MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

South East London and South East Sickle Cell Haemoglobinopathy Coordinating Centre

King's College University Hospital NHS Foundation Trust

Visit Date: 24th January 2024

Report date: 11th July 2024

Contents

Introduction

This report presents the findings of the review of King's College University Hospital NHS Foundation Trust that took place on 24th January 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:

- Haemoglobinopathy Coordinating Care Centre
- 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 King's College University Hospital NHS Foundation Trust. 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:

- Kings College University Hospital NHS Foundation Trust
- NHS England - London
- NHS South East 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 England - London and NHS South East 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 South East London 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

South East London and South East (SELSE) Sickle Cell Haemoglobinopathy Coordinating Centre

Introduction

This review looked at the co-ordination of health services provided for children, young people and adults with sickle cell disorders across South East London and South East. The HCC had close links with the West London Thalassaemia and Rarer Anaemias HCC led in partnership with University College London Hospitals NHS Foundation Trust and Imperial College Healthcare NHS Trust and NHS East London Thalassaemia and Rarer Anaemias HCC based at Barts Health NHS Trust.

King's College NHS Foundation Trust (KCH) in partnership with Guys and St Thomas' NHS Foundation Trust (GSTT) had been designated a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell disease in 2020 and was working in collaboration with two other Specialist Haemoglobinopathy Teams (SHT): University of Lewisham NHS Foundation Trust (Lewisham University Hospital and Queen Elizabeth Hospital), Croydon Health Services NHS Trust, and six local Haemoglobinopathy Teams (LHT) with varying patient populations of people with haemoglobin disorders in the region that were engaged with the HCC. There was clear evidence of cohesive working and partnership between KCH and GSTT in leading the HCC agenda.

As part of the review, reviewers observed a business meeting with staff from Lewisham and Greenwich NHS Trust and Croydon Health Services NHS Trust SHTs

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

- Clinical Lead for the HCC (1 PA)
- Deputy Lead for the HCC (1hr)
- HCC Network Manager (1 WTE)
- HCC Transcranial Doppler Lead
- Paediatric Clinical Lead for children, young people (0 PA)
- Education Lead (0.6 WTE)
- HCC network Coordinator (1 WTE)
- Data Coordinator (0.4 WTE)

The SELSE HCC had evolved from the South Thames Sickle Cell and Thalassaemia Network (STSTN) which had been in operation for a number of years and therefore relationships across the network were well established.

In addition to monthly strategy meetings, the HCC held regular business meetings during the year open to the whole HCC; SHTs, LHTs, commissioners and HCC patient representatives. As part of these meetings the annual programme of work and audit programmes were discussed and reviewed. Meetings were held remotely to promote engagement across the region. The specialist services quality dashboard data for HCCs and SHTs was monitored, and overall compliance included in the HCC annual report. The HCC had completed an audit of Transcranial Doppler ultrasound competences during the previous 12 months and an annual time to analgesia audit across the network. The business meeting observed during the visit had a set agenda part of which included updates from the participating SHTs.

The HCC had identified five key areas on their action plan; user involvement; access to apheresis, improving the time patients waited for analgesia in an emergency, formalising SLAs with the LHTs and the work to implement a community hub for patients residing in south London.

The HCC MDT was working effectively with evidence demonstrating the discussion of serious adverse events, length of stay for inpatients, the number of patients entered onto the NHR and the proportion of patients referred for gene therapy and haematopoetic stem cell transplantation. The Specialist Services Quality Dashboard (SSQD) data for SHTs was also discussed. The HCC monthly regional sickle cell multidisciplinary meetings had discussed a total of 142 cases between April 2021 and March 2022 with the 12 being the average attendance at these meetings. More complex patient cases were referred to the National Haemoglobinopathy Panel MDT.

The HCC had established mechanisms in place for involving patient and carers in strategy development and delivery of education.

There was an active and cohesive teaching programme. A red cell training day was held on a bi-annual basis aimed at specialist trainees and regional study days were held open to all stakeholders. An 'e' learning package developed by Kings Health Partners-Haematology was in the process of being rolled out to other stakeholders across the network. The SELSE HCC website had been re-launched and the HCC education lead had also begun to identify training needs for across the HCC. The lead for education also held an HCC Nursing Forum. There was an annual network staff and patient education and awareness day held remotely to enable users to attend from across the wide geographical footprint of the network, and including patient voice, with a short patient interviews for each topic (birth to old age, with interviews with parents of newborn with SCD, pregnant woman with SCD, an adult on red cell exchange programme, an adult who had completed a stem cell transplant, a patient on a clinic trial, an older patient discussing challenges with ageing).

