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Health Services for People with Haemoglobin Disorders

East London and Essex Sickle Cell Haemoglobinopathy Coordinating Centre

London and South East Thalassaemia and Rare Inherited Anaemia Haemoglobinopathy Coordinating Centre

Barts Health NHS Trust

Visit Date: 12th May 2025

Report Date: 27th October 2025

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Introduction

This report presents the findings of the review of Barts Health NHS Trust that took place on 12th May 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 Barts Health 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:

- Barts Health NHS Trust
- NHS England London Region
- 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 Disorder, Thalassaemia, and related conditions. The Forum is now a recognised and respected organisation involved in formulating national policy for screening and management of these conditions. The 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 Barts 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

East London and Essex Sickle Cell Haemoglobinopathy Coordinating Centre London and South East Thalassaemia and Rare Inherited Anaemia Haemoglobinopathy Coordinating Centre

General Comments and Achievements

Barts Health hosted two Haemoglobinopathy Coordinating Centres (HCC) networks. The Sickle Cell Disorder HCC and the Thalassemia and Rare Inherited Anaemias (RIA) HCC. Although both HCCs were separate in their commissioned functions the operational workings were joint across both HCCs, therefore the report below reflects this.

The East London and Essex Sickle Cell (SCD) HCC provided support and oversight for specialist and local haemoglobinopathy teams across East London and Essex which included three SHTs based at: Homerton Hospital, adults only (Homerton Healthcare NHS Foundation Trust -HH), Queens Hospital Romford (Barking Havering and Redbridge University Hospitals NHS Trust - BHRUT) and The Royal London Hospital (Barts Health - RLH). The HCC had four Local Haemoglobinopathy Teams (LHTs) apart from Whipps Cross University Hospital and Newham University Hospital which were part of Barts Health, these were based at Broomfield, Basildon and Southend Hospitals (Mid and South Essex NHS Foundation Trust -MSE), and Colchester Hospital (East Suffolk and North Essex NHSFT- ESNE).

The Thalassaemia and Rare Inherited Anaemias (RIA) HCC covered East London and the South East of England and included seven SHTs: Croydon University Hospital NHS Trust (CUH), Guys and St Thomas' Hospital NHS Foundation Trust (GSTT), Homerton Healthcare NHS Foundation Trust (HH) - adults only, Kings College Hospital NHS Foundation Trust (KCH), Lewisham and Greenwich NHS Trust (L&G), Queens Hospital Romford (BHRUT)) and The Royal London Hospital (RLH-Barts Health). The HCC had nine linked LHTs based at Broomfield, Basildon and Southend Hospitals (MSE), Canterbury Hospital (East Kent Hospitals NHS Trust), Colchester Hospital (ESNE), Dartford and Gravesham NHS Trust, Medway NHS Foundation Trust, Maidstone and Tunbridge Wells Hospitals (Maidstone and Tunbridge Wells Hospital NHS Trust), Princess Royal Hospital and Royal Sussex County Hospital (University Hospitals Sussex NHS Foundation Trust).

As of May 2025, the total number of patients across the HCC catchments with haemoglobinopathies was 2,470 made up of 2133 people living with a Sickle Cell Disorder and 337 people living with Thalassaemia or RIA.

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

- HCC Network Lead (2PAs)
- HCC Adult Lead (1PA)
- HCC Paediatric Lead (1PA)
- HCC Network Lead Nurse (1.0 WTE *in total for HCC and SHT roles)*
- HCC Network Manager (1 WTE)
- HCC Transcranial Doppler Lead (1PA)
- HCC Adult Education Lead (1PA)
- HCC Paediatric Education Lead (1PA)
- HCC Data Manager (1 WTE)
- HCC Research Lead (Network Lead)
- HCC Patient representatives

Quality Management and Governance Framework

The HCCs had a full-time Network Manager to coordinate the agreed quality management programme. Each role within the network had a designated lead as detailed above. In terms of trust governance, the Specialist Medicine Division provided the HCCs with support and clear lines of accountability. An annual report covering the work of both HCCs had been produced and disseminated.

The HCCs held several structured meetings to oversee the management, governance and work implemented across their HCC catchment areas. The meetings had enabled the Management Team to keep an overview of the functioning of the HCC arrangements and offer support to the SHTs and LHTs in attendance if/when required.

Relevant Clinical and Managerial representatives from the Trusts within the HCCs were invited to attend, and all discussions were documented. In addition to this, the management Team had started to engage more frequently and conducting site visits to the various LHTs across the Sickle Cell HCC to strengthen relationships with the teams at these hospital sites. Similar work with the LHTs in the Thalassaemia HCC had not yet been undertaken.

The East London and Essex Sickle Cell (SCD) HCC, in their annual report for 2023-24 and during the visit, had raised the ongoing difficulties with data management and were actively working to create better links with the SHT and LHT clinical and non-clinical operational management teams. The HCC had requested additional funding for data support and this had resulted in the development of additional data management posts for the LHT based in Basildon and the SHT at BHRUT, although at the time of the visit the posts had not yet been progressed to recruitment stage.

An agreed audit programme had been agreed for both HCCs and included for the Sickle Cell HCC the time to analgesia and pain management in the emergency setting audit of the NICE guidelines, the number of patients who were on and had been asked about Hydroxycarbamide which had been partially completed by the SHTs and some LHTs. The Thalassaemia HCC audits included endocrine complications in children with thalassaemia completed by the SHTs based in East London and Essex. There were plans to undertake an audit covering iron chelation.

The East London and Essex Sickle Cell (SCD) HCC held quarterly Transcranial Doppler (TCD) quality assurance meetings to ensure that sonographers across the network were maintaining their competencies aligned to the national TCD programme. The TCD QA programme was led by the HCC lead for TCD with a team of six accredited practitioners and four practitioners awaiting accreditation across the network.

As part of the NHSE funded quality improvement programme for Sickle Cell, a community project had been commissioned targeting patients who were both under the care of Royal London Hospital (RLH) and residing within the East London catchment area.

HCC Business Meetings

Meeting Title	Frequency
HCC SCD Business Meeting	Every six months
HCC Thalassaemia and RIA	Every six months
HCC Adult Sickle Cell MDT	Monthly 1st Monday of the month
HCC Thalassaemia MDT Meeting	Monthly 2nd Monday of the month
HCC Paediatric MDT Meeting	Monthly 3rd Monday of the month
HCC/ SHT Leads Team Meeting	Every three weeks
HCC Quality Assurance Meeting	Quarterly
HCC Neuroradiology MDT	Monthly – 4th Monday of the month
HCC Mortality and Morbidity Meeting	Every three months
Haemoglobinopathies and Network Leads Meetings	Every three months

HCC Funding and Monitoring

The HCC team reported that they had improved relationships with the host finance and management teams in terms of HCC budget oversight. They were however concerned about the difficulties they were experiencing in gaining agreement to utilise the funding and progressing any recruitment for the additional support workforce for data management and CNS in line with the commissioning requirements of the HCC.

The East London and Essex Sickle Cell (SCD) HCC would also be overseeing the expansion of Automated Red Cell Exchange Transfusion (ARCET) services across network via Med Tech funding for paediatric and adult services across the three sites RLH, Basildon Hospital (MSE) and Queens Hospital (BHRUT). This included initiation of paediatric and adult ARCET at Basildon Hospital (MSE) and paediatric services at Queens Hospital (BHRUT) sites.

HCC Multi-disciplinary Team Meetings

HCC Annual report data from the 2023/24 reported that seven paediatric SCD HCC MDT meetings had been held and seventeen patients referred for discussion. Eight adult SCD HCC MDT meetings had been held with nineteen patients referred. Six Thalassaemia HCC MDT meetings had been held during this time and eleven patients (children, young people and adults) had been referred for discussion. The HCC Neuroradiology MDT data from April 2023-March 2024 showed that six meetings had been held, 82 scans reviewed, and the meetings were well attended.

Patient deaths were discussed at local M&M meetings, however, if necessary, cases could be brought forward for discussion at HCC level and ultimately at the National Haemoglobinopathy Panel (NHP) if appropriate, and one case had been referred to the NHP for discussion. MDTs were in place each month with good attendance and representation from the SHTs and LHTs. Where SHTs considered that they needed more clinical support for patients with complex needs, they could refer to the HCC MDTs via the referral pathway. Following any in-depth discussion around case management the actions to take forward were documented.

HCC Education, Staff Training and Resources

A five day 'Haemoglobinopathy Care Programme' education course for nursing staff had been developed by the adult and paediatric SHT teams and was open to staff from across Barts Health. The HCC was financially supporting the accreditation of this course, making the programme available to nursing staff across the HCC.

Three monthly thalassaemia education sessions had been established which were reported as being well attended by both healthcare providers and patients. These sessions aimed to enhance the understanding and care for individuals living with Thalassaemia.

The East London and Essex Sickle Cell (SCD) HCC had a number of education and training plans which included supporting community and trusts across the HCCs for example; the awareness and roll out of the 'ACT NOW' initiative to improve patient experience and clinical outcomes for adults and children experiencing a Sickle Cell vaso-occlusive crisis, and training for community and primary care practitioners/nurses with a focus on standards of care for patients with living with a haemoglobin disorder covering the use of hydroxycarbamide, importance of vaccinations and infection risks.

HCC Network Policies, Procedures and Guidelines

The development of a pan London guideline for the management of acutely unwell children with Sickle Cell Disorder had been led by and implemented in primary and secondary care across the SCD HCC and wider London area. The one page algorithm with information about the pathway provided a clear and appropriate escalation pathway for managing sick children with living with a Sickle Cell Disorder.

HCC Patient Involvement and Support

The HCC had nominated SCD and Thalassaemia patient representatives and had plans to further strengthen the patient voice across the HCC activities for example; service evaluation, safety and transformation.

The East London and Essex Sickle Cell HCC had also partnered with the Sickle Cell Society to pilot their peer mentoring programme for patients across the North East London and the success of this initiative had seen the peer mentoring programme adopted in other areas across London. A Mental Health UK online programme for 14-17 year olds running on alternate months had also been promoted.

Research

Both HCCs had active clinical research programmes with several clinical trials that were network wide. The HCCs were keen to ensure that all patients across the network had access to clinical trials and used the MDTs and education sessions to highlight research trails that were open for participation across the HCCs.

Feedback from Stakeholders

The reviewers met with representatives from the SHTs at HH and BHRUT who were highly appreciative of the advice and guidance they received. They all commented on the good relationships they had with the HCCs and the level of expertise and learning available when attending the MDT and other HCC meetings.

The reviewers met with representatives from the SHTs at GSTT and KCH regarding the support from the Thalassaemia HCC and they were highly complimentary about the accessibility and responsiveness of the clinical and management team.

There were some comments received about funding streams and equitable access across the whole HCC.

Other Challenges

The East London and Essex Sickle Cell HCC were very aware of other challenges they faced. Demographic changes to the number of people with haemoglobinopathies residing in Essex in part driven by movement out of London, immigration and new birth rates, were causing capacity pressures, particularly for paediatric services across the region.

Many of the adult and paediatric LHTs were experiencing workforce capacity issues; consultant staffing, limited or no CNSs the lack of psychology support and administrators / data managers to ensure the NHR and other required data was collected and available. Ongoing difficulties in gaining consistent engagement with the LHTs across the network in MDT participation and educational activity citing clashing clinical commitments and time were also reported.

The SHTs across the East London and Essex Sickle Cell HCC were also experiencing medical workforce challenges, particularly the stability of the senior medical workforce at HH.

The HCC were in the process of developing a more coordinated approach to the growing number of young people transitioning to adult care across the network. Plans included agreeing the transition and shared care arrangements as well as escalation pathways across the trusts in the network for young people 16 years and older.

Good Practice

1. The East London and Essex SCD HCC had well-established clinical relationships with their SHTs and LHTs.
2. Good feedback was received about the Thalassaemia and RIA HCC Multidisciplinary Team Meetings, which were providing a commendable environment for shared learning, expert advice and support, as well as being highly educative for the participants.
3. The East London and Essex Sickle Cell HCC and SHT leads had supported the LHT at Basildon Hospital to provide more care locally e.g. developing a TCD service, delegation of patient annual reviews. At the time of the visit the HCC was supporting the local delivery of an elective automated red cell exchange (ARCET) service. The RLH team had also provided support to the team at BHRUT as they transitioned from LHT to an SHT.

4. The HCCs had an active clinical research programme with good engagement from the SHTs. The HCC were also active in promoting paediatric research across the network for the LHTs.
5. The TCD screening programme had clear governance and quality assurance structures in place with a well-developed practitioner training programme. The programmed had enabled a more resilient service for imaging and non-imaging TCD provision across the network with sessions outside the hospital setting and at weekends.
6. The HCCs had positive working relationships with NHSE London the London based ICBs.

