MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

Health Services for People with Haemoglobin Disorders

Croydon Health Services NHS Trust

Visit date: 20th February 2024

Report date: 11th July 2024

Contents

Introduction

This report presents the findings of the review of The Croydon Health Services NHS Trust that took place on 20th February 2024. The purpose of the visit was to review compliance with the Health Services for People with Haemoglobin Disorders Quality Standards Version 5.1, November 2021 which were developed by the UK Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit was organised by the Nursing and Urgent Care Team (NUCT) at the Midlands and Lancashire Commissioning Support Unit (MLCSU). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

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

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

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

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Any immediate risks identified will include the Trust and UKFHD/MLSCU response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in the Croydon 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:

- Croydon Health Services NHS Trust
- NHS England - London
- NHS South West London Integrated Care Board

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

About the UKFHD and MLCSU

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

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

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

Acknowledgements

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

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Review Visit Findings

Trust-wide General Comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders at the Croydon Health Services NHS Trust. During the visit, reviewers attended both the Croydon University Hospital where they visited the adult and paediatric emergency departments (EDs), assessment units and wards; and the Croydon Sickle Cell and Thalassaemia Centre where they met with patients and carers, and with staff providing services for the local health economy.

Croydon Health Services NHS Trust provided hospital and community services from a number of community and specialist clinics throughout Croydon within the South West London Integrated Care Board. These include Croydon University Hospital, Purley War Memorial Hospital, The Sickle Cell and Thalassaemia Centre in Thornton Heath and a minor injuries unit in New Addington. The Trust was formed on 1st August 2010 through the integration of Croydon Community Health Services and Mayday Healthcare NHS Trust and employs around 4,500 staff.

The Haemoglobinopathies Service at Croydon provided specialist, integrated care to children and adults with haemoglobin disorders. The Trust had been designated a Specialist Haemoglobinopathy Team (SHT) in 2019 following the national compliance exercise conducted by NHS England (NHSE) and was part of the South East London and the South East Sickle Cell Disease Haemoglobinopathy Centre (HCC) (SELSE), and the East London, Essex, Southeast London and the Southeast of England Thalassaemia and Rare Inherited Anaemias HCC. The SHT also had links with St George's University Hospital NHS Foundation Trust.

Acute, inpatient and outpatient care for patients with haemoglobin disorders was provided at Croydon University Hospital by the Adult Haematology and Paediatric Medical and Nursing Teams. Members of the team attended educational and organisational network meetings on a regular basis. The Haemoglobinopathy Service in the community had three Sickle Cell and Thalassemia Clinical Nurse Specialists, who were supported by 2 administration staff and based nearby the Trust at the Sickle Cell and Thalassemia Centre in Thornton Heath.

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 are the same for both the adult service and the children and young people service have been repeated in each section.

Trust-wide Good Practice

Trust-wide Good Practice – children and young people

1. Paediatric Support groups received positive patient feedback, as did the school visits by the CNS and the broad range of educational sessions provided.
2. The facilities in the paediatric emergency department, outpatient areas, and wards were excellent with new and recently renovated estates.
3. The paediatric phlebotomy services were particularly outstanding and stood out as an exemplary area of good practice. The specialist team highlighted the flexibility of the phlebotomy service to meet the needs of individualised patients.
4. The establishment of fully integrated care within the acute and community settings was commended.

Trust-wide Good Practice – adults

1. Success in securing financial support from NHS England to bolster community initiatives; aimed to establish dedicated psychology support and improve data management processes.
2. The establishment of fully integrated care within the acute and community settings, which works well in promoting holistic patient care.

Trust-wide Serious Concern

Trust-wide Serious Concern – children and young people

1 Consultant Staffing

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

b) At the time of the visit the Lead Consultant (general paediatrician with specialist interest in haemoglobinopathies) had a total of 1PA for direct clinical care of 265 patients with haemoglobin disorders, plus 1 PA for the SHT lead role. Based on the UK Forum recommendations, the consultant staffing is significantly under-resourced. This impacted on the consultant's capacity to attend network meetings, conduct audit/research and update policies.

c) There was no evidence of future proofing across the SHT, with the lead consultant having no deputy and there were no cover or arrangements in place for absence.

2. **CNS Staffing**

a) At the time of the visit, reviewers were seriously concerned that the service had insufficient CNS staffing with only one CNS (1 WTE) employed to cover hospital and community services and one CNS covering antenatal and newborn screening.

b) A lack of cross-cover arrangements for the Paediatric CNS's and at times of sickness or absence, this resulted in one CNS to cover hospital, community, and antenatal and newborn screening services.

c) This was compounded by the lack of support from other specialist services such as psychology, social care and welfare support leading to the CNSs spending time on non-clinical activities.

3. **Psychology support for patients**

There is no dedicated Clinical Psychology post. Patients in need of psychology support are referred to Kings, where the waiting list is notably extensive. User representatives have emphasised the crucial need for a dedicated psychology service at Croydon.

4. **Pain assessment and timely administration of pain relief:**

The most recent pain audit (audited April 2022-March 2023) showed that 69 percent of patients were given pain relief within 30 minutes of presentation with a sickle cell crisis and both patients and carers expressed concerns regarding the timeliness of pain assessment and administration of pain relief in the Emergency Department.

Trust-wide Serious Concern – adults

1. Consultant staffing

Despite the commendable efforts of the dedicated workforce; the team faced ongoing challenges stemming from inadequate consultant time to address the demand, with the workload consistently surpassing the available capacity, posing persistent obstacles for the team. The lead consultant was having to work in a manner felt to be unsustainable, with inadequate recognition in their job plan, in order to maintain the service.

2. Absence of psychology services

The lack of psychological support for haemoglobinopathy patients raised considerable concerns as it deprived them of vital mental health assistance that is crucial for managing the complexities and challenges associated with their conditions.

3. Nursing staffing:

The nursing team demonstrated unwavering dedication and commitment to adequately covering the service. Nonetheless, the continuous shortage of resources to address capacity demands created a noticeable deficit. While their dedication was apparent; the ongoing insufficiency of resources presented persistent challenges in fulfilling the needs of those under their care. The clinical nurse specialist team was having to work in a manner felt to be unsustainable, in order to deliver safe care.