The network manager had only been in post since October and was the fourth manager since the HCC was commissioned in 2020. Other HCC staffing had been relatively stable.

There was very good commissioner involvement with the HCC. Commissioners had been very engaged with the community hub development and supporting the emergency bypass model project.

SELSE HCC had an extremely active clinical research programme with several clinical trials running across the network.

Good Practice

1. The work across the HCC and commissioners to develop a community hub was impressive. The new model would build existing community services provided in south London and focus on long-term community support with enhanced benefits officers, psychology service, community pharmacist, dietician, and physiotherapy, as well as post discharge review to prevent re-admission and crisis avoidance for adults and children with sickle cell disease, including school care plans and liaison. The community hub once implemented would be available to all patients across the SELSE HCC network boundaries..
2. The e-learning module was very good and had been developed by the Kings Health Partnership (KHP) with embedded co-produced staff and patient videos to educate staff in an approachable and interactive manner. Reviewers were very impressed with the patient educational animated video about priapism.
3. The e-learning, module had been successfully rolled out as mandatory learning for patient facing staff in the Haematology at both the KCH and GSST sites including emergency and paediatric departments, with red sickle pin badges being awarded to the first 100 to successfully completed the module.
4. Reviewers were impressed by the work being undertaken across the HCC to develop an Emergency Department admission bypass pathway, which had the support and funding from the South London ICB and NHSE London.
5. The HCC Red Cell Newsletter was very good, the format was very clear, and it covered a wide range of information and topics, including patient testimonials. Reviewers were impressed that the HCC was able to produce such a high standard of newsletter four times a year.

Immediate Risks None were identified during the visit.

Concerns

1 HCC Leadership time

The nominated lead had insufficient time for their HCC leadership as well as other clinical commitments considering size and extent of the HCC. The deputy for the HCC had only 1 hour per week allocated for their HCC deputy lead activities. Formalising and recognition of the time needed within job plans for HCC leadership will be necessary to ensure sustainability of the HCC

2 24hr Advice across the HCC

A formalised 24hr network advice service had not yet been possible. In practice there were some informal processes for accessing advice. Reviewers were told that achievement of this was part of the 2023/24 HCC work plan.

3 LHT Support

Representatives for the LHTs who spoke to the reviewers reported that they were supported in terms of accessing advice from their SHTs but were struggling to provide services with an ever increasing population of adults, children, and young people with haemoglobin disorders. It was not clear about what actions the HCC had planned to support the LHTs particularly those outside of London.

4 Consultant Workforce across the HCC

With the shortfalls in consultant in workforce across the HCC. The HCC should consider including consultant succession planning to the work programme to ensure the sustainability of services for the future.

5 Apheresis Capacity

Reviewers were concerned about the waiting lists for patients due to the lack of capacity for automated red cell exchange apheresis for patients across the network with several trusts actively submitting bids to expand their services. Reviewers were concerned that the lack of capacity would become more marked with the increase in the number of service users likely to continue year on year that oversight by the HCC will be important to provide ongoing support and working with services to improve access.

6 Liaison with commissioners outside of London

There was very little or no engagement from ICBs responsible for covering the many LHTs outside of central London. As commissioning arrangements change over the next few years these relationships will be crucial to the provision of appropriately staffed services for patients and HCC involvement and advocacy will be key. The development of service level agreements with LHTs/ ICBs could have the potential to ease the commissioning transition planned for 2025.

Further Consideration

1. The HCC did not have a service operation policy covering the MDT process for reporting serious incidents. In practice serious incidents were reported and discussed at each MDT meeting.
2. The HCC PREMS had stated that each SHT had identified a quality and improvement project from their results at the time of the visit this was still work in progress and had not been identified in latest HCC work programme
3. The LHTS did not have any support to register patients on the national haemoglobinopathy register (NHR) The latest NHR reports identified that details on NHR were only updated by the SHT team after the patients annual review

4. Governance processes could be improved. Some documentation seen by the reviewers did not have version or review dates included or they were out of date. There did not appear to be a coherent document management policy/protocol. Not all meeting minutes of meetings had a list of attendees, apologies and attending organisation. Some of the minutes seen appeared to be a completed transcript of the conversations held during meetings which was necessary in view that the minutes were shared with stakeholders.
5. There was clear ambition and collaborative working aimed at the delivery of holistic care for their patient group however reviewers were concerned at the amount of administrative time this was taking to oversee multiple bids and projects for the small clinical and managerial workforce of the HCC. Important will be ensuring that bids for additional funding acknowledge the HCCs ongoing input in both time and fiscal terms.