Immediate Risks

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

Serious Concerns

1. **HCC Finance Management**

   Reviewers were seriously concerned at the effect on the East London and Essex Sickle Cell (SCD) HCC function due to the delays in being able to appoint key staff with the 2023/24 funding from NHSE to support services for the care of people living with haemoglobin disorders across the network.

   Financial scrutiny had become very complex even where funds were provided by NHSE and included multiple layers of internal agreement and sign off, then the Trust and NEL ICB to sign off any business cases for staff and service developments. At the time of the visit the applications for the additional CNS and data support posts for the LHT based at Basildon and SHT at BHRUT had been submitted to the joint oversight committee for funding allocated to the HCC 12 months ago. Some of the issues were reported by trust management to be related to requiring additional detail and not just trust related finance issues, which had caused the delays. Both the ICB and NHSE commissioners were aware of the delay in recruitment but no action had been taken to support the HCC in progressing these appointments.

2. **Workforce Challenges and SCD HCC pathways**

   From discussions during the visit, reviewers were seriously concerned about workforce challenges the HCC were experiencing and the pathways for patients residing within the East London and Essex areas.

   a. Demographic changes to the number of people with haemoglobinopathies residing in Essex had increased significantly, in part driven by movement out of London, immigration and new birth rates, and was causing capacity pressures, particularly for paediatric services across the region. Historically these patients would have received their specialist haemoglobinopathy care at Barts Health. This had resulted in many of the adult and paediatric LHTs experiencing workforce capacity issues with the lack of consultant staffing, limited or no CNS and the lack of psychology support for patients living with haemoglobin disorders.

   b. The SHTs across the network were experiencing medical workforce challenges, particularly the stability of the senior medical workforce at HH. The staffing challenges across the network had created additional pressure for the Barts Health SHT and potentially had issues for young people from the Essex LHTs who prior to 2024 transitioned to HH and were now transitioning to RLH and the LHTs were liaising with two different adult SHTs for their specialist care.

   c. The workforce capacity issues were impacting on the HCCs gaining consistent engagement with the LHTs based in Essex in MDT participation and educational activity, as staff could not attend as they did not have sufficient time or meetings clashed with prior clinical commitments.

   d. Many of the LHTs and some SHTs had limited or no support for data collection which impacted accurate data being available for audit, quality assurance and service improvement, which also impacted on the HCCs having clear oversight on the risks across the networks.

e. The combined governance and the need to standardise guidance and policies had also become problematic for the LHTs in Essex, who were navigating between SHTs. There were also pathway issues for East Suffolk and North Essex NHS Foundation Trust which LHTs based in Colchester and Ipswich were referring to two different SHTs.

Concerns

1. **Inequity of provision across the SHTs and LHTs**

   There had been a significant increase in the number of patients requiring care within the SHTs and LHTs across the East London and Essex, and associated with the increase in the patient population, were also changes in demographics across the HCC, with some LHTs having significant patient numbers (Basildon and Newham). Reviewers were concerned about the capacity within the SHTs to continue to provide the specialist support as required for the increasing number of patients being cared for by their LHTs.

2. **HCC guidelines**

   The Thalassaemia and RIA HCC had not yet agreed networkwide guidelines and the SCD HCC guidance was in draft. Reviewers were told that the SHTs and LHTs across the region were using local or guidance from other areas and were concerned that the lack of HCC wide guidance as the potential to create variations in patient care and potentially outcomes for patients.

3. **HCC Data and Audit**

   The SCD HCC had identified poor data management as a risk across the network which had impacted on the SCD HCC's ability to measure performance and have an active audit programme. The HCC was working to improve the data quality and support to LHTs. However, this had required the network manager and data manager to spend a considerable amount of time investigating the root causes of the poor quality of data and development of a performance metric for SHTs and LHTs to complete using manual data collection.

4. **HCC Structure and support**

   The HCCs were experiencing challenges in workforce and capacity across the network and reviewers were concerned that the HCC Operational Manager time was being utilised for non HCC work that was impacting on the time available for the HCCs to drive planned improvements.

Further Consideration

1. The HCCs did not have any network wide nursing forums/nursing advisory groups for sharing good practice, providing support and education, audit results and research outcomes. Reviewers considered that implementation of network wide nursing forums for each HCC would be highly beneficial in providing a platform for collaboration, knowledge sharing and peer support.
2. The HCC had informal arrangements for providing advice on emergencies outside of normal working hours, which reviewers considered should be formalised to ensure sustainability in the long term.

Review Visit Findings

Barts Health NHS Trust

Trust-wide General Comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders at Barts Health NHS Trust. At the time of the visit the trust served 778 patients who were registered on NHR with a Haemoglobin Disorder. The adult and paediatric Specialist Haemoglobinopathy Team (SHT) provided a service to the regions of East London and Essex.

Barts Health NHS Trust was established in 2012, merging Barts and the Royal London NHS Trust, Tower Hamlets Community Health Trust, Newham University Hospital NHS Trust (NUH) and Whipps Cross University Hospital NHS Trust (WCUH). The SHT team was then based at RLH and provided specialist care for the two LHTs based at NUH and WCUH. Following the national compliance exercise conducted by NHS England (NHSE) in 2019 the SHT had been designated as a provider of specialist services for haemoglobin disorders which would encompass all three hospital sites (RLH, NUH WCUH) as one SHT. At the time of the visit the SHT was working towards transitioning to a single service, providing, alongside LHT care some outreach SHT functions at the NUH and WCUH sites.

Prior to January 2024, the HH SHT was responsible for specialist services for adult patients living with a Sickle Cell Disorder residing in Mid, North and South Essex; however current shortages in specialist consultant staffing at the HH had resulted in the SHT responsibility for the Essex LHTs being transferred to Barts Health SHT.

During the visit, the reviewers attended the Royal London Hospital (RLH) site and visited emergency departments, assessment units and wards and they met with patients and carers, and with staff providing services for the local health economy. Reviewers did not visit NUH, WCUH or St Bartholomew's Hospital sites but information was provided about the care pathways for patients attending these hospitals which has been included in this report for context.

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

Reviewers identified a number of areas of good practice in the care of children, young people and adults which are detailed in the children and young people and adult sections of the report.

Trust -wide Serious Concerns

Trust-wide Serious Concern – children, young people and adults

1. **SHT Nurse leadership and CNS Workload**

   The level of leadership and CNS time was of concern. At the time of the visit the designated lead nurse had only one WTE time for leadership of the adult and paediatric SHT, clinical work with the paediatric service and leadership of both HCCs.

   The paediatric SHT had only two WTE CNS for the acute service at RLH which was insufficient for the 234 registered patients with a range of haemoglobin disorders seen solely at RLH and to provide support to the 327 children and young people based in the LHTs.

   The adult SHT had only two WTE CNS for the acute service at RLH which was insufficient for the 544 registered patients seen solely at RLH with a range of haemoglobin disorders and to provide nurse led clinics, and to provide support to the 323 adults based in the LHTs.

The lack of CNS time was impacting on the CNSs being able to provide the level of support to patients, undertake audits and staff education, and to provide support to their constituent LHTs as required by a specialist haemoglobinopathy team.

There was no adult CNS support for patients attending at NUH or WCUH, although there was a community CNS provided some support for patients admitted to WCUH.

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

1. **Neuropsychology Provision**

   Reviewers were seriously concerned that there was no established in house neuropsychology pathway for children and young people with haemoglobinopathies to receive neuro cognitive assessments following an abnormal TCD.

2. **Consultant Workload**

   Reviewers were seriously concerned that the service had insufficient consultant medical staff with appropriate competences in the care of children and young people with haemoglobin disorders to provide staffing for SHT network leadership and specialist advice and care, as well as routine and emergency care for the patients under their care.

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

1. **Access to Psychology**

   Patients did not have access to a psychologist with relevant experience in caring for patients and families with haemoglobin disorders. The SHT cared for 544 patients living with a haemoglobin disorder as well as supporting patients within the LHTs.

2. **Day Unit Capacity**

   a. Access to Elective Automated Red Cell Exchange

   Red cell exchange capacity and staffing was insufficient for the number of adult patients who required this service.

   Patients who were on the ARCET programme experienced delays, especially if they missed a session would have to wait as long as five weeks before they could attend.

   At the time of the visit 40 patients were on the waiting list and reviewers were seriously concerned that the delays in patients accessing treatment would increase the risk of these patients developing additional complications of their condition in the interim, some of which could be life threatening or life changing.

   b. Transfusion Dependent Thalassaemia Patients

   There was insufficient staff and space available on the day unit to enable patients requiring regular transfusions to be accommodated. Patients who met with the visiting team were very concerned about the extended intervals between their transfusions, the effect it was having on their day to day living and the risk to their health.

   c. Did Not Attend Rates (DNA)

   The number of patients who did not attend (DNA) for their ARCET or transfusions was high which was resulting in an underutilised service and inefficient use of resources. Patients who met with the visiting team were also concerned about the number of patients who did not attend, especially as they found it difficult to book timely appointments for their transfusions.

3. **Consultant Staffing**

Reviewers were seriously concerned that the service had insufficient consultant medical staff with appropriate competences in the care of adults with haemoglobin disorders at RLH to provide staffing for regular reviews, emergency care and clinics for the patients under their care. At the time of the visit the SHT had a total of 3.9WTE Consultants at RLH covering the adult Red Cell service for 544 patients. One consultant was on long term leave and the consultants were providing a 1:4 on call rota and 1:3 attending rota. The consultants were also providing specialist advice and support to Homerton HealthCare NHST Trust and for seven LHTs as well as their local catchment population.

Trust -wide Concern

1. **SHT Finance Management**

There remained a lack of clarity regarding the allocation and release of funding for both the paediatric and adult SHTs. Greater transparency around where funding sits and the mechanisms for accessing it would support more effective service planning and utilisation.

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

1. **Access to Psychology**

Children, young people and their families had insufficient access to a psychologist with relevant experience in caring for patients and families with haemoglobin disorders. The SHT had 0.5 WTE psychologist for 234 children, young people and their families living with a haemoglobin disorder, although this number did not include patients managed through shared care arrangements or those with other haematological conditions such as ITP. As such, the true ratio was likely to be much higher, reflecting an even more stretched service.

2. **Lack of Data Management Support**

The SHT had insufficient data management capacity, limiting its ability to effectively track clinical outcomes, support audits, and contribute to service improvement initiatives.

3. **Clinical Audit**

There was a notable absence of regular audits, including in key areas such as time to analgesia. Reviewers were concerned that the lack of routine monitoring limited opportunities for quality assurance and clinical improvement.

4. **Ongoing Pressure from Supporting Additional SHT Responsibilities**

At the time of the visit the SHT had continued to provide substantial support to other Specialist Haemoglobinopathy Teams, including Queen's Hospital (BHRUT), via telephone advice, care of unwell patients, and red cell exchange services. While this reflected strong collaborative practice, it was also placing additional strain on the already limited workforce resource.

Trust-wide Concern – adults

1. **SHT Leadership Time**

The designated lead for the adult SHT was also the lead for haematology and only had 0.5PA allocated for all leadership activities. Reviewers were concerned that this was insufficient time for the development of guidelines, protocols, training and audit related to haemoglobinopathies' and overall responsibility for liaising with other services. and would become unfunded when the lead ceased to be the clinical lead for haematology.

2. **Ward Nurse Education and Competence Framework**

Reviewers were concerned about the level of education available and competences for staff in the care of people living with haemoglobin disorders. *See adult section of the report for more detail*

Views of Service Users and Carers

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

The visiting team held focus groups prior to the visit and during the visit. In total the visiting team met with four adults, two were living with a Sickle Cell Disorder, and three adults with Thalassaemia, one of whom also provided feedback received from other patients. From the children's perspective we met with one family caring for children and young people living with a Sickle Cell Disorder during the visit but did not meet with any families living with Thalassaemia.

The user reviewer on the visiting team representing those living with thalassaemia did meet separately with three parents, two of which had young people who had transitioned to the adult service in the past two years and four individuals affected by thalassaemia (parents and adult patients).

The views of the users were wide ranging, and are documented in the children's, and adult specialist haemoglobinopathy team sections of the report.

The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences.

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Specialist Haemoglobinopathy Team (Children and Young People Services)

General Comments and Achievements

The Paediatric Specialist Haemoglobinopathy Team (SHT) at Barts Health was based at the Royal London Hospital. The SHT provided comprehensive, multidisciplinary care for children living with a haemoglobin disorder across the wide geographical area of East London and Essex.

The service was embedded within a trust-wide model of care, working collaboratively with medical and nursing teams at NUH and WCUH under shared protocols and policies. This integrated approach ensured consistent clinical standards across Barts Health NHS Trust.