4. Admission pathway:

Patients had reported very poor experiences in the Emergency Department, where they were routinely required to present for admission. The review team was informed of long waits for analgesia, lack of staff understanding and awareness of their condition or care plans, and a lack of empathy or belief in patients who reported severe pain. The team also observed that during busy periods, the queue of patients waiting to register in the Emergency Department extended outside the building, without adequate protection for patients from poor weather conditions. Patient experience in the Acute Medical Unit was also reported to be poor, with patients expressing similar concerns around a lack of specialist knowledge and empathy from staff. Delays in receiving timely treatment in the Emergency Department were also voiced, with the importance highlighted of establishing a process of prioritization and quick access for patients in crisis to the Emergency Department.

5. Financial support:

The specialised NHSE funding provided for Specialist Haemoglobinopathy Teams activities for Croydon University Hospital could not be accounted for. These monies should have been ring-fenced for haemoglobinopathy services but there was a lack of traceability and accountability in their usage.

6. Lack of Senior Management engagement:

There was a lack of engagement of senior management with the haemoglobinopathy services. Haematology sat within the Surgical directorate and the team reported a lack of prioritisation in comparison to surgical services. The haemoglobinopathy service manager role had been removed without adequate alternative cover provided, leading to a lack of support with business case preparation, strategic development, and governance activities.

Trust-Wide Concerns

Trust-wide concern – children and young people

1. Clinical Guidelines

Many of the Clinical Guidelines were unavailable or available only through the network and were out of date which may result in the latest national guidance not being implemented and the potential to obscure variation in practice. The Trust stated that there were national and relevant societies guidelines available for reference however they were not witnessed during the visit. The service lacked guidelines specifically addressing Thalassaemia despite not currently supporting any children and young people (CYP) diagnosed with the condition.

2. **No dedicated Haemoglobinopathies Social Worker post**

Having a dedicated social worker is critical for haemoglobinopathies patients as they play a crucial role in coordinating care; facilitating access to resources; and advocating for the patients' rights. The absence has resulted in unmet social needs and has impacted on the overall condition of the patient's well-being and quality of life.

Trust-wide Concerns – adults

1. Governance

Most of the leaflets and policies seen were outdated with some leaflets out of date by over a decade.

2. **No dedicated Haemoglobinopathies Social Worker post**

Having a dedicated social worker is critical for haemoglobinopathies patients as they play a crucial role in coordinating care; facilitating access to resources; and advocating for the patients' rights. The absence has resulted in unmet social needs and has impacted on the overall condition of the patient's well-being and quality of life.

Trust-wide Further Considerations

Trust-wide Further Considerations – children and young people

No further considerations to note.

Trust-wide Further Consideration – adults

No Further Consideration to note.

Views of Services users and Carers

Support Group available for patients and carers	Y/N
Sickle Cell Disease – Children and Young People	Y
Thalassaemia – Children and Young People	NA (no patients)
Sickle Cell Disease – Adults	Y
Thalassaemia – Adults	*Y*

During the visit the visiting team met with 2 paediatric patients plus their carers, and 3 adult service users, all of whom had Sickle Cell disease. In addition, the team met with one inpatient with SCD.

The views of the users were extensive and wide-ranging and are documented in the children's and adult's specialist haemoglobinopathy team section. The review team would like to thank them 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 specialised Haemoglobinopathy Paediatric team was a small team that demonstrated a remarkable level of experience, dedication, and enthusiasm working with significant staffing challenges. The team composition included the lead Consultant Paediatrician (2PAs), a Clinical Nurse Specialist (1.0 WTE) for both hospital and community services, and a Clinical Nurse Specialist (1.0 WTE) specialising in neonatal and newborn screening.

Throughout the visit, the assessment team noted the team's commendable efforts in delivering a high-quality specialist service to a substantial number of patients across hospital and community services. Additionally, they exhibited positive working relationships and a commitment to educating non-specialist colleagues. The seamless continuity of care across community and acute settings contributed to an excellent partnership between patients, the consultant, nurses, and the local voluntary support group. Service users were incredibly happy and grateful of the support they received from the specialist team.

SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE	
Croydon Health Services NHS Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)
	South East London and South East Sickle Cell HCC Thalassaemia and Rare Inherited Anaemias HCC - East London, Essex, Southeast London and the Southeast of England
	Linked Local Haemoglobinopathy Teams (LHT)

	NA

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[1]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Children & Young People	265	176	154	7	74/176	118
Thalassaemia	Children & Young People	0	0	0	0	.0	0

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual WTE (at time of visit)
Consultant haematologist/paediatrician dedicated to work with patients with hemoglobinopathies	265	2 PAs (includes 1 PA for Clinic and 1 PA for all other lead responsibilities)
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with hemoglobinopathies	265	1.0 WTE (plus 1.0 WTE neonatal and newborn screening CNS)
Clinical Psychologist for paediatric patients dedicated to work with patients with hemoglobinopathies	265	0

Urgent and Emergency Care

Patients attended the Paediatric Emergency Department (Paediatric ED) with specific flags on their electronic records indicating their haemoglobinopathy however service users reported that not all staff were aware of these flags. Additionally, the team informed reviewers that patients were aware of the necessity to disclose their Sickle cell diagnosis and were issued with a card stating that they have SCD and should receive assessment for pain relief within 30 minutes. There was no evidence of use of these cards and patients who in the focus group reported to not be aware of them. Upon arrival in ED, the pathway dictates that patients should then be triaged, and the paediatric team notified however concerns were raised by user reviewers in relation to the lack of specialist input out of hours.

For children requiring admission, they were admitted to the Rainbow Children's Unit, with patients allocated to either a general paediatric bed or a critical care bed based on their condition. In cases where patients were deemed to be in critical condition, there was a possibility of them being relocated to either the paediatric resuscitation area or the High Dependency Unit (HDU). If children needed intensive care, they were transferred out to the nearest PICU bed available. The Lead Clinician was reassuring of the timeliness of these transfers facilitated by a Consultant-to-Consultant referral but there was no formal evidence to support the timeliness of these transfers.

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

Although the Urgent and Emergency Care pathway was established, insights gathered from the patient focus groups and PREMS feedback indicate that, in practice, this pathway did not consistently function as intended. Concerns were expressed regarding the quality of care provided in the ED and timely access to pain relief. The most recent pain audit (audited April 2022-March 2023) showed that 69 percent of patients were given pain relief within 30 minutes of presentation with a sickle cell crisis.