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Review visit findings

King's College University Hospital NHS Foundation Trust

Trust-wide

General comments

This review looked at the health services provided for children, young people and adults with haemoglobin disorders. During the course of the visit, reviewers met with 12 patients, parents and carers, and with staff providing the services and visited the Emergency Department, day units and wards for both adults and children's services.

King's College Hospital NHS Foundation Trust provided specialist care for patients across a breadth of specialities from birth and throughout their lifespan. The hospital was also part of King's Health Partners (KHP) a partnership with Guy's and St Thomas' NHS Foundation Trust and South London and the Maudsley had formed the King's Health Partners (KHP) and an Academic Health Sciences Centre (AHSC), one of five AHSCs in the country.

At the time of the review there was a high prevalence of sickle cell disease in the local population and 1576 patients (adults and Children) were registered on the National Haemoglobinopathy Registry for the Trust.

The Haematology Departments worked collaboratively with the department at Guy's and St Thomas', and together were known as KHP Haematology, and were appointed jointly as the South East London and South East Haemoglobinopathy Coordinating Centre (SELSE HCC).

Paediatric and Adult sickle cell disease outreach clinics were held at a number of locations and also provided support to the SHTs based at the Lewisham and Greenwich NHS Trust.

Some issues in this report relate specifically to the Trust as a whole and have been included in the Trust-wide section of the report. Other issues that 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

1 An active cross site sickle cell committee was in operation led by the Chief Nurse at GSTT. Quarterly meetings were held which primarily focussed on the APPG report and its outcomes but was also looking at improving the patient experience and other governance issues relating to haemoglobinopathy provision of services at a trust wide level.

Trust-wide Immediate Risks: None were identified during the visit.

Trust-wide Serious Concerns

1 Consultant staffing Adults and Children and Young People Specialist Haemoglobinopathy Teams

Reviewers were seriously concerned that both the adult and children's SHTs had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders for the number of patients under their care. *See details in each SHT section of the report.*

2 Clinical Nurse Specialist Workload and Nursing Skill Mix – Children & Young People Specialist Haemoglobinopathy Team

The reviewers were seriously concerned by the CNS workload and the skill mix for the nursing team. At the time of the visit there was one wte CNS with 1wte community-based CNS for 462 children young people and their families. The SHT had a vacant CNS post (0.6 wte) post with haemoglobin disorders. Reviewers were told that all vacant nursing posts would not be recruited to until April 2024 at the earliest and the Trust would not consider initial pump priming posts via charitable funding which reviewers considered had the potential to enable service development.

3 Clinical Nurse Specialist Workload and Nursing Skill Mix – Adult Specialist Haemoglobinopathy Team

At the time of the visit the lead CNS for the SHT, who was also the transition lead, and 1 wte adult SHT CNS post were absent due to long-term sick leave. This had left the remaining nursing staff overstretched and had impacted their ability to provide some services e.g. transition, haematology nurse education and full establishment of haemoglobinopathy competencies.

Reviewers were concerned in particular that one acute trust CNS was trying to cover all aspects of the service for 1114 patients with no cover for absences which they considered was not sustainable.

Trust-wide Concerns

1 Trust financial climate

The reviewers were concerned that the Trust financial climate was creating a barrier to service development, staff recruitment, succession planning and expansion to meet the service needs. Reviewers were told that vacant posts would not be recruited to until April 2024 at the earliest.

2 Poor Patient Environment – Adult patient areas

The environment in the emergency department, outpatient clinic and apheresis areas were extremely crowded and cramped with insufficient space and not fit for purpose for the number of patients attending and for staff working in these areas.

3 Access to Red Cell Exchange Programme – Adults

The service had a large and expanding red cell exchange programme for patients with a haemoglobinopathy diagnosis, with 130 patients on the programme in December 2023. New patients could be accommodated if they had good peripheral access or a portacath as the service had recently moved to 7 day working, including Bank Holidays, but there were insufficient femoral vascath insertion slots in interventional radiology, so patients requiring this access experienced delays. The capacity of the service, especially space and equipment access would remain challenged with the increasing number of new patients likely to require apheresis in the future.

4 Access to Red Cell Exchange Programme - Children and Young People

There was limited capacity for red cell apheresis, due to staffing and available space. Apheresis could only be provided Monday to Friday, 9am – 5pm and was predominantly for outpatient elective transfusions, but also for acutely unwell patients on the ward requiring automated red cell exchange. This was

resulting in children being maintained on top up transfusions who should ideally be on an automated exchange programme.

