team were considering reestablishing the local patient support group.
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The designated Lead Clinician had only three PAs allocated for SHT leadership and to provide clinical care. Named deputies were in place.

Ref	Standard	Met Y/N	Reviewer comment
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.	N	The designated Lead Nurse (1.0WTE) worked across the SHT (adults and paediatrics) and had insufficient time for SHT leadership, service development and their clinical commitments.
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The SHT had insufficient medical staff with time allocated for clinics and regular reviews for the 396 patients under their care. The SHT Consultant staffing was a total of 4.5PAs rather than the expected 11.1PAs for the number of patients. None of the consultants had time allocated for hemoglobinopathy CPD.
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. SHTs and HCCs only: A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	A Consultant Haematologist was available by phone 24/7; consultant and/or specialist trainee residents were on site Monday to Sunday - 9am to 5pm.
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	

Ref	Standard	Met Y/N	Reviewer comment
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	Three CNSs (2.8 WTE) were in place to cover the acute and community service but were also covering other roles on the infusion suite. In practice the community element of the service was not fully implemented due to capacity of the team. The Infusion Suite/ Day Unit was newly acquired and at the time of the visit did not have a full complement of appropriately trained staff requiring the CNS team to provide cover. An HBO genetic counselling training competence framework was in place and the revised RCN Competence Framework was in the process of being implemented. A competence framework for Emergency Manual RCE was in place for ITU staff. Staff did have competences in cannulation and transfusion.

Ref	Standard	Met Y/N	Reviewer comment
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The SHT had one WTE Psychologist for the care of 396 patients which did not meet the recommended staffing level of One HCPC Senior Psychologist for 300pts. The Senior Psychologist did have some very limited support from an Assistant Psychologist (an informal agreement of half a day per week). In the Psychology Annual Report (2024-25) it was reported that 72 patients were on the waiting list and at the time of the visit the waiting list for adults to be seen was six months. Neuropsychology was provided by Queen's Hospital Neuropsychology Dept.
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 team did not have any support for data, although some data support was likely in the future from the HCC.
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	Automated RCE (f) was not available 24/7 but the service was planning to extend the hours the service was operational, depending on appropriate staffing, in the next eight to ten months.
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders. *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	Some bitesize teaching was provided for ED staff and ED nurses but training was not competence based and some staff who met with the reviewing team were not clear about the emergency pathway for this group of patients. The Audit of the NICE Clinical Guideline on the management of acute pain undertaken in 2025 showed that 2/41 patients (5%) had received analgesia within 30 mins of arrival to the ED which was a deterioration on the previous year's compliance of only 10%.

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	
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	Seen in Thalassaemia and SCD guidance and annual review proformas
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	Y	

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	Y	
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	An SOP covering the Nurse-Led Hydroxycarbamide Clinics was in place.
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	

Ref	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	Y	

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	Y	
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	Y	
HA-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	
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 operational policy covering the requirements of the QS. Arrangements were in place for MDT discussion, follow up of patients who did not attend and care coordination across hospital sites.

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 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	Local MDTs were held monthly.
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	There were no SLAs in place as per the QS. The SLA for provision of psychology services for NEL had expired and in the process of being re negotiated. See also patient feedback about communication with community leg ulcer and oxygen services.
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	A representative had only been able to attend one of the two business meetings held in 2024. At the time of the visit no meetings had been held in 2025.
HA-607 T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each HCC Business Meeting (QS HA-702).	Y	A representative of the SHT had attended both of the HCC meetings held in 2024.

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	The team did not have capacity to enter all data. Only registration of patients and their annual reviews were entered.
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	The SHT had not yet audited ‘a’ or ‘b’ Some general feedback about admissions to the Trust was collected as part of the Friends and Family Feedback (FFP) but this was not specific to haemoglobinopathy care.
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	Y	The SHT had completed the pain audit, however compliance had been consistently low.
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	N	Some psycho-social research had been undertaken but the SHT did not have capacity or support from the trials team to engage in clinical trials.
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	The service's multidisciplinary team, with patient and carer representatives, had not yet reviewed ‘a’ to ‘c’
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.	Y	Documentation seen was appropriately controlled.