In addition to intra-trust collaboration, the SHT maintained non-contractual shared care arrangements with a number of Local Haemoglobinopathy Teams (LHTs), ensuring equitable access to specialist input and support. The RLH SHT had also played a pivotal role in supporting Queen's Hospital (BHRUT) in achieving SHT status, further extending specialist haemoglobinopathy expertise across the region.

The RLH hosted a well-led and clinically robust SHT that demonstrated strong leadership and commitment to quality improvement, despite significant concerns raised by the review team regarding inadequate consultant and nursing capacity dedicated specifically to haemoglobinopathy patients. These workforce constraints were posing challenges in how the SHT was able to deliver sustainable, high-quality care, but the team had continued to maintain a high standard of service through close coordination and professional dedication.

The service model clearly defined roles and responsibilities for elective and emergency care, supported by robust access and escalation pathways. The SHT provided 24/7 consultant-led specialist clinical and laboratory advice, alongside access to specialist nursing, outpatient clinics, and participation in clinical trials.

The team also contributed significantly to wider service development and education, supporting both acute and community-based partners. While formal contractual relationships were limited, the SHT continued to provide guidance, education, and clinical support to ensure a cohesive and patient-centred approach to care delivery

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</table>

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

PATIENTS USUALLY SEEN BY THE SPECIALIST 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	489 (184 RLH)	489	255	28	65	139
Thalassaemia and RIA	CYP	72 (50 RLH)	72	50	38	0	0

Staffing

Specialist Haemoglobinopathy Team	Number of patients [3]	Actual PA or WTE (at the time of the visit)
Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies	234	13 PA (estimated) for all SHT work
Clinical Nurse Specialist dedicated to work with paediatric patients living with haemoglobinopathies	234	2.0 WTE *(who also covered other haematology conditions)*
Clinical Nurse Specialist dedicated to work with paediatric patients living with haemoglobinopathies in the community	234	Tower Hamlets (Barts Health) 1 WTE for Adults and Children Waltham Forrest (NELFT) 1WTE Adults 1WTE Paeds + the service lead Newham (ELFT) - 1WTE adults 1WTE adults/transition, 1WTE paeds & 1WTE vacant post + the service lead.
Clinical Psychologist dedicated to work with paediatric patients living with haemoglobinopathies	234	0.5

Urgent and Emergency Care

At RLH patients with acute complications were initially assessed through ‘streaming’ in the Paediatric Emergency Department (PED) which was nurse led. For children and young people living with a Sickle Cell Disorder, staff could access their Electronic Health Record (EHR) to view their Healthcare Passport and Universal Care Plan (UCP). The SHT had developed two generic analgesia protocols, one for children and one for adolescents aged 14 years and over. A small number of children and young people would have individualised protocols. For the management of acute pain for those experiencing a vaso -occlusive crisis, the first two doses of analgesia were administered in the PED. At the time of the review, there were no 'time to analgesia' audit results available to measure the effectiveness of pain management in the PED.

Following initial management, patients were assessed by the shared PED/paediatric medical team or, during normal working hours, by the paediatric haematology on-call team.

For patients living with thalassaemia or a rare inherited anaemia, guidance for PED staff was to contact the paediatric haematology team upon presentation to PED. At the time of the review, the team was actively working

[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.

[3] This number does not include the number of patients in the LHTs who have shared care with the SHT. These numbers are detailed in the table above

with patients and colleagues to explore whether Healthcare Passports should also be introduced for this patient group.

Outpatients requiring urgent review were seen in the Paediatric Assessment Unit (PAU) on ward 7D. This was a nurse-led service; however, the specialist medical team assessed all haematology patients. The PAU was primarily used for post-discharge reviews or for the monitoring of therapy where clinical review and assessment of haematological response were required. Admission could be arranged directly from the PAU if clinically necessary.

The service also had access to a 'Hospital at Home' programme. Selected patients were managed through daily reviews and treatment in the community, supported by a nurse-led pathway that covered boroughs within the North East London Integrated Care Board (NEL ICB)

At NUH, children who presented with acute complications were initially assessed in the children's Emergency Department (ED) following triage. The first assessment was conducted either by an ED doctor or the speciality trainee paediatric doctor. Patients with haemoglobinopathies presenting with an open-access 'passport' card were seen directly by the paediatric team. doctors. The Consultant Paediatric Haematologist at RLH could be contacted out of hours when specialist input was required. Individualised care plans from clinic letters were accessible to paediatric doctors via Healthcare Passports or Universal Care Plans (UCPs) on the Electronic Clinical Record (ECR) system. The community centre in East Ham was also notified of discharges from both the ED and Rainbow Ward to facilitate home follow-up and ongoing family support.

At WCUH, patients attending the Emergency Department (ED) were streamed directly to be seen by an ED doctor. The Universal Care Plan (UCP) and Healthcare Passport were accessible via the patients ECR. Patients were then seen directly by the paediatric team in ED.

Inpatient Care

Patients who required in-patient care were managed on one of the paediatric wards and were seen daily by the specialist paediatric haematology team. All new admissions were seen within 24 hours by the attending paediatric haematology consultant, with daily consultant-led ward rounds taking place thereafter.

Patients were typically prioritised for admission to a ward to manage acute pain episodes requiring regular opioid analgesia and close monitoring. However, no admission audit data were available at the time of the visit.

Out of hours, patients were reviewed by the paediatric medical team, with telephone advice provided by the paediatric haematology consultant on call (operating on a 1 in 5 rota). Two dedicated Clinical Nurse Specialists (CNS) for paediatric haematology reviewed patients on the ward and in the day care unit and supported the nursing staff. The paediatric haematology team also sought expert input from the pain team and other affiliated specialties as required.

Patients admitted to the monitored bay (HDU) and PICU wards were seen jointly with the paediatric intensivists.

Severely unwell children and those requiring urgent exchange transfusion were managed in the Paediatric Intensive Care Unit (PICU), under the supervision of the paediatric intensivist consultant and supported by the haematology team, in line with the pan-London escalation pathway for the management of acutely unwell children living with a Sickle Cell Disorder.

At the time of the review, red cell exchange transfusions on PICU were performed manually. Although a contractual arrangement with NHSBT (MedTech funded) had originally been proposed to support automated red cell exchange (ARCET), longstanding capacity issues had prompted a review of the model. A new proposal was in development to deliver the service in-house, using a team of trained intensive care nurses (MedTech proposal). Patients requiring level 2 high dependency support were managed in the newly designated 'monitored bay' on ward 7F, which had enhanced nursing provision.

Patients admitted to other hospitals within the network were reviewed virtually, with daily updates shared to support early escalation where necessary. Out-of-area patients requiring surgical intervention were managed under shared care arrangements with the relevant surgical teams.

At NUH, children and young people requiring admission were admitted to the Rainbow Children's Ward, which featured an 18-bed inpatient unit (including seven cubicles) and a six-bed day care unit, providing comprehensive care for children in crisis. Very unwell children, for example those presenting with acute chest syndrome or stroke, were admitted to the Rainbow Ward High Dependency Unit (HDU) for stabilisation and then transferred to the Paediatric Intensive Care Unit (PICU) at the Royal London Hospital (RLH), following discussion with the RLH haematology team and the Paediatric Critical Care Unit (PCCU). Depending on the child's clinical condition at presentation, some were retrieved directly from ED to RLH PICU by the CATS team, in accordance with the escalation pathway. At the time of the review, the delivery of patient-controlled analgesia (PCA) was not possible at NUH, and therefore, children requiring PCA were transferred to the RLH.

At WCUH, children and young people requiring admission were admitted to the 20–27 bedded paediatric ward (Acorn Ward). They were admitted under the care of the general paediatric attending consultant, who was resident until 8:00 p.m. on weekdays. Out of hours, paediatric haematology consultants at RLH provided specialist advice. Patients experiencing severe or life-threatening crises were transferred to the Royal London Hospital under the care of the paediatric haematology and PICU teams.

Day Care

The day unit provided paediatric medical and surgical day care services, with designated beds for both surgical and medical patients. For paediatric haematology, services included simple top-up transfusions, infusion therapies, automated red cell exchange transfusions, and venesection. The unit had the capacity to transfuse up to six patients per day, three days a week. The transfusion pathway was nurse-led. A ward-based resident paediatrician was available to review patients presenting with medical concerns.

At the time of reporting, the unit was able to support up to six elective ARCET transfusions per week. For the year 2024/2025, the haematology day unit performed approximately 225 apheresis exchanges. The unit operated from 08:30 to 21:00, Monday to Friday. The Royal London Hospital (RLH) was the only paediatric centre in North East London (NEL) and Essex offering elective ARCET.

The two nurse specialists supported the day unit nursing staff as required. Children were often reviewed during their transfusions, which included an assessment of their general health, evaluation of compliance with chelation therapy, adjustment of dosages where necessary, and identification of other concerns affecting overall wellbeing, such as school attendance and performance.

Multidisciplinary support was available through access to play therapy, psychological services, and educational resources provided by the hospital school service.

The Paediatric Assessment Unit (PAU) on ward 7D functioned as an ambulatory care unit for urgent reviews. Patients could be booked for medical assessments, including post-discharge follow-up or monitoring of treatment responses.

At NUH there was a six-bedded day care facility that was used for simple top-up transfusions. Nursing and clinical reviews were conducted to inform chelation dosing, assess treatment adherence, and manage drug-related toxicities. Due to a change in ward policy, open access reviews were redirected to the Emergency Department (ED), and patients living with Sickle Cell Disorders and Thalassaemia were issued 'passport' cards to facilitate

access for such reviews. Clinicians were also encouraged to access the Universal Care Plan (UCP) and Healthcare Passports. Routine transfusions were carried out only on Wednesdays, with no out-of-hours provision in place.

At WCUH daycare facilities were available on the Acorn Medical Day Unit (MDU), which was led by two Band 7 paediatric nurses. The MDU provided specialist investigations, including sleep studies, and accommodated patients requiring regular blood transfusions.

Outpatients

At RLH there was a total of 17 monthly consultant-led clinics: Three regular Wednesday morning multidisciplinary lists (covering Sickle Cell Disorders, Thalassaemia, rare anaemias, and general non-malignant paediatric haematology) were held. The acute hospital-based and community-based nurse specialists would attend the clinics and arrangements could be made for children and young people to be introduced to the paediatric psychologist at this time.

A monthly one-stop annual review and TCD clinic was held for patients living in Essex, with the majority seen in the outreach clinic at Orsett. An outreach clinic for one-stop reviews of Colchester patients was expected to begin in August 2025. Twice-monthly thalassaemia and rare anaemia clinics took place, during which all patients with transfusion-dependent thalassaemia (TDT) in East London and Essex were seen for annual review and a monthly transition clinic and a monthly Teenage and Young Adult (TYA) clinic were also conducted.

On average, three dedicated TCD lists ran each month at the Royal London Hospital (two sonographer-led lists on Wednesdays and one non-imaging consultant-led list). In addition, a monthly community-based consultant-led TCD clinic was held on Saturdays, along with a monthly community-based consultant outreach one-stop annual review and TCD clinic in Essex.

The joint haematology/endocrine clinic was held quarterly in February, May, August, and November.

CNS-led clinics included a weekly hydroxycarbamide monitoring clinic run by the two hospital-based nurse specialists.

At NUH, Rainbow Ward had an outpatient department where children attended haematology clinics every Monday and Wednesday. A joint transition clinic was held four times a year. A monthly community-based clinic was run from the East Ham Sickle Cell and Thalassaemia Centre. Additionally, a transcranial Doppler scanning clinic was held once a month on Saturdays. The lead consultant also provides evening outreach clinics, enhancing access and flexibility to better meet the needs of patients.

At WCUH Paediatric clinics were based in the paediatric outpatient department. Three clinics per month were held on Tuesday afternoons, attended by the paediatric specialty doctor with a special interest in haematology and the clinical nurse specialist. An outreach clinic was conducted monthly by one of the paediatric haematologists.

Community- based care

Tower Hamlets Community Service

The community CNS, part of the SHT supported both adult and paediatric patients across Tower Hamlets and families with newly diagnosed infants.

The Hackney Sickle and Thalassaemia Centre

The community-based centre was part of the integrated service provided by HH. Services were provided for Hackney based patients who attended the RLH, with a designated paediatric CNS.

The service supported families with newly diagnosed infants, provided education and support, health promotion, transition preparedness clinics and workshops, training, and awareness programmes, preconceptual and genetic counselling, psychological assessment and support, welfare benefits advice, home visits, GP Liaison, 24-hour helpline, and a monthly support group.

The Newham Sickle and Thalassaemia Centre

Services provided at the centre included education and support, health promotion, training, and awareness programmes as well as Trans Cranial Doppler scanning and education and home visits for children and adult patients and families residing in Newham. There was also a transition nurse based at the centre.