5 Access to medications – Children and young people

Parents and carers who met with the reviewing team reported gaps in supply of essential medications when collecting their prescriptions from the pharmacy department , which had resulted in their children's medications being couriered to them at a later date and children missing doses of essential medication for several days.

Trust-wide Further Consideration

1 Patients reported very long delays and waiting times to collect their prescribed medication from the pharmacy department and commented that the queue of patients waiting was often outside of the department. This was reported as being a long standing problem and patients having to wait an excessive length of time had been normalised by the Trust.

Views of Service Users and Carers

During the visit the visiting team met with a total of 12 users and carers representing the adult and children services; seven adults with a sickle cell disorder, five parents caring for children with a sickle cell disorder and one parent caring for a child with thalassaemia. The reviewers did not meet with any adult service users and carers with thalassaemia. The views of the users are documented in the children and young people and adults specialist haemoglobinopathy team sections. The review team would like to thank them for their openness and willingness to share their experiences.

Support Group available for patients and carers	Y/N
Sickle Cell Disease – Children and Young People	Y
Thalassemia – Children and Young People	Y
Sickle Cell Disease – Adults	Y
Thalassemia – Adults	N

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Specialist Haemoglobinopathy Team (Children and Young People Services): King's College University Hospital NHS Foundation Trust

General Comments and Achievements

This was an enthusiastic and hard working team. There was a strong working relationships between members of the multidisciplinary team and with services in the community and other allied health professionals. The paediatric service had a strong commitment to research.

All children with haemoglobinopathies were registered on the national haemoglobinopathy registry and their annual reviews had been completed.

A community service was in place but understaffed. An NHS England community funded project was in the process of being developed which would build on the existing community offer at Wooden Spoon House (Elephant and Castle) and focus on long-term community support with enhanced social work, benefits officers, psychology service, as well as post discharge review to prevent re-admission and crisis avoidance for adults and children with sickle cell disease, including school care plans and liaison. It was planned that the community hub would be available to all patients across the SEL HCC network boundaries. Satellite clinics at Waldron House (New Cross) and Queen Elizabeth Hospital (Woolwich) ensure support across the SEL footprint.

Transition for young people commenced around the age of 14. Monthly joint transition clinics were held, and formal transition would not be completed till they reached the age of 18 years or had finished their schooling. However, for most young people by the age of 16 they would be admitted to adult inpatient beds.

Patients on an exchange blood transfusion programme were managed by the existing haemoglobinopathy clinical nurse specialist, with up to date competencies in cannulation, including ultrasound guided cannulation, blood transfusion and apheresis. There was limited capacity for red cell apheresis, due to staffing and available space. The service was only able to provide apheresis between Monday to Friday, 9 am to 5 pm. This was predominantly for outpatient elective transfusions, and acutely unwell patients on the ward requiring automated exchange. See Concerns section of the report. All manual exchange transfusions take place in the Paediatric Critical Care Unit.

A joint specialist sickle cell neurology clinic was held every two months and there were good links with other specialist services at either KCH or Evelina London Children's Hospital

SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE			
Kings College Hospital NHS Foundation Trust	**Linked Haemoglobinopathy Coordinating Centres (HCC)**		
	South East London and South East Sickle Cell HCC (Joint HCC with Guys and St Thomas' NHS Foundation Trust **Thalassaemia and Rare Inherited Anaemias HCC - East London, Essex, Southeast London and the Southeast of England**		
	Linked Local Haemoglobinopathy Teams (LHT)	**Patient Distribution**	
		SCD	**Thal.**
	Dartford and Gravesham NHS Trust - Darent Valley Hospital	**1**	**?1**
	Maidstone and Tunbridge Wells NHS Trust	**7**	**0**
	Medway Maritime Hospital NHS FT	**42**	**1**
	University Hospitals Sussex NHS Foundation Trust - Royal Sussex County Hospital	**10**	**2**
	Canterbury and East Kent	**5**	**2**

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM- CHILDREN AND YOUNG PEOPLE						
Condition	**Registered patients**	**Active patients *[1]**	**Annual review ****	**Long-term transfusion**	**Eligible patients - hydroxycarbamide**	**In-patient admissions in last year**
Any Haemoglobin Disorder	**462**	**462**	**462**	**5 Red Cell Exchange** **16 Top up transfusions**	**188**	**~185**
Sickle Cell Disease	**446**	**446**	**446**	**5 Red Cell Exchange** **14 Top up transfusions**	**188 on HU** **308 eligible**	**~185**
Thalassaemia	**13**	**13**	**13**	**2**	**0**	**0**