In-patient Care

The Rainbow Children's Unit comprised of 12 general paediatric beds, 4 critical care beds, and 2 oncology beds. Additionally, there were adolescent cubicles available, along with separate play areas and a sensory room for both adolescents and younger children. Children were admitted under the care of the on-call consultant. Given the substantial cohort of paediatric patients with Sickle Cell Disease (SCD), the nursing and medical teams possessed extensive experience. Patients were also routinely reviewed by the paediatric Sickle Cell Nurse Specialist (CNS). When necessary, consultations included input from the designated paediatric Sickle Cell lead, or the HCC team at King's College Hospital. Patients requiring Patient-Controlled Analgesia (PCA) or those experiencing chest crises were accommodated in the High Dependency Unit (HDU), a critical care area within the children's unit.

Deteriorating patients underwent a three-way discussion involving paediatricians, the South Thames retrieval team, and paediatric haematologists to formulate an appropriate plan of escalation.

The Rainbow Children's Unit was equipped with a play specialist team consisting of two specialists closely collaborating with children and young people (YP). Their role involved providing support during painful procedures, acute admissions, and educational activities.

There was also a 7 bedded short stay unit.

Day care and Outpatients

The day unit featured 10 beds, catering to patients attending for scheduled blood transfusions 7 days per week.

Patients attended Willows Outpatient Clinic for Sickle Cell Clinic reviews, including appointments for new patients, routine check-ups, annual reviews, and Transcranial Doppler examinations. Paediatric phlebotomy services were co-located within the Outpatient Department.

The Sickle Clinic was led by the lead haemoglobinopathy paediatric consultant and Sickle Cell Nurse Specialist (CNS). Monthly Transcranial Doppler clinics were conducted by a Paediatric Haematology Consultant and Clinical Vascular Scientist, as part of the outreach service from King's College Hospital, with support from the lead paediatrician and Sickle CNS.

Prescription clinics for Hydroxycarbamide were conducted virtually by the lead consultant.

Community-based Care

Community-based Care was provided at the Sickle Cell and Thalassaemia Centre and was facilitated by the Clinical Nurse Specialists (CNS). The two Sickle Cell CNSs (paediatric and antenatal) conducted consultations with patients, caregivers, and couples at risk of having a child with haemoglobin disorders. Additionally, the specialist nurse had the capability to perform blood tests on adults or older children who faced challenges attending hospital phlebotomy services. The centre was supported by two administrative and data support staff (1.6 WTE).

The Croydon Sickle Cell and Thalassaemia Support Group held regular meetings at the centre, actively engaging in the education and support of patients with SCD. Monthly meetings for the babies and toddler group were also conducted at the centre, while transition workshops took place during the summer.

The Children's Community Nursing Team (Children's Hospital at Home - CHAH) played a crucial role in community-based care. They conducted blood tests, including cross-matching, for children on regular blood transfusion programs, as well as those requiring more frequent blood tests due to changes in chelation

medication dosing. Additionally, they conducted sleep studies at home for sickle patients suspected of obstructive sleep apnoea.

Views of Service Users and Carers

The review team met with two mothers of children with Sickle Cell Disease. The children were aged seven and age four. Feedback included:

1. Main access to the service is via the CNS, with no information on how to contact specialist support Out of Hours (OOH). In emergencies, the advice is to call an ambulance.
2. GPs have limited knowledge and understanding of hydroxycarbamide. Also, obtaining penicillin powder for mixing at home is a challenge via the GP.
3. Regarding vaccinations, there is a reliance on parents to report which immunisations have been administered. The hospital systems pulled through some of the notes from the GP systems however vaccination history was unclear, particularly regarding pneumococcal vaccination (Pneumovax). The information provided in the Red Book was deemed insufficient.
4. One of the carers fed back that some patients are transferred to local hospitals, such as St Helier, by the London Ambulance Service (LAS), where they perceived that care was provided by non-specialist staff.
5. There were concerns about the staff attitude in the Emergency Department (ED), with reported instances of staff not listening to parents' views and advice.
6. School Care plans are updated regularly and positive feedback on teacher training was provided.
7. Extended stays in the ED resulted in inadequate pain relief and there was a lack of awareness among reception staff who do not listen to patients.
8. Patients were flagged as having a diagnosis of sickle cell disease on the Electronic Patient Record when attending the ED, but, according to patients, the staff seemed unaware of the flags.
9. Despite challenges, service users spoke very highly of Clinical Nurse Specialists (CNS) and lead paediatric consultant.
10. During a period of penicillin shortage, there was a lack of awareness amongst the team therefore it was suggested that more information should be shared regarding medication issues.

Good Practice

1. The paediatric team demonstrated exceptional passion and maintained effective communication among its members.
2. The team's dedication and sincerity were evident, as they worked diligently to deliver the best possible service within the constraints of available capacity and resources. They exhibited a keen understanding of the patient population they served.
3. The facilities in the paediatric emergency department, outpatient areas, and wards were excellent with new and recently renovated estates.
4. The paediatric phlebotomy services were particularly outstanding and stood out as an exemplary area of good practice. The specialist team highlighted the flexibility of the phlebotomy service to meet the needs of individualised patients.
5. Support groups received positive patient feedback, as did the school visits by the CNS and the broad range of educational sessions provided.

Immediate Risk

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

Serious Concerns

1.Consultant Staffing

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

a) At the time of the visit the Lead consultant (general paediatrician with specialist interest in haemoglobinopathies) had a total of 1PA for clinical care of 265 patients, plus 1 PA for the lead role. Based on the UK Forum recommendations, the consultant staffing is significantly under-resourced. This impacted on the consultant's capacity to attend network meetings, conduct audit/research and update policies.

b) There was no evidence of future proofing across the SHT, with the lead consultant having no deputy and there were no cover or arrangements in place for absence.

2. CNS Staffing

At the time of the visit, reviewers were concerned that the service had insufficient CNS staffing.

a) There was only one CNS (1 WTE) employed to cover hospital and community services for 265 patients plus one CNS to cover neonatal newborn screening.

b) Cross cover arrangements for the Paediatric CNS's left the service extremely vulnerable. At times of sickness or absence, there was only one CNS to cover hospital, community, and antenatal and newborn screening services. This was deemed insufficient.

3. Psychology support for the service

There was no local psychology service. Patients who required psychology support were referred to the team based at Kings College Hospital which had an extensive waiting list. User representatives emphasised the crucial need for a dedicated psychology service at Croydon. Reviewers were concerned as without timely access to psychology support 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.

4. **Emergency Care and Pain Relief**

There were no available pain audit results, and both patients and carers expressed concerns regarding the timeliness of pain assessment and relief in the ED. They reported to have had experience of delays in being assessed and accessing timely analgesia. Additionally, the patient group indicated that the referral pathway was not always followed, particularly concerning the referral of patients to the specialist team.