The Waltham Forest service

The service provided counselling and screening to the public for haemoglobin types. There was a specialist nurse for paediatrics services. and one for adult services. Together, they provided community and follow-up care for affected babies, children, teenagers and adults; some education and training, transition preparation clinics and workshops; advocacy and clinical support and follow up of investigations and treatments.

Community support for network patients residing in Essex

There was a community based paediatric nurse specialist who was responsible for following up on positive neonates born in Essex, ensuring entry into care, contact with specialist centre, and some support of children and their families.

Views of Service Users and Carers

The visiting team held focus groups prior to the visit but did not meet with any families living with Children and Young people with Thalassaemia. During the visit we met with one family caring for children and young people living with a Sickle Cell Disorder. The user reviewer on the visiting team representing those living with Thalassaemia did meet separately with three parents, two of which had young people who had transitioned to the adult service in the past two years and one who was still under paediatric care.

Service User Feedback

- All praised the SHT members and felt that they were 'listened to' and that the team would always address any concerns they had when attending clinics.

Information Received

- Parents of CYP living with thalassaemia indicated that they did not receive sufficient condition specific information about their children's conditions throughout their care journey.
- Not all the parents of CYP living with thalassaemia were aware of the Trust/ HCC website and those who had reviewed the content did not consider the information available was inadequate and not particularly relevant to their children's specific conditions reported receiving information only at the time of diagnosis, with little follow-up cod educational content thereafter.

Care Plans

- Parents were not clear if their children had care plans, although they did receive copies of their clinical letters.
- They appreciated that the paediatric teams tried to accommodate their children's school schedules when scheduling appointments.
- They also believed that the service did not adequately prioritise the perspectives of those affected by thalassaemia in its development or service improvements.

Transfusion Experience

- Parents found it easy to schedule appointments for transfusions and clinic visits, and their children received the necessary routine scans appropriately.
- Parents generally expressed satisfaction with the blood transfusion service and felt well-supported by the clinical team.

- However, some noted a lack of clinical nurse specialist (CNS) care at WCUH, which changed after their departure to RLH.

Staff Attitudes and Care

- While they felt that consultants and senior CNS staff were knowledgeable about their children's care, they expressed concerns that more junior staff lacked sufficient understanding. They also believed that the service did not adequately prioritise the perspectives of those affected by thalassaemia in its development or improvement.
- Parents felt comfortable reaching out to nurses with questions or for advice in emergencies.

Emergency Department and Ward Care

- Feedback on care received in ED was mixed, with many parents feeling that ED staff did not fully understand the needs of patients with thalassaemia.
- One parent recounted an incident where their child, who was very unwell, was not triaged properly or escalated until the child was on the verge of collapsing whilst the ED staff tried to discharge them.
- They felt their concerns were not heard or respected, emphasising that they know when it's necessary to bring their children in, especially when unsure of what is wrong or when lacking necessary medication.
- There was also a sentiment that ED staff lacked knowledge about the risks associated with thalassaemia, secondary conditions, and the implications of iron chelation.

Access to Psychology

- Parents also commented that from time to time the psychologist or a member of the psychology team would pop in to visit their children during their transfusions.

Transition

- Experiences varied, but many parents felt that they did not receive adequate information about this process early enough. Most noted that their children were only informed about the transition around the age of 17 years of age and were moved to adult services by the age of 18. There was apprehension about the adult service, influenced by feedback from other parents and patients.

Good Practice

1. The service maintained a collaborative and proactive relationship with commissioners, with regular contact that supported ongoing service development and oversight.
2. There were well-established clinical relationships with Local Haemoglobinopathy Teams (LHTs). Consultants and doctors in training reported feeling well supported, particularly in managing complex cases, with advice and guidance readily available both during and outside of working hours.
3. The SHT had played a key role in supporting the LHT based at Basildon University Hospital to increase their local service provision over the past five years. The service now independently delivered transfusions and annual reviews, had two practitioners performing TCDs, and was progressing towards delivering an automated red cell exchange service.
4. The HCC lead nurse was commended for their significant role in developing paediatric Clinical Nurse Specialists (CNSs) across both the HCC and Specialist Haemoglobinopathy Team (SHT) networks.
5. The service was research-active and supported LHTs in delivering research locally, enabling patients to participate in studies closer to home.
6. NUH provided evening outreach clinics, enhancing access and flexibility to better meet the needs of patients.

7. The service had developed a robust transcranial Doppler (TCD) service, with eight registered practitioners and the provision of weekend clinics to ensure timely access.
8. A dedicated red cell paediatric haematology rota was in place, providing reliable consultant cover. There was also access to a wide range of paediatric subspecialties within the trust.
9. The service was in the process of accrediting its five-day haemoglobinopathy training course, aiming to enhance uptake and support workforce development.
10. The hospital provided excellent schooling for inpatients and day cases, with access to a dedicated school area or bedside teaching tailored to individual needs.
11. Doctors in training (ST3+) and haemoglobinopathy specialty registrars had dedicated outpatient clinic lists, supporting their development and exposure to ambulatory care as part of their training.

Immediate Risks

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

Serious Concerns

1. **Consultant Workload**

   Reviewers were concerned that the service had insufficient consultant medical staff with appropriate competences in the care of children and young people living with haemoglobin disorders to provide staffing for SHT network leadership and specialist advice and care, as well as routine and emergency care for the patients under their care.

   a. At the time of the visit, there were 2.4 WTE Consultant Paediatric Haematologists who covered all non-malignant paediatric haematology with approximately 13 programmed activity (PA) sessions for haemoglobinopathy work. Reviewers were concerned that this was insufficient for the 234 registered patients with a range of haemoglobin disorders seen solely at RLH, and to provide specialist advice and support to the 327 children and young people based in their constituent LHTs.

   b. The SHT consultants were also the working across three trust sites (RLH, NUH, WCUH) and providing non-malignant haematology on call 1:4 to 1:5 on-call out of hours rota for East London and Essex Network.

   c. As part of their SHT and HCC responsibilities were leading on the training, quality assurance and governance programme for TCD scanning across the network.

2. **SHT Nurse leadership and CNS Workload**

   The level of leadership and CNS time was of a serious concern for the following reasons:

   a. At the time of the visit the designated lead nurse had only one WTE time for leadership of the adult and paediatric SHT, clinical work with the paediatric service and leadership of both HCCs.

   b. The SHT had only two WTE CNS for the acute haematology service at RLH which was insufficient for the 234 registered patients with a range of haemoglobin disorders seen solely at RLH and support to the 327 children and young people based in the LHTs. The lack of CNS time was impacting on the CNS being able to provide the level of support to patients, undertake audits and staff education, and to provide support to their constituent LHTs as required by a specialist haemoglobinopathy team.

3. **Neuropsychology Provision**

   Reviewers were seriously concerned that there was no established inhouse neuropsychology pathway for patients with haemoglobinopathies to receive neuro cognitive assessments following an abnormal TCD.

Reviewers were told that informal links had been made with the Sickle Cell Psychology Service based at King's College London, which offered a robust neuropsychology service, and would see some patients. At the time of the visit the SHT did not have clarity on how routine referrals would be made, how the pathway would be structured, and whether it would require formal commissioning and funding from North East London ICB.

Reviewers were concerned that even if there was an interim plan to cover assessments, and if and how this could be established officially, it would be beneficial for the service to provide in house neuropsychology assessments (via the psychology service in Sickle Cell & Thalassaemia) in terms of continuity of care, holistic care and patient experience.

4. **Delays in Accessing Ring-Fenced HCC Funding for Data Management Support**

   The service had been unable to access HCC ring-fenced funding intended to support data management roles. This delay has been attributed to the "Triple Lock" approval process, requiring sign-off by multiple committees, and compounded by recent operational restructuring-specifically the transfer of oversight from the Pathology to the Clinical Directorate. These prolonged delays were hindering progress in strengthening essential service infrastructure and posed a risk to the effective management and reporting of clinical data.

Concerns

1. **Access to Psychology**

   Children, young people and their families had insufficient access to a psychologist with relevant experience in caring for children, young people and families with haemoglobin disorders. Reviewers were concerned as without a dedicated psychological practitioner individuals affected by these disorders will have limited specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition.

   The SHT had 0.5 WTE psychologist for 234 patients, although this number did not include patients managed through shared care arrangements or those with other haematological conditions such as ITP. As such, the true ratio was likely to be much higher, reflecting an even more stretched service.

   There was also no cover for the psychologist for absences, though ad hoc interim support was sometimes available via the hospital’s Paediatric Liaison Team (PLT).

   The level of psychology provision available did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE clinical health Psychologist for 300 patients.

2. **Transition Pathway - Basildon Paediatric Patients**

   Reviewers were concerned about disjointed pathway for the transition of paediatric patients to adult services at Basildon University Hospital. Since 2024, due to shortages in specialist consultant staffing at adult red cell services at HH, the responsibility for the Essex LHTs had temporarily been transferred to the RLH SHT. This had resulted in young people from the same LHT, pre 2024 and those since, being cared for by two adult SHTs. From discussions with the representatives from the Basildon LHT they were delaying transitioning young people until there was greater clarity as this misalignment introduced potential gaps in continuity and oversight of care for this patient group.

3. **Lack of Data Management Support**

   The SHT had insufficient data management capacity, limiting its ability to effectively track clinical outcomes, support audits, and contribute to service improvement initiatives. Access to robust data is a critical component of high-quality care in specialist services and warranted urgent attention.

4. **Clinical Audit**

   There was a notable absence of regular audits, including in key areas such as time to analgesia. Reviewers were concerned that the lack of routine monitoring limited opportunities for quality assurance and clinical improvement.

5. **Ongoing Pressure from Supporting Additional SHT Responsibilities**

   At the time of the visit the SHT had continued to provide substantial support to other Specialist Haemoglobinopathy Teams, including Queen's Hospital (BHRUT), via telephone advice, care of unwell patients, and red cell exchange services. While this reflected strong collaborative practice, it was also placing additional strain on the already limited workforce resource.

Further Considerations

1. Local Haemoglobinopathy Teams (LHTs) expressed a need for unified clinical guidelines and patient information materials covering Thalassaemia. Due to the low number of patients in individual centres, standardised resources would be required to support consistent care and education.
2. Clinical Nurse Specialists (CNSs) had responsibilities extending into non-malignant haematology, which was impacting their capacity to fully support haemoglobinopathy care and further clarity was needed around their role and remit.
3. Several clinical policies were found to be in draft form without clear review dates. A structured policy management process, including regular review and version control, would ensure clinical governance and patient equity standards are met.
4. At the time of the visit children and young people did not have access to patient-controlled analgesia (PCA) at NUH requiring patients to be transferred to RLH. This was raised as a concern by the NUH team, and local PCA access may improve patient experience and care continuity.
5. While clinical integration between paediatric and adult services was strong, this level of alignment was not yet mirrored at the divisional management level. Improved collaboration at this level could help resolve operational challenges more effectively. The review team were unable to meet with divisional nursing and clinical leadership during the visit, and future engagement would be beneficial.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

This was a well organised and hard working team who were flexible to the needs of their patients and families and had good relationships across the multidisciplinary team. Patients who met with the visiting team were extremely positive about the team.

The adult haemoglobinopathy service at RLH managed the care of 1014 adults with haemoglobinopathy diagnoses who were registered on the National Haemoglobinopathy Register (544 were cared for directly by RLH). Over the past 10 years the SHT and linked LHTs had seen a considerable increase in the number and complexity of patients under their care. At the time of the visit the trust was awaiting a decision on extra NHSE funding that would enable extension of the RLH day unit opening hours that would create capacity and enable more support to the Essex LHTs.

Staffing consisted of four consultant haematologists totalling 3.9 WTE with dedicated for haemoglobinopathy work**.** The SHT had a Lead Nurse who covered the adult and paediatric services and both HCCs, and two clinical nurse specialists (CNS). The clinical nurse specialists provided support to patients across the three boroughs, working closely with their community-based colleagues. The SHT had administrative and data management support.

Progress had been made to develop the SHT on the three Barts Health sites (NUH, RLH and WCUH) this included appointment of additional consultants, development of cross-site working and remote nurse-led therapies clinics, standardised acute pain management plans for patients living with a Sickle Cell Disorder, shared guidelines and MDT meetings as well as a programme of service improvement for all three sites.

The SHT had implemented the universal care plan (UCP) for patients living with Sickle Cell Disorder and at the time of the visit 98% of patients had a UCP which would enable GPs to access patients pain management plans. The SHT had also developed a Health Care Passport for patients, which included pertinent information that may be required in an acute setting such as transfusion history, the contact details of the haematology team and basic sign posting to guidance around other urgent complications of Sickle Cell Disorders. Following feedback from their patients living with Thalassaemia, the SHT were considering patients considering implementing a similar system of universal care planning.