Staffing

Specialist Haemoglobinopathy Team	Number of patients	**Actual PA/WTE (at time of visit)**
Consultant haematologist/paediatrician dedicated to work with patients with hemoglobinopathies	462	4 haematology consultants = 2wte 2 Paediatricians with Haem/oncology interest = 1wte
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with hemoglobinopathies	462	1wte band 7 0.6wte – vacancy 1wte Community based CNS
Clinical Psychologist for paediatric patients dedicated to work with patients with hemoglobinopathies	462	2wte

Emergency Care

There was a separate area in Emergency Department for the Paediatric Emergency Department (PED). Patients up to their sixteenth birthday were managed in the PED. All patients were booked in and then triaged by a nurse on arrival which included a pain assessment.

The medical assessment and management of the children were carried out in three distinct streams:

The first were those managed by the paediatric emergency medicine team in the PED. PED provided 08.00-17.00 consultant cover on weekdays with on call cover from the general ED consultant on call.

The second group were those assessed by the primary care team. The ED at KCH ran a model whereby GPs were scheduled to provide sessions as part of a co-located urgent care service. They would see children of all ages in whom the triage nurse deems that the child's presentation is one which is compatible with those

[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 .

routinely being managed in primary care and in patients that are unlikely to need speciality investigations or other input.

Finally, the paediatric team would assess medically unwell children under 12 months in whom it is deemed inappropriate for a GP to see first. They would also assess patients who are referred from the ED staff and GPs for further evaluation.

Children with sickle cell disease presenting to the PED at Kings could therefore be managed by any one of the above three teams depending on their presentations. There was a paediatric sickle cell clerking proforma readily available on the ED KWIKI (Kings wiki intranet pages) for use by all ED and paediatric doctors in the initial assessment of a child with sickle cell disease. There was also an algorithm for the management of pain in a paediatric sickle cell crisis. Pain scores and time to analgesia are regularly audited in the PED- see main report.

The PED would still see those young people with chronic conditions, including sickle cell disease, beyond the age of 16 whilst their care is being transitioned to adult services. Patients were assessed on a case by case basis as to whether they would be managed on a paediatric ward (by paediatricians) or an adult ward (by general medicine or adult haematology) if admission was deemed necessary.

In-patient Care

Children could be admitted to Toni & Guy ward (paediatric medical ward), Princess Elizabeth ward (paediatric surgical ward) or in uncomplicated cases to the Paediatric Short Stay Unit. Children referred directly to the Hepatology/Gastro team were admitted to Rays of Sunshine ward. Children may get admitted to PHDU, PICU and occasionally to Lion, the neurosurgical ward.

Children were seen daily by the paediatric team and by the haematology registrar (on rotation). Consultants were available daily and undertook a formal ward round on Monday and Friday mornings preceded by a ward discussion about each child. Unwell children were reviewed by the consultant as needed. PICU referrals were consultant to consultant referrals.

The CNS would see all the children admitted to the inpatient wards daily, either on their own or with the haematology SpR or paediatric team.

Surgical admissions (emergency or elective) are admitted to the Children's Surgical Unit. Elective surgical patients were predominantly admitted for neurosurgery, complex dental and general surgical procedures. A large proportion of those patients were referred from other haemoglobinopathy services in the region (SE England). To streamline this process, the specialist haemoglobinopathy team (SHT) were alerted directly by the surgical team or pre-assessment team with a TCI date. The SHT would then organise a face to face or telephone consultation with the parent/carer, liaise with the local team for pre-operative optimisation and document a plan in the clinical notes in preparation for surgery. The SHT would routinely review them at time of admission/ post op.

Day Care

An MDT transfusion clinic was held on the third Monday afternoon of every month. Children on transfusions were assessed and a detailed history of acute episodes, significant chronic complications and treatments were taken. A detailed physical and neurological examination is undertaken in each clinic visit and . The clinic provides an opportunity to reinforce the importance of continuous, regular monitoring to avoid long term complications.

Philip Isaacs was a nine spaced unit with a variety of beds and chairs which catered for children requiring day case investigations and treatments such as transfusions and red blood cell exchanges. It was open 8am to 6 pm Monday to Friday and two Saturdays a month.