Concerns

1. **Access to Social Worker support**
   Patients with hemoglobinopathy disorders did not have easy access to social, immigration or benefits advice. The chair of the Sickle Support Group, who had a background in social work, offered sporadic assistance with tasks like processing Disability Living Allowance forms. However, this support was provided on a voluntary and goodwill basis and clinical staff were also spending time supporting patients and their families with welfare issues.

2. **Transition to adult services.**
   There was no lead for Transition who would have oversight of the young people and to ensure that their transition passports were completed. At the time of the visit transition clinics were not taking place, although a yearly transition workshop was held. It was observed that transitional care should ideally begin early with the assistance of a dedicated coordinator.

3. **Administrative support**
   At the time of the visit the SHT had insufficient data and administrative support. This lack of data support had resulted in outdated information on the National Haemoglobinopathy Registry (NHR).

4. **Clinical Guidelines**
   Many of the Clinical Guidelines were unavailable or available only through the network and were out of date which may result in the latest national guidance not being implemented and the potential to obscure variation in practice. The Trust stated that Links to National and relevant societies guidelines were available for reference and use however these were not seen during the visit.

   The service also lacked guidelines specifically addressing Thalassaemia despite not currently supporting any children and young people (CYP) diagnosed with the condition. Despite the absence of such cases, it is essential for the service to have comprehensive local guidelines in place to ensure preparedness for any future occurrences.

5. **Competency framework**
   An up-to-date formal competency framework was not yet in place. CNS and Ward nurses had training in haemoglobinopathies but a process for assessing knowledge and ongoing competence was not in place, The SHT were planning to review and update their existing framework in line with latest RCN sickle cell and thalassemia nursing competencies and more recently published guidance.

Further Considerations

1. Consideration should be given to a review of support services, with a specific emphasis on recruitment to a Clinical Psychologist, a dedicated Social Worker, and enhancing administrative support.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

This team reviewed the healthcare services provided to adults with haemoglobin disorders at Croydon University Hospital. There were 304 adult sickle cell disease registered patients in the London Borough of Croydon, of which 183 patients received active monitoring from Croydon University Hospital. The discrepancies in the figures resulted from a significant portion of patients residing in the area being registered at other SHTs for their ongoing treatment. Additionally, there were 8 adult thalassemia patients registered and receiving treatment at Croydon University Hospital. The review involved visits to both Croydon University Hospital and the Croydon Sickle Cell and Thalassemia Centre, which is community based. The evaluation included interactions with patients, caregivers, and healthcare staff across various essential facilities such as the emergency department, the adult haematology day unit, a dedicated inpatient ward, and outpatient services. The outpatient services were available at both the main hospital and the community centre ensuring comprehensive care across different settings.

The Haemoglobinopathies service at Croydon Health Services NHS Trust was commissioned as a Specialist Haemoglobinopathy Centre in 2019 and operated within the Southeast London and Southeast HCC network (SELSE). Collaborating centres included Kings College Hospitals NHS Foundation Trust and Guys and St Thomas NHS Foundation Trust. Croydon Health Services NHS Trust provided hospital and community services across Croydon under the Southwest London Integrated Care Board.

The Croydon Sickle Cell and Thalassemia Support group had been successfully running for 35 years. The group had conducted fundraising initiatives to offer patients essential information about their condition and arranges events in collaboration with the mayor to support fundraising.

The haemoglobinopathies community pilot project, funded by NHSE for a two- year period, was in development with several new appointments recently made. Once fully active, it was anticipated that additional members of the community team would include one Matron, two Nurses, two Psychologists, one administrative staff member, and one Data Manager. The project aimed to establish dedicated psychology support and improve data management processes with oversight of the Matron.

The visiting team also heard about plans to establish an elective red cell exchange transfusion service at the trust, with a bid via the Medtech Mandate funding in progress. Capital support for the procurement of an apheresis machine had already been secured. At the time of the visit, there was no plan to be able to provide out of hours emergency automated red cell exchange transfusion.

Lead Consultant, and Deputy lead Consultant for the service, demonstrated commendable dedication to their patients and the specialised service, alongside their team.

CARE OF ADULTS	
Croydon Health Services NHS Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)
	South East London and South East Sickle Cell HCC Thalassaemia and Rare Inherited Anaemias HCC - East London, Essex, Southeast London and the Southeast of England
	Linked Local Haemoglobinopathy Teams (LHT)
	NA

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[1]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Adults	304	183	306/384	15	47/75	146
Thalassaemia	Adults	8	8	Takes place at Tertiary centres as care is shared	2	N/A	0

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

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/ WTE (at time of visit)
Consultant haematologist dedicated to work with patients with hemoglobinopathies	191	5 WTE *
Clinical Nurse Specialist for adult patients dedicated to work with patients with hemoglobinopathies with the hospital and community	191	1 WTE
Clinical Psychologist for adult patients dedicated to work with patients with hemoglobinopathies	0	0

*There are five haematology consultants however there was no dedicated HBO clinic /ward round time etc, therefore the proportion of time allocated to HBO services could not be clearly delineated.

Emergency Care

All adult patients with haemoglobinopathies requiring urgent review or admission arrived via the Emergency Department (ED), where they underwent registration, triage, and initial evaluation. It was noted at the time of the visit that there was only one person carrying out initial registration, and prior to this, patients were required to wait in a queue which could extend out of the main entrance doors during busy periods. This led to patients waiting outside the building, including in poor weather conditions, without adequate provision for shelter. Haemoglobinopathy patients did not have alert cards, flags on their electronic records, or any way in which ED reception and triage could be alerted to their need to be seen quickly.

Depending on the severity of their presentation, patients were either reviewed in the Majors or Resus area. There was an algorithm set for medications used in acute pain management set up in the ED which staff were familiar with and which was quick and simple for them to use. An ED guideline for the management of sickle cell-related emergencies was available, although had not been reviewed since 2015. There were no ED guidelines relating to the management of acutely unwell individuals with thalassaemia.

Following stabilisation, care was taken over by the on–call general medical team and subsequently patients were referred to the haematology team. During periods of high bed occupancy, patients often spent over 24 hours in ED whilst awaiting a bed on the Acute Medical Unit or Haematology ward. Access to 24–hour haematology advice was readily available for clinical support, with ED staff reporting the on-call haematologists to be reliably accessible and approachable. Review by a senior haematology decision maker usually occurred within 14 hours of admission but could be longer for patients presenting over a weekend.