The SHT had developed four standard pain management protocols and patients would have one selected as their acute hospital pain management protocol. Bespoke hospital pain management protocols were also in place for patients with complex pain syndromes. There were electronic prescribing bundles created to support the prescription for each of the standard acute pain management protocols, ensuring that all supporting medication was prescribed alongside analgesia.

The SHT haemoglobinopathy MDT meetings took place twice a month on the first and third Tuesday of the month and included representation from across the Trust and community teams. For extremely complex cases single patient MDTs could be scheduled in an ad hoc manner and with tailored membership. Where appropriate, patients, carers or their representatives could be part of the MDT.

Nurse led Hydroxycarbamide telephone and face to face monitoring clinics were well established and a range of joint specialist Sickle Cell Disorder clinics were in place with hepatology, transition, obstetric, pain, endocrinology and a quarterly nephrology MDT. There were good links with other specialist services.

Tertiary cardiology, cardiothoracic and haematopoietic stem cell transplant services were based at St Bartholomew's Hospital and patients who required these services were managed at this site with input from the RLH SHT clinical team. For novel cellular therapies joint consultations were delivered at St Bartholomew's Hospital alongside existing Transplant clinic. Inpatients undergoing these treatments were seen at least once a week by the RLH SHT consultant alongside the transplant team whilst inpatients, or more often if required.

Progress had been made in the transition of children and young adults to adult services. The Trust had implemented the 'ready, steady, go, hello ‘pathway. At the RLH, a TYA clinic had been piloted which was co-located with the regular adult red cell clinic as a final check and welcome to the adult service. This clinic had also helped with the transition of children from the Basildon LHT. The SHT had plans to implement a similar service across all the Barts Health sites (NUH and WCUH).

SPECIALIST HAEMOGLOBINOPATHY TEAM- ADULT [4]			
Barts Health NHS Trust: - Royal London Hospital	Linked Haemoglobinopathy Coordinating Centres (HCC)		
	East London and Essex Sickle Cell Haemoglobinopathy Coordinating Centre London and South East Thalassaemia and Rare Inherited Anaemia Haemoglobinopathy Coordinating Centre *(both hosted by Barts Health NHS Trust)*		
	Linked Local Haemoglobinopathy Teams LHT	Patient Distribution	
		SCD	Thalassaemia
	Basildon University Hospital - Mid and South Essex NHS Foundation Trust	82	7
	Broomfield Hospital Chelmsford - Mid and South Essex NHS Foundation Trust	0	0
	Colchester University Hospital -East Suffolk and North Essex NHS Foundation Trust	35	<=5
	Newham University Hospital *(part of Barts Health)*	222	6
	Southend University Hospital - Mid and South Essex NHS Foundation Trust	<=5	<=5
	Whipps Cross University Hospital *(part of Barts Health)*	104	8

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLONOAPTHY TEAM							
Condition		Registered patients	Active patients*[5]	Annual Review **	Long term transfusion	% Eligible patients on hydroxycarbamide	Inpatient admissions in the last year
Sickle Cell Disorder	Adults	867 (422 RLH)	867	358	132	154	504
Thalassaemia and RIA	Adults	147 (122 RLH)	147	78	59	-	-

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	544	3.9WTE
Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies for acute service and community service	544	3WTE
Clinical Psychologist dedicated to work with patients living with haemoglobinopathies	544	Vacant post

[4] 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.

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

Urgent and Emergency Care

Patients with acute complications attending the RLH when arriving by ambulance were triaged in the emergency department (ED) which was usually ED consultant led. Those presenting at the front door, presented to the administrative team, then would wait to be clinically triaged by a nurse. Once triaged if there was capacity they would be cared for on a trolley in an appropriate bed space, otherwise they would be seated on plastic chairs and receive pain relief. The ED team acknowledged that there was nowhere comfortable for patients to rest and manage their pain in the ED. Staff had access to the patient's Electronic Health Record (EHR) and patient's Health Care Passport that included the patient's individualised pain management protocol. Trust wide guidance was in place across all EDs that included instructions on how to access the Electronic Health Care Passport. All EDs had been provided with education resources to enable them to teach new, locum and bank staff and the lead for education provided a range of training for medical and nursing staff in the ED.

Reviewers were told that the RLH site had seen unprecedented number of admissions through the ED and this included nearly 2000 patients with living with a haemoglobin disorder. Patients who met with the reviewing team were concerned about the prolonged periods they spent in ED and cared for in suboptimal settings at times of peak pressure. The trust were aware of the capacity issues in the ED and had instituted a 'rapid release' policy to try and mitigate the risks for patients attending and reduce the pressure in the ED. Whilst the ED team had improved time to first dose of analgesia, they acknowledged that the time to subsequent doses could be lengthy.

There was 24-hour, 7 day a week specialist support from a specialist registrar (StR) who was non-resident outside normal working hours and after 5pm at weekends, and a specialist consultant who would be non-resident outside normal working hours. For complicated presentations such as acute stroke, acute chest syndrome, delayed haemolytic transfusion reaction, the specialist haematology team would attend the patient in the RLH ED. Patients with uncomplicated pain presentations were transferred to the haematology team at the 09:00 handover meeting.

For patients with Thalassaemia or rare inherited anaemias guidance was in place that recommended that the specialist red cell team were contacted on presentation to ED.

At NUH and WCUH sites, patients attending the ED were triaged in the ED. Staff had access to the electronic health care records, the patients' Health Care passport and electronic prescribing bundles for pain management.

In-patient Care

If admission was required for patients attending the RLH, patients were referred to the acute medical team and transferred to the acute medical unit on wards 11E & F. Patients could also be transferred directly to the haematology ward, 13D which was shared between the haematology teams and the metabolic team. Wards 11E & F were short stay wards and patients likely to require an admission for more than 48 hours or requiring additional specialist input such as for example patient-controlled analgesia (PCA) were transferred to the specialist ward 13D. Reviewers were told that it would be unusual for patients cared for outside these areas unless medically indicated.

The specialist red cell team would take over the care of all patients admitted with complications of their Sickle Cell Disorder the morning after admission regardless of which ward they had been admitted to. ward. All patients were seen within 24 hours of admission by a consultant. During the weekend this was the acute medical consultant followed by review by haematology SPR and telephone discussion with specialist red cell consultant. All patients were seen by a consultant at least twice during their admission. The haematology team would seek expert input as required from other specialist teams and worked closely with the acute pain team.

On ward 13D, to improve patient care and access to timely analgesia the team were piloting the use of subcutaneous patient controlled administration (PCAs) systems for pain management in a small subset of patients. Staff who met with the visiting team on the day of the visit did not seem aware of condition based protocols other than the protocols for pain relief.

At NUH patients with haematological diagnosis were preferentially admitted to Plashet Ward.

At WCUH there was no preferred ward and patients could be admitted to any medical ward.

Day Care

The RLH Haematology Day Unit was located on the Second Floor, South Tower and was open from 09:00-17:00 Monday to Friday. The day unit provided specialist services to patients with haemoglobinopathies, rare congenital anaemias, haemophilia, and general haematological diagnoses for patients cared for at the RLH and NUH. The day unit also housed the anticoagulation team for the RLH, and some anticoagulation clinics were run from this site. Services provided in the Haematology Day Unit for those living with a Sickle Cell Disorder and Thalassaemia included, automated red cell exchange transfusions, simple top-up transfusions, infusions, Portacath or other central venous access management, blood tests and bone marrow biopsies. The unit also had three consulting rooms which were used for urgent clinical and planned out-patient appointments. The specialist haemoglobinopathy nursing team was also based on the unit. For 2024/2025, the haematology day unit performed 706 apheresis exchanges.

The unit had 13 chairs, with four dedicated red cell apheresis beds. The phlebotomy service on the unit was available by appointment for patients having transfusions only, patients requiring other blood tests attended one of the other Trust phlebotomy departments. Patients who met with the visiting team commented that when they attended, if the Day Unit was busy, they would be asked to attend one of the other phlebotomy departments on site.

The Day Unit was working at maximum capacity and remained under significant pressure. Patients who met with the visiting team were also very concerned about the capacity in the unit because the intervals between their transfusions were often extended to accommodate the number of patients requiring day services.

At NUH there was no adult day care unit. Patients requiring regular transfusion were managed at RLH. There were no Clinical Nurse Specialists on site at NUH.

At WCUH the Haematology Day unit that cared for both cancer and non-cancer haematology and patients haemoglobinopathies could receive top up transfusions. It was open Monday, Tuesday, Thursday and Friday 09:00-17:00. There were no dedicated haemoglobinopathy clinical nurse specialists on site at WCUH.

At St Bartholomew's Hospital there was a haemato-oncology day unit where patients undergoing cellular therapies were managed.

Outpatients

At the RLH, weekly red cell clinics were held on a Friday morning, with three consultant lists and supported by a supernumerary Specialty Registrar. Once a month a dedicated Thalassaemia clinic was held with two Consultants attending and patients living with thalassaemia could attend for their annual reviews. Some clinic appointments were collocated on the Haematology Day unit to enable patients to coordinate clinic and their transfusion during one visit.

The SHT held a number of joint specialist clinics all of which offered hybrid appointment types. All joint clinics were available to patients from outside the RLH from across the Northeast London Network and referrals were accepted from both LHTs and SHTs. Specialist Transition and Young adult clinics were held monthly. Monthly joint chronic pain multidisciplinary clinic, attended by the chronic pain specialist, haematologist, clinical psychologist and physiotherapist; a monthly joint urology clinic; joint obstetric clinics and a complex transfusion and cellular therapies clinic was due to commence. Quarterly joint endocrine clinic and a joint hepatology clinic were held and in lieu of a joint renal clinic the SHT held a joint renal haematology MDT that was open to all SHTs across the Network.

Dedicated telephone nurse led specialist clinics were held weekly for hydroxyurea monitoring and weekly for iron chelation optimisation. The nurse led clinics supported patients who attended both RLH, NUH and for iron chelation patients whose local centre was WCUH.

At NUH specialist red cell consultant clinics were held twice a month. All patients living with Thalassaemia were followed up at RLH. A monthly joint obstetric clinic was held at NUH supported by a RLH consultant. Quarterly joint clinic with paediatrics were in place to support the transition of young people to adult care.

There were no dedicated adult red cell outpatient clinics at WCUH. Patients were seen in a community clinic (provided by NELFT) attended by a haematology consultant from Bart's Health with support from a GP and CNSs. At the time of the visit the service was being reviewed to the possibility of including an outreach specialist consultant from the RLH SHT team. Patients on hydroxycarbamide were monitored in the community clinic by the CNS with input from a GP with specialist interest and supervised by a haematology consultant.

Community- based care

The levels of community-based care varied across the four local boroughs and was likely to change following the assessment of the NHSE London Community pilot for East London.

Tower Hamlets Community Service

The community CNS was part of the SHT and supported both adult and paediatric patients across Tower Hamlets and families with newly diagnosed infants.

The Hackney Sickle and Thalassaemia Centre

The community-based centre was part of the integrated service provided by HH. Services were provided for Hackney based patients who attended the RLH, with a designated paediatric CNS. The adult CNS used to attend the RLH MDT each month to provide support the adult patients at RLH, but this had not been possible over the past 18 months due to staffing.

The service supported families with newly diagnosed infants, provided education and support, health promotion, transition preparedness clinics and workshops, training, and awareness programmes, preconceptual and genetic counselling, psychological assessment and support, welfare benefits advice, home visits, GP Liaison, 24-hour helpline, and a monthly support group.

The Newham Sickle and Thalassaemia Centre

Services provided at the centre included education and support, health promotion, training, and awareness programmes, TCD scanning and education. The service also undertook home visits for children and adult patients and families residing in Newham.

The Waltham Forest Service

The service provided counselling and screening to the public for haemoglobin types. There was a specialist nurse for paediatrics and one for adult services. Together, they provided community and follow-up care for affected babies, children, teenagers and adults; some education and training, transition preparation clinics and workshops; advocacy and clinical support and follow up of investigations and treatments.

Community support for network patients residing in Essex

At the time of the visit there was no community support for adult patients, apart from in the area covered by Queens Hospital (BHRUT).

Feedback from LHTs

Reviewers met with representatives from Colchester and Basildon who were highly appreciative of the advice and guidance they received from the SHT. Neither LHTS had support for data and data submission to the NHR and the Colchester LHT did not have access to NHR. The Colchester LHT expressed concerns about the patient pathway

and the difficulties for young people transitioning to adult care at Ipswich since their trust merger as young people attending Ipswich were linked to the SHT based at Cambridge. Also raised by the Colchester LHT was whether patient annual reviews could be undertaken locally.

They commented that they used guidance from a range of sources and would value the development of network guidance to reduce variation in guidance used and ensure consistent patient management. Both teams expressed a desire for more robust pathways, particularly out of hours and improved communication from the SHT especially notification to the LHT following patient discussion at the SHT MDT and clarity about who should be presented at the SHT and who at the SHT should receive copies of patient letters.