Outpatient Care

General paediatric haematology clinics were held every Tuesday morning. Children could also attend without an appointment and would be triaged by the CNS. The majority attending were children with sickle cell disease or thalassaemia but children with general haematology problems were also seen. Every family was phoned by the CNS counsellor (community) prior to their appointment. Staffing included three consultants, one clinical fellow,

one registrar in haematology on rotation, clinical specialist counsellor (community), clinical nurse specialists (acute), clinical psychologist and lead for transition. Outpatient notes were still handwritten but in patient notes, results, correspondence was all available electronically.

Children due their transcranial Doppler scan were booked in on the same morning as their clinical appointment and seen were seen in the same clinical area for their scans, blood tests and clinic reviews. Results were available immediately, electronically. TCDs were booked for the 2 year visit and then annually if no concern. If the first TCD was inadequate due to non-compliance then TCD is requested for 3-6 months' time.

A joint sickle cell neurology clinic was also held for those children who have had an overt stroke or other ongoing neurological problems. The clinic was preceded by an MRI/radiology meeting.

Community-based Care

The community team was based at Elephant and Castle, Wooden Spoon House, hosted by the Evelina Children's Hospital, Guy's and St Thomas' NHS Foundation Trust. They undertook all the new-born screening, communication of results for affected babies, home visits, support and written information. Counselling was available to couples at risk, prenatal and antenatal testing referrals and support for PIGD referral. They offered support to patients with complex needs, poor compliance with medication, and supporting those young people transitioning to adult care.

Views of Service Users and Carers

The visiting team met with a group of five parents of children with sickle cell disorder and one with a child with thalassaemia during the visit. Their views were as follows:-

- All those who spoke to the reviewing team held the member of the team in high regard. They felt 'safe secured and heard'. 'Staff were amazing'.
- One parent described a difficult time around the thalassaemia diagnosis of their baby as the diagnosis had been delivered by a phone call.
- They said that the sickle cell disorder joint clinical review with the psychology team and administrative support worked really well.
- Parents had been asked to feedback on their experience and had been able to see improvements in the service following their recommendations.
- They were aware of how to access care in an emergency though patients were not aware of any fast track process when they attend
- Comments were made about the process for blood taking, which they considered was disjointed. Often blood request forms were not prepared in advance, resulting in them having to wait longer than necessary for their blood sample to be taken.
- Pharmacy and access to medication was a significant and frequent issue. Some spoke about medication not being available and having to wait with children or have medication couriered when available. Several complained that their child had then missed doses. Often they experienced delays to discharge because their take home medications were not ready.
- Those who had to access care at their local trust commented that it was difficult and 'not linked up', and they preferred to seek care at 'Kings' rather than attend local services, even if this meant travelling long distances.
- Parents liked the emergency alert cards which meant that if they need to access any other health services, they or other professionals could contact their team at 'Kings'.

- Not all those who met with reviewers were clear if they received any copies of their clinical letters.
- They liked the option of telephone appointments.
- The children all had school care plans and parents commented that they valued the support and education they and the school staff received about care at school.
- Two of the parents commented that they had early discussions about transition when their child was 14.
- The parents talked about good 'Pill school' run by the pharmacy department. Children attended in person and the sessions taught children to take tables rather than liquids. The sessions included education about medication and the importance of medicine compliance.
- All commented about the lack of privacy when attended the emergency department and the clinic area and that acute pain management could be improved.

Good Practice

1 Parents were appreciative of the plastic emergency cards that they were given which had team contact numbers. This made it easy for them to make contact or provide the details for other health care professionals who may need to contact the SHT for advice and support.

2 The 'pill school' run by the pharmacy department was very good. Children attended in person and the sessions delivered taught children how to transition from taking liquid medication to taking tablets. The sessions included education about medication and the importance of medicine compliance.

3 The individual care plans that were seen on the EPIC patient record system were excellent. The patient alert and care plan had been developed by the team and included a mechanism whereby the record would show a 'flagged' alert so that staff could not proceed to the patient care plan until the alert had been acknowledged. The care plan was very well structured, easily accessible, and easy to read.

4 Reviewers were impressed with the excellent relationships the SHT had with their patients, other nursing and medical staff, and local teams in the LHTS across the region.

5 The SHT was very proactive in providing staff development.

6 The psychology service was very good and well-staffed. This had resulted in the team being able to provide a more targeted approach to supporting children young people and their families and more patients were receiving timely neuropsychology assessments. The team had established a patient support group and other provided other activities to promote their client groups health and wellbeing.