Feedback from service uses indicated that the pathway in ED did not operate smoothly with prolonged waits to be seen and delays in administration of analgesia were reported. The patient group also indicated that the referral pathway was not appropriately utilised in ED specifically concerning the referral of patients to the Haematologists upon their arrival in the ED. Further information on patient experience will be provided below in the appropriate section.

Inpatient Care

Patients requiring in–patient care could be admitted either to the Acute Medical Unit, which comprised of 6 male and 6 female beds and 6 side rooms, or directly to the Fairfield 2 ward, contingent upon bed availability. The Fairfield 2 Ward served as a designated haematology ward featuring 3 bays with 6 beds each and 3 side rooms. Following referral to the haematology team, efforts were made to transfer the patient to Fairfield 2 Ward promptly. Once admitted, patients were seen regularly by the haematology team including a daily review by a specialist nurse throughout the admission.

In the event of a clinical deterioration the critical care outreach team assessed the patient with the option to access the High Dependency Unit (HDU) and Intensive Care Unit (ICU) facilities if necessary. Patients with haemoglobinopathies necessitating admission for other conditions would be directed to the relevant wards by the corresponding teams, with input from the haematology team. Additionally, 24- hour haematology advice was available through the on–call haematologist.

Day Care and Outpatients

The Neil Hawkins Lifeblood Suite Haematology Day Unit catered for patients with general haematology, haemato-oncology and haemoglobinopathy conditions, as well as internal medicine. The unit was equipped with 7 reclining chairs and 2 side rooms and was staffed by 4 nurses and 1 administrator. At the Haematology Day unit patients with Haemoglobinopathies including sickle cell disorder, thalassaemia major, and thalassaemia intermedia received various treatments including transfusions and manual exchange transfusions. Haematology consultations and clinical review by a haematologist was also conducted as required on the day unit.

The facilities on the Day Unit were good, with spacious and well-equipped areas, and experienced staff. Transfusion services were offered Monday – Friday, 08:00 am-17:00 pm, with no option for evening or weekend transfusion.

Outpatient care for haemoglobinopathy patents was delivered in the main outpatient's department of Croydon University Hospital. Patients were seen in generic haematology clinics rather than dedicated haemoglobinopathy clinics and were seen by any of the 4 haematology consultants or specialty registrar. The Clinical Nurse Specialist was also variably available to support clinic appointments. Each week the haematology outpatient clinics offered 25 slots for new patients and 146 slots for follow – up patients, across the whole of haematology.

The Haemoglobinopathy Clinical Nurse Specialist for adults conducted dedicated annual review clinics in the main outpatient department twice a week, with a total of 4 slots per week. During these clinics, annual reviews for Haemoglobinopathy patients were carried out in collaboration with the designated Haematology Consultant for each patient.

The environment in the outpatient clinic was clean and bright. The strategic proximity of the outpatient clinic and phlebotomy services was perceived as advantageous as patients could conveniently access blood tests without extensive walking following their clinic appointments. It was observed that important SCD information was prominently displayed on the walls of the department, ensuring easy access for patients.

Additionally, there were monthly twilight clinics at the Sickle Cell and Thalassemia Centre, held on Mondays from 5pm to 8 which provided consultations to patients with sickle cell disease and monitored patients receiving hydroxycarbamide treatment. Couples at risk of having a child with a haemoglobin disorder received consultations on a weekly basis at the Sickle Cell and Thalassemia Centre.

Community-Based Care

Community-based care was delivered at the Sickle Cell and Thalassaemia Centre within Thornton Heath, a component of Croydon Health Services. The CNSs for Sickle Cell and thalassaemia conducted consultations with patients, caregivers, and couples at risk of having children with haemoglobin disorders.

During the visit a service user recalled an episode when the Nurse Specialist accompanied her to attend a GP appointment as she was not receiving repeat prescriptions and her condition was not appreciated by the practice.

Views of Service Users and Carers

Two adult sickle cell patient representatives attended the meeting; and one patient from the in-patient ward but there were no representatives of patients with thalassaemia present. They spoke highly of the care provided by the doctors and nurses, praising the team's dedication. They had a few concerns and highlighted good practice. These are described below:

1. Service users spoke about being able to contact the service directly, with the assurance that someone was consistently available by phone to offer support and advice at the community centre, within hours. This provided them with not only comfort but also invaluable relief.
2. Concern was highlighted around the ED flow. It was reported that haemoglobinopathy patients were experiencing long waits in the ED to receive initial assessments and appropriate analgesia. Frustration was also expressed about the referral system in ED; sharing an anecdote where they spent over 24hours in the ED without a referral being made until a haematologist coincidentally saw them the following day. However, they commended the proactive approach of the haematology nurses and doctors noting that they often personally checked on their patients in the ED without relying solely on referrals. Additional remarks from a patient included concerns that patients were fearful and reluctant to visit the ED due to poor staff attitudes observed in both the ED and Acute Medical Unit (AMU). These attitudes included staff's lack of

awareness regarding the presence or accessibility of the patient's care plan, a deficiency in empathy, and instances where patients feel disrespected and unfairly labelled as 'drug-seekers'. The patient further reported submitting numerous complaints through PALS (Patient Advice and Liaison Service) but did not receive satisfactory feedback. Additionally, the patient expressed feeling disbelieved when they presented with pain.

3. They voiced their desire for a system that saw them receiving priority in the Emergency Department when they arrived in a crisis. They were unaware of the Sickle Cell Society cards.
4. One of the patients expressed some difficulty she was having with her General Practitioner (GP) and shared her gratitude to the nursing team who accompanied her to the GP practice to speak with the GP after her discharge from hospital.
5. Concern was expressed that when patients visited the ED with symptoms of pain not associated with their condition, it was felt that their complaints were not heard. It was noted that all pain experienced was almost always attributed to their existing condition, and therefore, the causes of new pain symptoms were not thoroughly investigated.
6. The patients reported issues and concerns with the knowledge and understanding of the Emergency Department and Acute Medical Units staff had around their condition and treatment. They confirmed that once on the Fairfield 2 (Haematology designated) ward they felt safe and comfortable with the knowledge of the staff.