The LHTs had limited CNS support although at Basildon this potentially would improve following the successful MedTech funding. They reported that some informal discussions had taken place with the SHT Lead nurse about how the SHT could better support their CNSs.

Views of Service Users and Carers

The visiting team held focus groups prior to the visit and during the visit, and in total met two adults living with a Sickle Cell Disorder and three patients living with Thalassaemia, one of whom also provided feedback received from other patients. The user reviewer on the visiting team representing those living with Thalassaemia met separately with three parents, two of which had young people who had transitioned to the adult service in the past two years and four individuals affected by Thalassaemia (parents and adult patients).

Service User Feedback - General comments

- All praised the SHT members and felt that they were 'listened to' and that the team would always address any concerns they had when attending clinics. One patient said 'staff are really nice and feels like I am home'

Contacting the Team

- Patients valued being able to contact their consultant directly that tended to receive a prompt response although this was not the case for all the patients that we spoke to.
- They felt confident in their consultants' advice and experience of Thalassaemia and commented that they had strong positive relationships with most.
- For non-emergency advice, not everyone knew how to contact the team. Some would try the consultant secretary and other said they could use a generic email address although they reported that they would either not receive a response or it would take a few days.
- If they rang the reception desk in the day unit it was often not answered and they commented that had been none or very little reception at the front desk. They considered that having a point of call when they were ill would be helpful as it had been extremely difficult to get through to speak to a clinical member of the team.
- Whilst the patient who met with the visiting team were all concerned about capacity on the day unit they did say how much they liked and appreciated the day unit staff.
- Comments were received about patients being admitted at WCUH for other conditions and not being seen or assessed by their haematology team.

Information Received

- Views were mixed with some patients saying that they were adequately informed about their condition and that they would receive updates when they attended for their clinic appointments. Others talked about researching for their own information and accessing the Sickle Cell Society and UK Thalassaemia Society websites.
- Those who met with the reviewing team were keen to receive feedback from the peer review visit and see the visit report.

GP Experience

- All patients stated that their GPs also held copies of their care plans and clinical letters.

Access to Psychology

- There were mixed views about whether there was any access to psychology with the view that the service was intermittent as the post was vacant. Those living with Thalassaemia commented that their psychological needs were not addressed, with some stating that despite requesting help or referrals, they received none. When they approached their GP for support, they were advised to self-refer to community services.

Pharmacy

- The pharmacy experience was often challenging, with delays arising from inaccurate prescriptions at times. Comments were also received that the pharmacy would not prepare medications until they attended and they experienced lengthy waiting times.

Feedback

- They all reported receiving texts requesting feedback and if they had any issues would try and see a member of staff and they also knew how to contacts PALS.

Support Groups

- There was a local support groups for people living with a Sickle Cell Disorder and a WhatsApp group was in operation for patients living with Thalassaemia which had approximately 15 members. There were no other local support groups for people living with Thalassaemia or their families.

Sickle Cell Disorder Patient Feedback Meeting

Care Plans

- Care plans had generally been in place and were updated regularly when they attended for clinic appointments. Care plans were held electronically so they did not have a copy unless they requested.

Emergency Department and Ward Care

- The pathway was via the ED. Previously they had been able to contact the team and attend the day unit but they thought the day unit was now only for those attending for ARCET and transfusions. They would try to avoid seeking advice until normal working hours when they would contact the CNS in advance who would advocate for them and try liaising with the nursing team in the ED.
- On arrival to the hospital, they would queue until triaged when usually the ED would access their care plan and they were seen more quickly. Initial doses of analgesia were usually timely although subsequent doses were not always given. They commented that they felt ‘forgotten’, especially if they were in the seated areas.
- ED staff knowledge about their condition was variable with comments being made the medical staff had better understanding than the nursing staff.

Staff Attitudes and Care on the Wards

- Feedback on the hospital environment had varied. With patients commenting that the wards were cold due to the air conditioning. Care on the haematology ward tended to be better than other wards. Recent experiences were mixed and patients did comment that the night staff were often agency staff and were less empathetic and caring.
- Requesting analgesia, they often felt as though they were asking for ‘the impossible’ and at night they often had to wait for analgesia ‘until staff returned from their break.’

- They commented that staff lacked understanding about their condition and how they would have been in pain at home for many hours and then spent a lengthy time in the ED, and by the time they were admitted they were exhausted and all they were asking for was analgesia, fluid, rest and some support for personal care.

Transfusion Experience

- They did sometimes experience long waits when attending the day unit for phlebotomy. The day unit staff would make you comfortable when attending for ARCET and they commented on the good relationships they had built up with staff.
- They commented that if they missed their ARCET appointment they could have to wait another five to eight weeks for their ARCET.
- They were offered drinks and could order food.

Thalassaemia Patient Feedback Meeting

Care Plans

- The views about care plans were mixed. Care plans had generally been in place, with annual reviews for all patients undertaken with the SHT.
- They commented that they were referred to specialists for ongoing monitoring and scans, eyes hearing assessments were planned, although some comments were made that they had to remind staff to arrange these. Some however were not aware of any care plans, although they mentioned that clinical letters were sent to them and their GPs after clinic visits.

Day Care, Cannulation and Transfusion Experience

- The day unit was accessible for all haematology patients and they were offered drinks and could order food.
- Patients talked about the delays they experienced attending for their transfusion as the unit had insufficient capacity for them to attend. They were very concerned that their transfusion intervals were delayed/extended and the impact this was having on their health. They reported that capacity on the day unit was a long standing issue and had been raised with Trust staff at various levels to no avail.
- They were also concerned that capacity was lost due to patients not attending for their transfusions despite receiving reminder texts of upcoming appointments. Patients talked about the increase in the numbers of young people who were now transitioning on a regular basis to the day unit. They expressed anxiety about the number of patient requiring care, especially as more young people would transition to adult services and how all patients would be accommodated.
- They could attend the day unit for their blood tests but could wait up to two hours on the unit and if the unit was short staffed they would be referred to the general phlebotomy service.
- The day unit receptionists would book their next two transfusion appointments when they attended but if they had any other hospital appointments or commitments it was very difficult to get another day in the required week for their transfusion. They commented that previously this had not been an issue.
- Patients who me with the visiting team said there had been medical cover on the unit but thought this had changed and now if they were unwell when they attended they would have to wait to be seen by the on call team, which could be several hours. They commented that 'staff do not know what to do if you are ill' and they would be advised to go to their GP or the ED department. Others commented that sometimes clinics were held in a room in the day unit so they might be able to see a member of the team.
- The environment, in addition to capacity issues was challenging. There were no beds for patients to use when attending for their transfusion and the chairs were very uncomfortable and inappropriate if they experienced a transfusion reaction and when sitting for extended periods of time.

- The unit did now have a blood fridge which had reduced the time they waited for their blood.
- They could experience delays in starting their transfusions which would result in them not receiving their third unit, or the delivery of their transfusion was accelerated. Some were concerned at the affect this may have on their health if their blood was delivered too quickly.
- In general, there were no issues with cannulation when they attended for their transfusions.
- They all noted instances where they felt they were not treated with the same level of kindness, compassion and empathy as some other patients with different conditions. It was concerning to hear that they sometimes felt scared or anxious about attending the unit for future transfusions or blood tests due to the way the day unit staff treated them. While not all staff exhibited this behaviour, a few did, leading them to remain silent when not addressed in fear of 'being told off'.

Transition to adult services

- Parents and patients expressed a lack of confidence in the transition process to the adult care team. They felt their children did not receive adequate support and noted that in the adult service, patients were expected to book their own transfusions and crossmatches without prior notification. On some occasions, they reported being shouted at, which made them feel unintelligent in front of other patients and staff when they forgot to make an appointment, further isolating them.
- In contrast, they appreciated that in paediatrics, nurses and staff would handle bookings based on patients' needs before they left. The lack of communication in the adult service led to their children / themselves missing transfusions for 5-6 weeks due to a perceived lack of availability, as they failed to book the necessary appointments. They were advised to go to ED for emergency transfusions, as they could not be accommodated in the day unit.

Emergency Department

- Responses regarding ED at the RLH, WCUH and NUH were mixed, most indicated that the staff when they attended were not knowledgeable about Thalassaemia. Some commented that staff in the ED found it difficult to cannulate them.

Access to welfare advice and support

- Comments were received that they did not receive any help for benefits etc at the hospital. They were told to access in the community who would then advise that they could not help and that the patients would not be eligible for financial support even before their case was reviewed.

Feedback

- Some felt that they could give feedback via a QR code that was displayed in the day unit. They also felt comfortable providing feedback to the team or using the Patient Advisory Liaison Service (PALS).
- Others were uncertain about how to provide feedback or whether there were opportunities to share their experiences, both positive and negative, without fear of repercussions to their treatment.

What could be better

- A designated ward where staff really understood your condition, access to regular analgesia, fluid and rest as this would enable them to recover more quickly and be a shorter hospital stay.
- Better nutritional value of hospital food as by the 'nature of our condition we have to be careful'.
- Patients had to ask medical staff to organise their MRI, audiology and DEXA scans, which could take some time to arrange and they wondered if this could be done automatically.

- More flexibility in attending for phlebotomy as it takes up half of a working day and it would be helpful if the Day Unit was open till 6pm or at least one evening till 8pm and Saturdays which may help with capacity and provide a more flexible approach for those who were working.
- The Day Unit should start canulations earlier and start transfusions quickly so that three units can finish on time without speeding up their transfusion.
- They would like to be able to book their next blood transfusion appointment with the receptionists so their appointments do not clash with any other clinical appointments.
- Patients living with Thalassaemia should also have alert cards that they can show when attending in an emergency and they would also like to have more access to educational days.

Good Practice

1. Patients who met with the visiting team were highly appreciative of the support and respect they had for the SHT.
2. All the LHTs who spoke to the visiting team felt supported by the SHT and in particular valued the advice available and the educational sessions that were included as part of all MDT meetings.
3. Since the last visit the SHT had been able to increase their consultant time which had enabled some stability for the red cell service. The SHT were also planning how they could expand the outreach provision to deliver specialist care locally where possible.
4. Reviewers were impressed that 96% of people living with a Sickle Cell Disorder had a Universal Care Plan (UCP) and with the development of Health Care Passports for patients, key information was available to staff working in primary care and other clinical services. The SHT were also considering implementing similar digital care plans for patients living with Thalassaemia
5. The SHT had a good relationship with the Sickle Cell Society in the piloting of a project to develop peer mentoring for young people residing in North East London. The project had evaluated well resulting in peer mentoring being adopted elsewhere.
6. The SHT had good relationships with the staff in the ED which had resulted in and education programme for staff on the care of patients with a haemoglobin disorder attending in an emergency and the identification of a link consultant role. The ED had also implemented a Quality, Innovation, Productivity, and Prevention (QIPP) initiative to improve the care for patients attending the ED, particularly the access to analgesia within 30 mins of arrival for those experiencing a vaso- occlusive crisis.
7. A GP with a special interest in the care of people living with a haemoglobin disorder based in Waltham Forrest was providing primary care support locally and would liaise with the SHT and attended the SHT MDTs.
8. Reviewers were impressed with the work undertaken at NUH to develop an appropriate escalation and management pathway with the Intensive Care Team for the management of sick patients who required emergency manual exchange. Implementation of the pathway had resulted in patients being assessed by the ITU team in the ED and escalated more quickly for emergency management.
9. The service was in the process of accrediting its five-day haemoglobinopathy training course, aiming to enhance uptake and support workforce development.
10. To promote the awareness of patients living with a haemoglobin disorder, patient stories had been presented to Trust staff as part of the Trust 'Grand Round' education programme.
11. Reviewers were impressed with the SHT plans to develop a 'Sickle Cell Board' which would meet monthly with involvement from patient representatives, the SHT, Divisional Medical Director and chaired by the RLH and Mile End Hospital Medical Director.

Immediate Risks

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

Serious Concerns

1. **Access to Psychology**

   Patients did not have access to a psychologist with relevant experience in caring for patients and families with haemoglobin disorders. The SHT cared for 544 patients living with a haemoglobin disorder as well as supporting patients within the LHTs. The British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommends one WTE clinical health Psychologist for 300 patients.

   Reviewers were seriously concerned as without access to a dedicated psychological practitioner individuals affected by these disorders will have limited specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition.

2. **Day Unit Capacity**

   a. Access to Elective Automated Red Cell Exchange

   Red cell exchange capacity and staffing was insufficient for the numbers of patients who required this service. The Day Unit was open from 9am to 5pm Monday to Friday had four beds and three machines for apheresis, which meant they could only undertake one ARCET procedure per day per machine and a total of 15 procedures a week.