7 The collaborative working of the SHT, and allied health professionals had enabled them to develop good mechanisms for enabling patient engagement and ensure that the patient voice was forefront of service improvement and development.

8 Reviewers were impressed with the work undertaken with patients to co-produce videos for educational purposes, which would be shared initially via the KHP e-learning hub and then once available published on the Sickle Centre of excellence website. The videos covered "How a sickle cell crisis presents", "Managing pain" and "Being heard" and the videos were also used as part of study days. There was also an excellent animated short educational video about priapism.

9 Parents who met with the visiting team spoke highly of the community law centre and the colocation of a benefits advice service. This meant that families were able to easily access both legal and welfare advice and support.

Immediate Risks: None were identified during the visit. See Serious Concern

Serious Concern

1 Consultant staffing

Reviewers were seriously concerned that the Paediatric SHT had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders to provide ward and on call cover.

a At the time of the visit there were four haematology consultants equating to 2 wte and two consultant paediatricians with a total time of one wte for the whole haematology oncology service providing 1:3 prospective ward cover. In addition, only two of the paediatric haematologists were available to provide on call cover as part of the red cell/paediatric on call cover in a 1:8 rota. Reviewers considered this was not sustainable due to the frequency of on call and ward cover commitments and that clinicians were unable to reduce other planned activities when on call.

b There was limited consultant time available, due to clinical commitments and no time allocated in job plans to develop and support the local haemoglobinopathy teams (LHTS). The LHTS were also experiencing a significant increase in patient numbers and reported the increasing pressure of trying to care for this cohort of patients with the limited staff with experience in caring for patients with haemoglobinopathies.

c Two consultants were approaching retirement age which was also likely to have a significant impact.

The Trust was aware of the situation; however, reviewers were concerned that the lack of capacity will become more pronounced with the increase in the number of service users within likely to continue year on year. There was no evidence of a plan in place to remedy the situation.

2 Clinical Nurse Specialist Workload and Nursing Skill Mix

The reviewers were seriously concerned by the CNS workload and the skill mix for the nursing team. At the time of the visit there was one wte CNS with one WTE community-based CNS for 462 children young people and their families. The SHT had a vacant CNS post (0.6 wte) post with haemoglobin disorders. Reviewers were told that all vacant nursing posts would not be recruited to until April 2024 at the earliest and the Trust would not consider initial pump priming posts via charitable funding which reviewers considered had the potential to enable service development.

Concerns

1 Red Cell Exchange Apheresis Service

There was limited capacity for red cell exchange, due to staffing and available space. Apheresis could only be provided Monday to Friday, 9am – 5pm and was predominantly for outpatient elective transfusions, but also for acutely unwell patients on the ward requiring automated red cell exchange. This was resulting in children being maintained on top up transfusions who should ideally be on an automated exchange programme. The service was also under threat as there was no trained nurse with skills in red cell exchange within team. The SHT were in the process of submitting a business case to the MedTech funding mandate to expand the service to provide a dedicated apheresis space, consumables and staffing so that a 6 day working model could be introduced. At the time of the visit, it was not clear if and when this service would be expanded to meet the clinical needs of the patient population and reviewers were concerned that access to a red cell exchange programme would not be resolved without funding and active involvement at trust level.

2 Access to medications

Patients who met with the reviewing team reported gaps in supply of essential medications when collecting their prescriptions from the pharmacy department , which had resulted in their children's

medications being couriered to them at a later date and that their children were then missing doses of essential medication for several days.

3 Guidelines for thalassaemia

Very few guidelines were in place for the care of patients with Thalassaemia which may result in the latest national guidance not being implemented and the potential to obscure variation in practice.

Further Consideration

1 Parents reported that when they attended for blood tests the request forms were often not completed which meant that they were spending a significant amount of time waiting for the forms to be completed before their samples could be taken. This most likely reflects the inadequacy of clinician time.

2 One parent reported that they attended the ED with their acutely unwell baby and were concerned that they had not been managed sufficiently to prevent their baby needing an emergency transfusion. As a parent with a newly diagnosed baby, they felt they were not clear about important signs and symptoms and when to seek help so as to prevent an emergency admission. Reviewers considered that further work with newly diagnosed families of children with haemoglobin disorders to may be sensible to identify whether their information needs were being met and that the issues reported by the parent were not more widespread.

3 Transition pathway was not consistently implemented. Reviewers were told that some patients did not start transition till the age of 16 which reviewers considered was late and not consistent with the Trust policy of starting at the age of 14, particularly as by the age of 16 young people would be admitted adult wards for inpatient care.