Good Practice

1. The Team consistently showcased outstanding dedication. Both the nursing and medical teams demonstrated exceptional commitment to the service and patients.
2. The Clinical Nurse Specialist (CNS) had implemented an after-hours 'twilight' clinic for patients who were generally well and were in employment or education. They had identified that this group of patients often experienced difficulties in getting time off to attend their appointments and feedback was that they valued this flexible approach.
3. The team had established a focus group looking at enhancing the ambulance services response and treatment of haemoglobinopathy patients. The group were due to have their first meeting on the 23rd of February 2024 with the ambulance service.
4. The teams had close working relationships with the Croydon Sickle Cell and Thalassemia support group and were active in supporting public fundraising and public awareness to haemoglobinopathies.
5. Strong partnerships existed between acute and community services to provide an integrated approach to the care of patients with haemoglobin disorders.

Immediate Risks

No immediate risks were identified during the visit.

Serious Concerns

1. **Consultant staffing**

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

   The lead consultant had time allocated in their job plan for their SHT lead role; but in practice it was utilised for direct clinical care.

   The review team were told that recruitment to an additional substantive consultant post had been unsuccessful An Agency locum was hired in the haematology to meet the demands of the outpatient clinic. There was uncertainty about the duration of the tenure due to the short notice of cancellation

The lack of doctors in training to support the haematology service further increased the pressure on the consultant body who were required to fill roles and complete tasks which would normally be undertaken by doctors in training.

2. **Access to Psychology**

   The lack of psychology services for haemoglobinopathy patients was of concern regarding their comprehensive care and overall well-being. Patients requiring specialised haemoglobinopathy psychology input were reportedly referred to the psychology services at Guys and St Thomas' NHS Foundation Trust or St George's University Hospitals NHS Foundation Trust, but in practice, the referral pathway was not utilised due to both services having lengthy waiting list for consultations. Reviewers were concerned as without timely access to psychology support 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.

3. **CNS Nurse Staffing**

   At the time of the visit, reviewers were concerned that the service had insufficient CNS staffing to cover the care of 191 patients across the acute and community services. This was compounded by the lack of support from other specialist services such as psychology, social care and welfare support leading to the CNS spending time on non-clinical activities and outside of the remit of her role.

4. **Emergency Department Pathway**

   Patients who met with the reviewing team reported a lack of prioritisation of haemoglobinopathy patients attending in the ED during emergencies and in the Acute Medical Unit. They experienced delays in being assessed and accessing timely analgesia. Additionally, the patient group indicated that the referral pathway was not always followed, particularly concerning the referral of patients to the Haematologists upon their arrival in the ED. Upon arrival at the Emergency Department (ED), all adult patients with haemoglobinopathies requiring urgent review or admission underwent registration, triage, and initial evaluation. It was observed during the visit that there was only one person handling initial registration. Prior to this process, patients had to wait in a queue that could extend beyond the main entrance doors during busy periods, leading to patients waiting outside the building, sometimes in poor weather conditions, without adequate shelter. Haemoglobinopathy patients did not possess alert cards, flags on their electronic records, or any mechanism to alert ED reception and triage staff to their need for prompt attention.

   Depending on the severity of their presentation, patients were reviewed either in the Majors or Resus area. An established algorithm for medications used in acute pain management within the ED was known to staff, who found it quick and simple to use. Although an ED guideline for managing sickle cell-related emergencies was available, it had not been reviewed since 2015. Furthermore, there were no ED guidelines concerning the management of acutely unwell individuals with thalassaemia.

Concerns

1. **Access to Information**

The leaflets distributed both on the wards and the community centre were found to be outdated. Some of them were over a decade old containing incorrect and obsolete information.

2. **Transition**

There was a lack of clear transitional care provided. There was no lead for Transition who would have oversight of the young people and to ensure that their transition passports were completed. At the time of the visit transition clinics were taking place, with the next one planned for March. They have been run jointly with the Paediatric and Adult leads and the Paediatric and Adult CNS- clinics take place twice per year.

Although a yearly transition workshop was held. It was observed that transitional care should ideally begin early with the assistance of a dedicated coordinator.

3. **Guidelines**

There was a lack of up-to-date trust or network haemoglobinopathy guidelines. This may result in the latest national guidance not being implemented locally and obscure variation in practice. The trust stated that there were national and relevant societies guidelines available, they were not witnessed during the visit. In addition, there were few guidelines in place for the care of patients with Thalassaemia. Shared care arrangements with tertiary centres were in place however the lack of access to guidance for this group of patients may result in the latest national guidance not being implemented locally.

4. **Access to welfare and benefits support**

Patients with haemoglobinopathy disorders did not have easy access to social, immigration or benefits advice and clinical staff were also spending time supporting patients and their families with welfare issues.

5. **Support for research**

The SHT did not have any support from the Trust research department to undertake haemoglobinopathy clinical trial activities either locally or those agreed by the HCCs. This had resulted in the lead haematology consultants having to spend time conducting eligibility screening and consent processes, so that local patients would have access to important clinical trial entry.

6. **Lack of Competency framework**

An up-to-date formal competence framework was not yet in place. CNS and Ward nurses had training in haemoglobinopathies but a process for assessing knowledge and ongoing competence was not in place. The SHT were planning to review and update their existing framework in line with latest RCN sickle cell and thalassemia nursing competencies and more recently published guidance.

Further Considerations

1. The plans to set up an elective automated red cell exchange service at Croydon University Hospital did not appear feasible in terms of nurse staffing. The funding bid was anticipated to include one additional nurse to run the service, without adequate plans for support or cover for absences, which reviewers considered would not be sustainable. There was also no plan in place to provide out of hours emergency automated red cell exchange, which is a recommended service.
2. Reviewers considered that the reorganisation of haematology outpatient clinics to allow specialist haemoglobinopathy clinic set up may streamline provision of specialist outpatient services, for example by allowing the CNS to plan availability around a set clinic time and would also assist with monitoring of activity levels.
3. Provision of out of hours transfusion and phlebotomy services could be considered, to improve patient convenience.
4. Feedback from patients with Thalassaemia: the service had not conducted a patient experience feedback exercise for their patients with thalassaemia. Reviewers considered it would be important, to receive feedback on their views of local care as well as their experience of their shared care provision with other centres.

Commissioning

The review team had discussions with the regional NHS specialist commissioner and the local commissioner from NHS South London ICB. Several of the issues in this report will require the active involvement of the Trust leadership team and commissioners to ensure that timely progress is made.

The review team identified the below considerations:

1. A long-term strategy for the provision of the service should be developed and agreed across the system by commissioners, trust executives, the speciality team and service users. This should include plans for expansion and implementation of specialist roles as detailed in the report.