   Patients who were on the ARCET programme experienced delays, especially if they missed a session would have to wait as long as five weeks before they could attend. At the time of the visit 40 patients were on the waiting list and reviewers were seriously concerned that the delays in patients accessing treatment would increase the risk of these patients developing additional complications of their condition in the interim, some of which could be life threatening or life changing.

   The SHT had been successful in receiving some funding from Med Tech which would allow the service to increase their staffing, and if operational from 8am to 8pm would enable an additional four procedures per day. However, reviewers were concerned that the additional capacity may not resolve the waiting list completely and that the moneys made available to expand this service may be blocked by the "triple lock" oversight process. *See also HCC serious concerns and trust wide concerns sections of the report*.

   b. Transfusion Dependent Thalassaemia Patients

   There was insufficient staff and space available on the day unit to enable patients requiring regular transfusions to be accommodated. Patients who met with the visiting team were very concerned about the extended intervals between their transfusions, the effect it was having on their day to day living and the risk to their health.

   c. Did Not Attend Rates (DNA)

   The number of patients who DNA for their ARCET or transfusions was high which was resulting in an underutilised service and inefficient use of resources. Patients who met with the visiting team were also concerned about the number of patients who did not attend, especially as they found it difficult to book timely appointments for their transfusions.

3. **Consultant Staffing**

   Reviewers were seriously concerned that the service had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care and clinics for the patients under their care.

At the time of the visit the SHT had a total of 3.9WTE Consultants covering the Adult Red Cell service for 544 patients. One consultant was on long term leave and the consultants were providing a 1:4 on call rota and 1:3 attending rota. The consultants were also providing specialist advice and support for 6 LHTs based in Basildon, Colchester, Chelmsford*,* Newham, Southend, Whipps Cross, as well as their local catchment population.

4. **Nurse leadership and CNS Workload**

The level of SHT nurse leadership and CNS time was of a serious concern for the following reasons:

a. At the time of the visit the designated lead nurse had only 1WTE time for leadership of the adult and paediatric SHT, clinical work with the paediatric service and leadership of both HCCs.

b. The SHT had only two WTE CNS for the acute service at RLH which was insufficient for the 544 registered patients seen solely at RLH with a range of haemoglobin disorders and to provide nurse led clinics, and to provide support to the 323 adults based in the LHTs.

c. The lack of CNS time was impacting on the CNSs being able to provide the level of support to patients, undertake audits and staff education, and to provide support to their constituent LHTs as required by a specialist haemoglobinopathy team. Patients who met with the visiting team commented that it was difficult to get a timely response to queries if when they tried to contact the CNSs via email.

d. Reviewers were told that the RLH CNSs would only visit the wards once a week outside of the ward rounds to see patients unless the ward staff requested otherwise, which was of concern considering that acute inpatient admissions had been reported as 504 patients in 2024-25.

e. The absence of a psychology service for patients with haemoglobin disorders had also resulted in the trust CNS trying to cover these requirements supporting patients wellbeing

f. Reviewers were seriously concerned that the CNS workload was not sustainable and that CNS staffing for the future would also need to take account of increasing patient numbers, longevity and complexity.

g. There was no CNS support for patients attending at NUH or WCUH, although there was a community CNS provided some in reach support for patients admitted to WCUH.

Concern

1. **SHT Leadership Time**

The designated lead for the adult SHT was also the lead for haematology and only had 1PA allocated for all leadership activities. Reviewers were concerned that this was insufficient time for the development of guidelines, protocols, training and audit related to haemoglobinopathies' and overall responsibility for liaising with other services and would become unfunded when the led ceased to be the clinical lead for haematology.

2. **Ward Nurse Education and Competence Framework**

Reviewers were concerned about the level of education available and competences for staff in the care of people living with haemoglobin disorders for the following reasons: -

a. Ward nurses did not receive any induction training on the care of patients with haemoglobinopathies when commencing on Wards 11E & F or 13D, the haematology ward. Nursing staff on the wards visited had competences in transfusion and cannulation but staff commented that they would value more specific training in haemoglobin disorders.

b. At the time of the visit there was no competence framework in place covering the different staff competences needed for the different haemoglobinopathy conditions and areas of work. From discussions during the visit, it was not clear of the timeframe for the introduction and monitoring of staff competences in the care of people living with these conditions.

c. The practice nurse educators provided education of ward staff and it was unclear what they were providing for haemoglobinopathies as staff reported that they did not received any haemoglobinopathy related education, and there was little involvement by the CNS team. Reviewers were concerned that the involvement of the CNS team was crucial to provide a specialist level of expertise.

d. The service had developed a five day haemoglobinopathy education programme however ward staff told reviewers that it was very difficult to release staff for this length of time.

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. In particular the trust plans to address capacity on the day unit.
2. Patients who were transfusion dependant were annoyed that the beds had been removed in the day unit and they now spent long periods of time receiving their transfusions on chairs. They reported that the chairs were uncomfortable, especially for those with mobility issues and felt they were treated less equitably than those who attended for ARCET who would have access to a bed.
3. The SHT covered a wide region, with LHTs crossing multiple ICB boundaries. At the time of the visit the service level agreements (SLA) between the SHTs and LHTs had not been agreed but were planned. Reviewers considered having approved SLAs with the LHTs would have the potential to clarify clinical responsibilities between teams and improve communication and engagement.
4. There was very little information about haemoglobin disorders visible on ward 13D, whose beds were shared for patients requiring an inpatient admission with haematology and metabolic conditions. Reviewers considered that ward personalisation could be improved to make patients with haemoglobin disorders feel as important as patients with other conditions cared for on the ward.
5. With the level of expertise and engagement in research across the SHT, the SHT should consider how it could support and include research involving nurses and Allied Health Professionals.

Commissioning

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

Serious Concern

1. **HCC Finance Management**

   Reviewers were seriously concerned at the effect on the East London and Essex Sickle Cell (SCD) HCC function due to the delays in being able to appoint key staff with the 2023/24 funding from NHSE to support services for the care of people living with haemoglobin disorders across the network.

   Financial scrutiny had become very complex even where funds were provided by NHSE and included multiple layers of internal agreement and sign off, then the Trust and NEL ICB to sign off any business cases for staff and service developments. At the time of the visit the applications for the additional CNS and data support posts for the LHTs based at Basildon and Newham had been submitted to the joint oversight committee for funding allocated to the HCC 12 months ago. Some of the issues were reported by trust management to be related to requiring additional detail and not just trust related finance issues, which had caused the delays. Both the ICB and NHSE commissioners were aware of the delay in recruitment but no action had been taken to support the HCC in progressing these appointments.

Concern

1. **ICB Commissioning of NHSE Community Project**

   The NHSE commissioned East London Sickle Cell and Thalassaemia Community Project Pilot only had funding for two years. The review team were concerned that the political climate specifically around shifting ICB and NHSE finances may disrupt such highly valued services.

Appendix 1 Membership of Visiting Team

Visiting Team		
Isabel Adams	Haemoglobinopathy Liaison Sister	Birmingham Women & Children's NHS Trust
Funmi Dasaolu	User Representative -Sickle Cell Disorders	
Leah Denver	HCC Network Manager	Birmingham Women & Children's NHS Trust
Maria Goridari	Clinical Psychologist	South London and Maudsley NHS Foundation Trust
Sandy Hayes	Haemoglobinopathy Senior Specialist Nurse	Retired
Asiawu Kolewole Imam	Sickle Cell CNS	West Hertfordshire Hospitals NHS Trust
Andrea Leigh	Paediatric Consultant Haematologist	University College London Hospital NHS Trust
James Leveson	Haematology Registrar	University College London Hospital NHS Trust
Roanna Maharaj	User Representative - Thalassaemia	
Elizabeth Rhodes	Consultant Haematologist	St George's University Hospital NHS Trust

Clinical Leads		
Emma Drašar	Consultant Haematologist	Whittington Health NHS Trust
Mark Velangi	Consultant Paediatric Haematologist	Birmingham Women & Children's NHS Trust

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

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
East London and Essex Sickle Cell Haemoglobinopathy Coordinating Care Centre	13	11	85%
London and South East Thalassaemia and Rare Inherited Anaemias Haemoglobinopathy Coordinating Care Centre	11	8	73%
Specialist Haemoglobinopathy Team (SHT) Children and Young People	49	34	69%
Specialist Haemoglobinopathy Team (SHT) Adults	45	20	44%

Quality Standards – East London and Essex Sickle Cell Disorder HCC - All Ages

Ref	Standard	Met Y/N	Reviewer comment
H-198 S	**Network-wide Involvement of Children, Young People, Families, Patients and Carers (SCD)** The Sickle Cell Disorder HCC should have mechanisms for involving children, young people, families, patients and carers, including representation at HCC Business Meetings (QS H-702)..	N	Patient representatives were not yet fully involved in the business of the HCC. The HCC had identified patient representatives and did provide network wide patient education sessions.
H-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	Y	Designated Lead had two PAs for the leadership of both HCCs. The HCC had Deputy Clinical Leads Adults and Paediatrics who each had one PA allocated for HCC activity
H-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	The designated Lead Nurse (0.5WTE) covered both HCCs.
H-202A	**Lead Manager** A lead manager should be available with: a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs b. Responsibility for liaison with other services within the network The lead manager should have appropriate time for their role.	Y	

Ref	Standard	Met Y/N	Reviewer comment
H-203	**Lead for Transcranial Doppler Ultrasound** The HCC should have a nominated lead for Transcranial Doppler Ultrasound screening.	Y	The TCD Lead had one PA for HCC TCD activity
H-602S	**HCC Service Organisation (SCD)** A Sickle Cell Disorder HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including: a. Telephone or email advice for outpatient and inpatient care b. Advice on emergencies outside of normal working hours	Y	
H-605S	**HCC Multidisciplinary Discussion (SCD)** MDT meetings for the discussion of more complex patients with sickle cell disorder should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use.	Y	
H-609	**NHS Blood and Transplant Liaison** The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies.	Y	One consultant haematologist was a joint appointment with NHSBT with 5 PAs allocated to provide dedicated transfusion expertise. Transfusion MDTs were also held.

Ref	Standard	Met Y/N	Reviewer comment
H-702S	**HCC Business Meetings (SCD)** The Sickle Cell Disorder HCC should organise at least two meetings each year with its referring SHTs and LHTs to: a. Agree network-wide information for children, young people, families, patients and carers of all ages b. Agree network-wide policies, procedures and guidelines, including revisions as required c. Agree the annual network education and training programme d. Agree the annual network audit plan, review results of network audits undertaken and agree action plans e. Review and agree learning from any positive feedback or complaints involving liaison between teams f. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams g. Review progress with patient experience and clinical outcomes (QS H-797) across the network and agree any network-wide actions to improve performance h. Consider the TCD annual monitoring report and agree any actions required (QS H-704	Y	
H-703	**HCC Annual Programme of Work** The HCC should meet with their commissioners at least annually in order to: a. Review progress on the previous year's annual programme of work b. Review progress with improving patient experience and clinical outcomes across the network (QS H-797) *c.* Agree the annual programme of work for the forthcoming year.	Y	

Ref	Standard	Met Y/N	Reviewer comment
H-704S	**Transcranial Doppler (TCD) Monitoring Report** The HCC TCD lead should monitor and review at least annually: a. The list of staff undertaking TCD ultrasound and whether they have undertaken 40 procedures in the last year (QS HC-209) b. Results of internal quality assurance systems (QS HC-504) c. Results of National Quality Assurance Scheme (NQAS) for TCD ultrasound (when established) or local peer review arrangements (until NQAS established) d. Number of TCD ultrasounds performed and the number of abnormal TCDs across the network e. Whether any changes to the TCD Standard Operating Procedure (QS HC-504) are required	Y	
H-707	**Research** The HCC should have agreed a list of research trials available to all patients within the network and SHTs should actively participate in these trials.	Y	
H-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Many of the documents either had no review date or were in draft form.

Quality Standards – London and South East Thalassaemia & RIA HCC - All Ages

Ref	Standard	Met Y/N	Reviewer comment
H-198 T	**Network-wide Involvement of Children, Young People, Families, Patients and Carers (Th)** The Thalassaemia HCC should have mechanisms for involving children, young people, families, patients and carers, including representation at HCC Business Meetings (QS H-702).	N	Patient representatives were not yet fully involved in the business of the HCC. The HCC had identified patient representatives and did provide network wide patient education sessions.
H-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	Y	The designated Lead had two PAs for the leadership of both HCCs. The HCC had Deputy Clinical Leads Adults and Paediatrics who each had one PA allocated for HCC activity.
H-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	The designated Lead Nurse (0.5 WTE) covered both HCCs.
H-202A	**Lead Manager** A lead manager should be available with: a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs b. Responsibility for liaison with other services within the network The lead manager should have appropriate time for their role.	Y	

Ref	Standard	Met Y/N	Reviewer comment
H-602T	**HCC Service Organisation (Th)** A Thalassaemia HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including: a. Telephone or email advice for outpatient and inpatient care b. Advice on emergencies outside of normal working hours	N	The SOP was in draft. In practice ‘a’ and ‘b’ were met.
H-605T	**HCC Multidisciplinary Discussion (Th)** MDT meetings for the discussion of more complex patients with thalassaemia should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use.	Y	
H-609	**NHS Blood and Transplant Liaison** The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies.	Y	One consultant haematologist was a joint appointment with NHSBT with 5 PAs allocated to provide dedicated transfusion expertise. Transfusion MDTs were also held.

Ref	Standard	Met Y/N	Reviewer comment
H-702T	**HCC Business Meetings (Th)** The Thalassaemia HCC should organise at least two meetings each year with its referring SHTs and LHTs to: a. Agree network-wide information for children, young people, families, patients and carers of all ages b. Agree network-wide policies, procedures and guidelines, including revisions as required c. Agree the annual network education and training programme d. Agree the annual network audit plan, review results of network audits undertaken and agree action plans e. Review and agree learning from any positive feedback or complaints involving liaison between teams f. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams g. Review progress with patient experience and clinical outcomes (QS H-797) across the network and agree any network-wide actions to improve performance *h.* Consider the TCD annual monitoring report and agree any actions required (QS H-704)	Y	
H-703	**HCC Annual Programme of Work** The HCC should meet with their commissioners at least annually in order to: a. Review progress on the previous year's annual programme of work b. Review progress with improving patient experience and clinical outcomes across the network (QS H-797) ***c.*** Agree the annual programme of work for the forthcoming year	Y	
H-707	**Research** The HCC should have agreed a list of research trials available to all patients within the network and SHTs should actively participate in these trials.	Y	
H-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Many of the documents either had no review date or were in draft form.

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	

Ref	Standard	Met Y/N	Reviewer comment
HC-102	**Information about Haemoglobin Disorders** Children, young people and their families should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Parental or self-administration of medications and infusions	N	Patient information was not seen covering sickle cell disorders other than the family handbook. Information was available covering thalassaemia (US Booklet which had not been localised), Desferal pumps, NHR and blood transfusion. 'a-b' met on the website however families stated that they were unaware of the website.
HC-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	Y	
HC-104	**What to Do in an Emergency?** All children and young people should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	

Ref	Standard	Met Y/N	Reviewer comment
HC-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents [SCD and Th] c. Guidance for GPs on: Immunisations Contraception and sexual health (if appropriate) d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
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	

Ref	Standard	Met Y/N	Reviewer comment
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	Y	
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service *iv.* Communication with their new GP	Y	
HC-197	**Gathering Views of Children, Young People and their Families** The service should gather the views of children, young people and their families at least every three years using: a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder' b. UKTS Survey for Parents of Children with Thalassaemia	Y	

Ref	Standard	Met Y/N	Reviewer comment
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	N	The patient survey results had been analysed but it was not clear about the mechanism for 'b' and whether changes had been made as a result of feedback, 'c'. 'a' was met.
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session(s) identified for the role within their job plan and cover for absences should be available.	Y	
HC-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The designated lead nurse had insufficient time for leadership of the SHT as defined by the QS. At the time of the visit the lead nurse covered both adult and paediatric SHTs, had a clinical workload and was also the lead nurse for two HCCs.

Ref	Standard	Met Y/N	Reviewer comment
HC-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The SHT had 2.4WTE Consultant Paediatric Haematologists who covered all non- malignant paediatric haematology with approximately 13 programmed activity (PA) sessions for haemoglobinopathy which was insufficient for the 184 registered patients with haemoglobin disorders seen solely at RLH, to provide specialist advice and support to the 163 children and young people based in their constituent LHTs.
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	The paediatric haematology consultants provided 1:4 – 1:5 on call out of hours providing non-malignant haematology on call to East London Essex network.
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	All haematology resident doctors in training rotated to paediatric haematology for three to four months. Additionally, two core paediatrics resident doctors ST2+ and one senior paediatric ST3+ resident rotated 6 monthly covering paediatric haematology and oncology.

Ref	Standard	Met Y/N	Reviewer comment
HC-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. Clinical nurse specialist(s) with responsibility for the acute service b. Clinical nurse specialist(s) with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The SHT did not have sufficient acute CNS time for the number of patients. There were two WTE hospital CNS for CYP plus the Lead Nurse for the HCC who covered both adults and CYP and had a clinical workload. There was no evidence of completed competencies and nursing staff in ED/PAU reported to be unaware of how to access the specialist training. Community nursing was provided by the various community teams across the region.
HC-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. An appropriate number of regular clinical session(s) for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	There was 0.5 WTE Psychologist in post for the service with no formal cover arrangements in place. There was no psychology provision at NUH or WCUH. There was no neuropsychology provision. *It was noted that the patient feedback regarding the psychologist was excellent.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	There was only one WTE data manager in post who covered the HCC. Funding had been agreed for two additional data managers for the HCC however recruitment had not commenced *(see concerns section of report).* Secretarial administrative support was provided by other paediatric specialities.
HC-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required: a. Social worker/benefits adviser b. Play specialist/youth worker c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Child and adolescent mental health services	N	There was no access to a social worker/benefits advisor for the service. Referrals were made to the community advocacy team for support and signposting. 'b-f 'was met.
HC-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	There was no provision for ARCET, however Med Tech funding had been approved to provide this through PICU and there was an approximate. six month timescale for commencement of 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	NHS East and Southeast London Pathology Partnership

Ref	Standard	Met Y/N	Reviewer comment
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, Medical Admissions Units and any other areas to which 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	
HC-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HC-195)	Y	
HC-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for children, young people and their families.	Y	

Ref	Standard	Met Y/N	Reviewer comment
HC-504	**Transcranial Doppler Ultrasound Standard Operating Procedure** A Standard Operating Procedure for Transcranial Doppler ultrasound should be in use covering at least: a. Transcranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Transcranial Doppler ultrasound (QS HC-209) d. Arrangements for ensuring staff performing Transcranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	Y	

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

Ref	Standard	Met Y/N	Reviewer comment
HC-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring complications Indications for discontinuation	Y	
HC-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	
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	N	No evidence of acute guidelines for Thalassaemia (l-m).

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	
HC-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of children and young people with sickle cell disorder and thalassaemia during anaesthesia and surgery.	Y	
HC-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	

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

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

Ref	Standard	Met Y/N	Reviewer comment
HC-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	
HC-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions	N	There was no evidence that audits covering 'a-b' had been undertaken.
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	Y	
HC-707	**Research** The service should actively participate in HCC-agreed research trials	Y	
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 service's multidisciplinary team, with patient and carer representatives had not yet reviewed 'a-c'.

Ref	Standard	Met Y/N	Reviewer comment
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.	N	Many of the documents either had no review date or were in draft form

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 National Haemoglobinopathy Registry, its purpose and benefits Self-administration of medications and infusions	N	Patient information was not seen or written guidance on where to access information covering sickle cell disorders. Information was available covering thalassaemia (US Booklet).

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)	N	The general booklet covered where to attend but did not have any indications about what to do in an emergency for those living with thalassaemia. This QS was met for those living with SCD.
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: Immunisations Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	N	The written guidance for GPs did not appear to be ratified and included names of previous staff. Patients who met with the visiting team reported that GPs did receive copies of their letters.
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	

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	Sickle Cell Survey undertaken in Feb 2025 – 450pts/55 responses Thalassaemia undertaken in Feb 2025 – 112pts/20 responses Survey responses had been analysed and actions identified.
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) Examples of changes made as a result of feedback and involvement	Y	

Ref	Standard	Met Y/N	Reviewer comment
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The designated lead had on 0.5PA for leadership of the SHT and for all of non- malignant haemoglobinopathy.
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 had insufficient time for leadership of the SHT as defined by the QS. At the time of the visit the lead nurse covered both adult and paediatric SHTs, had a clinical workload and was also the lead nurse for two HCCs.
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 at RLH had a total of 3.9WTE Consultants covering the Adult Red Cell service for 544 patients. At the time of the visit one consultant was on long term leave and the consultants were providing a 1:4 on call rota and 1:3 attending rota. The SHT were also providing specialist advice and support for six LHTs based in Basildon, Colchester, Chelmsford Newham, Southend, Whipps Cross, as well as their local catchment population.
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	

Ref	Standard	Met Y/N	Reviewer comment
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	All haematology residents rotated to the adult red cell service for 3-4 months.
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	The complexity of the services was challenging in terms of acute and community cover. Nurse- led hydroxycarbamide review and chelation clinic were in operation. The CNSs would also attend the wards once a week and at other times if requested. They had insufficient time to provide support to their constituent LHTs or lead on education. There was no CNS at NUH or WCUH, although there was a community CNS provided some support for patients admitted to WCUH. Some education was provided by the trust practice educators but staff on the day unit or wards did not have induction or ongoing training in the care of patients living with haemoglobin disorders. A competence framework was not in place for any of the nursing staff. Nurses did have competences in cannulation and transfusion.
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	Patients did not have access to a psychologist. The SHT had a 1 WTE vacancy for a psychologist but this would still not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE clinical health psychologist for 300 patients.

Ref	Standard	Met Y/N	Reviewer comment
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	The SHT had only 1WTE x B3 Administrator and 1WTE x B4 Community Patient Care Co-Ordinator, which was insufficient for number of patients cared for.
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	Y	
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	The SHT had 40 patients on the waiting list to access the ARCET programme. The service was not available 24/7. All other aspects of the QS were met.
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	NHS East and South East London Pathology Partnership

Ref	Standard	Met Y/N	Reviewer comment
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, Medical Admissions Units and any other areas to which 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	The SHT had developed an education programme raising awareness of acute complications of sickle cell disease and the patient lived experience to staff in ED, acute medicine and anaesthetics which had been delivered across the three trust sites. The ED department were also leading on a QIPP (Quality, Innovation, Productivity and Prevention) programme specifically to improve access the analgesia for patients with experiencing a sickle cell vaso occlusive crisis.
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	

Ref	Standard	Met Y/N	Reviewer comment
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.	N	The information seen was not clear. The guidance seen did not appear to have an approval date, and some of the references were not up to date.. The eye care section suggested that annual screening was not recommended and patient should attend their optician every two years. The section on AVN shoulder and hips as title, appeared to describe other areas. Sickle cell trait was discussed in renal complications? The guideline/template covering Thalassaemia was in draft..
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	N	Manual exchange policy dated 2020, no review date listed. Cannulation PowerPoint in the transfusion policy submitted appeared to be in draft and had no version control or trust header.

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	N	The guidance did not have an effective date or clear from the outset that it related to paeds or adults or both. The guidance tended to use the phrase 'sickle cell anaemia' although it did mention thalassaemia later in the document.
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	N	The guidance provided was in draft guidance with significant track changes.

Ref	Standard	Met Y/N	Reviewer comment
HA-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC/SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred For patients with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation	N	It was not clear if the guidance had been ratified and was in use. As comment at HA-502

Ref	Standard	Met Y/N	Reviewer comment
HA-510	**Clinical Guidelines: Chronic Complications** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Pulmonary hypertension f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea g. Endocrine problems, including endocrinopathies and osteoporosis h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology i. Chronic pain j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease k. Urological complications, including priapism and erectile dysfunction l. Dental problems	N	The guidance did not have an approval date although stated effective from April 2025 but did have an identifying number. The guidance title was the management of adults with SCD but did include some reference to those with thalassaemia. Dental problems 'i' was not included in the guidance.
HA-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery.	N	The guidance covered SCD and not thalassaemia and was an embedded document in the management of adult with sickle cell disease which did not have appear to have an approved date.

Ref	Standard	Met Y/N	Reviewer comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	N	The guidance did not cover arrangements for 'ii and iv or v'
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.	N	Not all staff who spoke to the reviewing team were able to locate the guidance.

Ref	Standard	Met Y/N	Reviewer comment
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	Y	Operational policy and annual report- April 2025.
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	At the time of the visit shared care agreements with LHTs were not in place.
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	

Ref	Standard	Met Y/N	Reviewer comment
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	Service level agreements for support from community services covering 'a' and 'b' were not yet in place. Community services were provided by two community trusts (ELFT and NELFT).
HA-607 S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each HCC Business Meeting (QS HA-702).	Y	
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	
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	N	Audits covering 'a-b' had not been undertaken. The audit covering time to analgesia had been completed.
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	N	It was not clear if the SHT had participated in the HCC agreed audit plan for 2024-25.
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	

Ref	Standard	Met Y/N	Reviewer comment
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 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	
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Many of the documents seen did not have approval or review dates.