2. Funding for the 2-year community pilot project had been agreed but there was no assurance of ongoing support beyond this period. This prohibited the appointment to substantive positions within the project, and it was considered that this may limit success in recruiting and retaining the required members of staff.

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Appendix 1 - Membership of Visiting Team

Visiting Team		
Doreen Richards	Specialist Nurse practitioner	Nottingham University Hospital
Sandy Hayes	Adult Haemoglobinopathy Senior Specialist Nurse	
Indu Thakur	Consultant Paediatric Haematologist	Cardiff and Vale University Health Board
Anna Dillon	Consultant Paediatric Haematologist	Children's Health Ireland
Sarah McDonald	Paediatric Haemoglobinopathy Nurse Educator	Royal Manchester Children's Hospital
Victoria Barton	ANNB screening lead	East and North Herts NHS Trust
Rosie Peregrine-Jones	Assistant Director of Quality	North Central London ICB
Romaine Maharaj	User Representative	United Kingdom Thalassaemia Society
Sabrina Emanuel-Malins	User Representative	Liverpool Sickle Cell and Thalassemia Support Group

Clinical Lead		
Clare Samuelson	Consultant Adult Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust

MLCSU Team		
Rachael Berks	Clinical Lead	Nursing and Urgent Care Team - MLCSU
Samantha Singh	Clinical Lead	Nursing and Urgent Care Team - MLCSU

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Appendix 2 - Compliance with the Quality Standards

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

Percentage of Quality Standards met

Service	Number of Applicable QS	Number of QS Met	% Met
Specialist Haemoglobinopathy Team (SHT) Children and Young People	49	22	48%
Specialist Haemoglobinopathy Team (SHT) Adults	45	17	40%

Specialist Haemoglobinopathy Team for Children and Young People with Haemoglobin Disorders

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-102	**Information about Haemoglobin Disorders** Children, young people and their families should be offered written information, or written guidance on where to access information, covering at least: a) A description of their condition (SCD or Th), how it might affect them and treatment available b) Inheritance of the condition and implications for fertility c) Problems, symptoms and signs for which emergency advice should be sought d) How to manage pain at home (SCD only) e) Transfusion and iron chelation f) Possible complications g) Health promotion, including: i. Travel advice ii. Vaccination advice h) National Haemoglobinopathy Registry, its purpose and benefits i) Parental or self-administration of medications and infusions	Y	
HC-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	Y	
HC-104	**What to Do in an Emergency?** All children and young people should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents [SCD and Th] c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health (if appropriate) d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HC-106	**Information about Transcranial Doppler Ultrasound** Written information should be offered to children, young people and their families covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	Y	
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.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	Y	
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	N	There was no named coordinator for transfer of care.
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	PREMS Sickle children and carers survey had been undertaken in 2023 with responses from 38 parents and 40 children and YP. The team did not have any patients with Thalassaemia under their care.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	Y	
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	There was a lead for the SHT who had 1 PA allocated for SHT leadership however there was no deputy in place and arrangements for cover of absence.
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 lead nurse did not have time for their leadership role. 1.0 WTE Paediatric CNS in post to cover acute and community. 1.0 WTE Antenatal and newborn screening nurse. Cross cover arrangements for clinical care were from the antenatal and newborn screening but not for leadership of the SHT.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The lead nurse did not have time for their leadership role. 1.0 WTE Paediatric CNS in post to cover acute and community. 1.0 WTE Antenatal and newborn screening nurse. Cross cover arrangements for clinical care were from the antenatal and newborn screening but not for leadership of the SHT.
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	On call system in place with option of escalation out of out of hours to consultant on call via the 24hr HCC on call advice provision
HC-206	**Doctors in Training** If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders.	Y	
HC-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	A competence framework was not in place. Educational sessions however were provided by the team for a wide audience of healthcare providers (including schools) in haemoglobinopathies and HD management.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	There was no access to psychology. Patients could be referred to the service at Kings College Hospital NHSFT.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A	TCD were undertaken by the network wide service
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	The team had insufficient admin/data collection support to ensure that NHR data was up to date. Bank staff provided some support with data
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	'a' not met as there was no access to a social worker. The Chair of Sickle Support Group provided ad hoc support to process DLA forms and other benefits

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	'e,f,g' were not met Patients who required manual and automated red cell exchange were referred to PICU. There was no access to a pain team for children under 16 years Level 2 critical care only. Patients who required access to Level 3 Critical care were transferred to Evelina Children's Hospital.
HC-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders.	N	In house training was provided however feedback from patients (PREMS feedback, patient focus group feedback) was that ED staff did not appear to have sufficient knowledge and competences in the urgent care of children and young people with haemoglobin disorders, Patients also raised concern regarding timeliness of pain relief being administered. No pain audit results were seen by reviewers.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HC-195)	Y	Guidelines were in place however there was no 'allocated coordinator for transfer of care'.
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.	N	Guidelines did not cover patients with thalassaemia which should be in place even though at the time of the visit the team were not caring for any CYP with Thalassaemia All other aspects were met for those with sickle cell disease

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Arrangements for accessing staff with cannulation competences f. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion g. Patient pathway for Central Venous Access Device insertion, management and removal	N	The policies were generic and not up to date. There were no specified timeframes for cannulation or transfusion procedures; and there was a lack guidance covering transfusions for those with thalassaemia
HC-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: Indications for chelation therapy a. Choice of chelation drug/s, dosage and dosage adjustment b. Monitoring of haemoglobin levels prior to transfusion c. Management and monitoring of iron overload, including management of chelator side effects d. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 e. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible	Y	

Ref.	Quality Standards (Children)	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 e. Indications for discontinuation	Y	
HC-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	N	Guidelines were not seen covering the requirements of the QS
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	Guidelines were out of date and incomplete and did not cover ‘h,l,j &m’.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-510	**Clinical Guidelines: Chronic Complication** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea f. Endocrine and growth problems, including endocrinopathies and osteoporosis g. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology h. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease i. Growth delay / delayed puberty j. Enuresis k. Urological complications, including priapism l. Dental problems	N	National UK Sickle Cell Society Guidelines were in use but these had not been adapted to cover local management.
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.	N	Guidelines were in place but were out of date.
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.	N	Many of the guidelines were out of date, not locally ratified or incomplete.

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HC-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HC-503) d. National Haemoglobinopathy Registry data collection (QS HC-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HC-607) (if applicable) g. Participation in HCC-agreed audits (HC-706)	N/A	The SHT did not have any linked LHTs
HC-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when required, representatives of support services (QS HC-301).	Y	
HC-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of children and young people with haemoglobin disorders b. Two-way exchange of information between hospital and community services	N/A	Combined healthcare trust
HC-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each SCD HCC Business Meeting (QS HC-702).	N	There was no evidence to show that a representative attended each of the SELSE HCC meetings.
HC-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HC-702).	N	There was no evidence to show that a representative attended each of the East London and South East Thalassaemia and RIA HCC meetings

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-608	**Neonatal Screening Programme Review Meetings** The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results, identify issues of mutual concern and agree action.	N	Agenda seen but not evidence to show that the SHT attended
HC-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	N	Insufficient data support meant that not all patients had been entered on to the NHR
HC-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions	N	Audits covering 'a' and 'b' had not been completed
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS HC-702d).	Y	
HC-707	**Research** The service should actively participate in HCC-agreed research trials.	N	No evidence
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	No evidence of patient survey results/audits being discussed with patient representative

Ref.	Quality Standards (Children)	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	Guidelines were out of date/overdue review.

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Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-101	**Haemoglobin Disorder Service Information** Written information should be offered to patients and their careers, and should be easily available within patient areas, covering at least: a. Brief description of the service, including times of phlebotomy, transfusion, and psychological support services b. Clinic times and how to change an appointment. c. Ward usually admitted to and its visiting times. d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: I. Contact the service for help and advice, including out of hours. II. Access social services III. Access benefits and immigration advice IV. Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent) V. Give feedback on the service, including how to make a complaint VI. Get involved in improving services (QS HA-199)	**N**	No written information addressing the highlighted points from a to g. Furthermore, leaflets found on the ward were outdated and contained incorrect information

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-102	**Information about Haemoglobin Disorders** Patients and their carers should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	**Y**	
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	**Y**	
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	N	There was no clear evidence indicating that information had been shared with the primary health team. Feedback from a patient representative revealed that she had experienced hospitalisation because of the challenges in receiving her repeat prescription from her GP. Another expressed difficulty in obtaining penicillin during a shortage when attempting to refill their prescription; and the primary care team not understanding the urgency.
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	N	There was no evidence of the 'transition passport' being available on site for either thalassemia or SCD patients. Additionally, there was no designated lead/coordinator for transition. There was verbal discussion of a yearly transition workshop that occurred; however, there was lack of evidence regarding the attendance numbers. It was positive to observe that consultants do not hastily transfer care until both the patient and their family feel prepared for the transition

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	N	Although information regarding SCD survey was available; there was no evidence of thalassemia surveys being conducted. Additionally, while a generic patient feedback form was seen at the community centre; none of the staff present were certain whether it was actively being utilised.
HA-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback b. Mechanisms for involving patients and their carers in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HA-797) c. Examples of changes made as a result of feedback and involvement	N	Only the Sickle Cell Society survey had been undertaken and no other evidence was noted. No results were presented from the friends and family survey making it difficult to determine if it was conducted. Neither patients nor carers were who met with the reviewing team were aware of any additional feedback process. A patient shared their experience of submitting multiple complaints without receiving any response suggesting a lack of a robust process in place.
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.	**Y**	
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	**N**	There were four substantive consultants in post and one locum covering a vacancy. The lead consultant had time allocated in their job plan for this lead role; but in practice it was utilised for direct clinical care. Ward rounds and clinics cover all areas within haematology rather than being haemoglobinopathy-specific, consequently, it was challenging to ascertain the specific amount of time allocated and utilised for haemoglobinopathy activities. However, it was clear that the medical team were understaffed and overall had insufficient time to deliver the haemoglobinopathy specialised services.
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	**Y**	
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	**Y**	
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	**N**	The SHT did not have any Psychology staff for the care of haemoglobinopathy patients and that patients are referred to either Guys and ST Thomas' Hospital NHSFT or St George's Hospital NHSFT. Staff commented that the referral pathway was not in use due to the long waiting times to be seen.
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**	Inadequate cover for the service 1.6 WTE support covered the community Adult; Paediatrics' and antenatal services and 0.8 WTE post was vacant

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	**N**	Patients did not have easy access to a social worker or benefits adviser available to provide access to advice specifically tailored to haemoglobinopathy patients. All other aspects of the QS were met.
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**	Patients did not have access to automated red cell exchange and were either referred to Kings College Hospital or St George's Hospital; or they are directed to St Thomas hospital, if they were capable of travelling. Although there were plans to implement an apheresis service this would not be 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**	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	**N**	There was no indication of nurse training occurring in the Emergency Department (ED). A teaching timetable was seen for the medical staff.

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	**N**	None of the policies were up to date. There were no specified timeframes for cannulation or transfusion procedures; and there was a lack guidance covering transfusions for those with thalassaemia.
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	**N**	There were no guidelines in place.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring of complications e. Indications for discontinuation	**N**	BSH guidance had been adopted but not adapted for local use. The network document was being updated and was not available.
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	No guidelines in place
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	N	Guidelines did not cover all the requirements of the QS.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-510	**Clinical Guidelines: Chronic Complications** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Pulmonary hypertension f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea g. Endocrine problems, including endocrinopathies and osteoporosis h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology i. Chronic pain j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease k. Urological complications, including priapism and erectile dysfunction l. Dental problems	**N**	There were no guidelines for thalassaemia. All aspects were met for SCD
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**	No Guidelines covering Thalassemia and the SCD guidelines were out of date.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	**N**	No local guidelines or pathways were in place
HA-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	**N**	The policy had been updated in 2024 but was still in draft form. The service organisation policy was from 2012 and not reflective of the current service.
HA-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HA-503) d. National Haemoglobinopathy Registry data collection (QS HA-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HA-607) (if applicable) g. Participation in HCC-agreed audits (HA-706)	**N/A**	The SHT did not have any linked LHTs

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when requested, representatives of support services (QS HA-301).	**Y**	
HA-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services	**N/A**	
HA-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each Sickle Cell Disorder HCC Business Meeting (QS HA-702).	**N**	Team was not able to attend meetings due to clinics running at the same time and other clinical activities.
HA-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HA-702).	**N**	No evidence seen of a representative attending meeting
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**	No evidence or data to suggest either audit had been completed.
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	**Y**	
HA-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HA-197) compared with other services c. Results of audits (QS HA-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	**N**	'c' was not met as no audits had been conducted.
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**	All observed documents were outdated and a few of the documents had outdated advice. Some of the documents more than a decade out of date.