4 Representatives for the LHTs who spoke to the reviewers reported that they were supported in terms of accessing advice from the SHT but were struggling to provide services with an ever increasing population of children and young people with haemoglobin disorders. It was also not clear about the relationship and arrangements for liaising with the LHTS about transition for their young people who were being cared for locally.

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Specialist Haemoglobinopathy Team (Adult Services): King's College University Hospital NHS Foundation Trust

General Comments and Achievements

This was an extremely hard working and experienced team. It was evident that there were strong working relationships between members of the multidisciplinary team and with services in the community and other allied health professionals.

The adult specialist haemoglobinopathy (SHT) service managed the care of 1114 patients aged 18 and over with haemoglobinopathy diagnoses. They were an SHT and a joint HCC in partnership with Guy's and St Thomas' NHS Foundation Trust with whom they worked closely. Over the past 10 years their patient numbers had grown significantly and space to care for patients on an outpatient basis were severely challenging.

The SHT consisted of three wte consultant haematologists with dedicated haemoglobinopathy sessions. There was one full time advanced clinical practitioner (ACP), three clinical nurse specialists and one community nurse. At the time of the visit there was one psychologist as the additional post was vacant, and a 0.5wte social worker.

The team was committed to teaching, training with teaching, and training undertaken by all team members across the breadth of the MDT within the hospital and beyond.

The SHT had an impressive and active research program with patients being considered for and having discussions about available clinical trials and some actively participating in current trials. They had participated in a number of commercial trials and had the Hibiscus, VIT-2763-SCD-202, REDRESS and Natural history studies actively recruiting.

The team were active in ensuring that patients had prompt access to novel therapies, including administration of the first UK dose of Crizanlizumab and rapid development of a pathway for local and regional MDM discussion of individuals seeking treatment, establishment of day unit capacity and pathway, patient information for crizanlizumab and staff and pharmacy support for treatment and administration. Voxelotor had been made available a soon as there was an Early Access scheme, with similar pathways for local and network MDM discussion and pharmacy support.

The commissioning of fully matched sibling reduced intensity stem cell transplants for patients over 18 years of age in December 2019 resulted in rapid availability of tissue typing for interested and eligible patients and their siblings. The teams had been selected as a site for gene therapy and were working towards making this a reality, pending NHSE decisions regarding funding.

A new Unit 6 haematology outpatient area was planned with construction due to start mid-2024.

The team were aware of the risks and challenges that they faced in terms of facilities, capacity and workforce and had where possible put mitigations in place to avoid harm or risk. Reviewers were still concerned about the pressures faced by the SHT in delivering services – see the issues section of the report.

SPECIALIST HAEMOGLOBINOPATHY TEAM - - ADULTS			
Kings College Hospital NHS Foundation Trust	**Linked Haemoglobinopathy Coordinating Centres (HCC)**		
	South East London and South East Sickle Cell HCC (Joint HCC with Kings College **Thalassaemia and Rare Inherited Anaemias HCC - East London, Essex, Southeast London and the Southeast of England**		
	Linked Local Haemoglobinopathy Teams (LHT)	**Patient Distribution**	
		SCD	**Thal.**
	Dartford and Gravesham NHS Trust - Darent Valley Hospital	**74 (16 attend KCH and 58 attend GSTT)**	**2**
	Maidstone and Tunbridge Wells NHS Trust	**0 on NHR** **Appx <20**	**0 on NHR** **1 shared care GSTT**
	Medway Maritime Hospital NHS FT	**96**	**0**
	University Hospitals Sussex NHS Foundation Trust - Royal Sussex County Hospital	**29**	**0**
	Canterbury and East Kent	**30**	**5**

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM						
Condition	Registered patients	Active patients *2	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Any Haemoglobin disorder	1137	1114	N/A	145	N/A	
Sickle Cell Disease	970	830	~600 ~368 (Apr – Nov 23)	138	~264	926*
Thalassaemia	43	32	~28	7	1	2

* Based on average 14 inpatient numbers and average length of stay for adults 5.4 days)

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

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant haematologist dedicated to work with patients with haemoglobinopathies	1114	25.5 PAs
Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies	1114	1 wte Advanced Clinical Practitioner (ACP) 3 wte Clinical Nurse Specialists (CNS) 1 wte community based CNS
Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies	1114	2 wte Psychologists. One post vacant

Emergency Care

Patients were admitted via the emergency department or via the Haematology Supportive Therapy Unit (HSTU) which was open 8am – 8pm, seven days a week, including for un-booked 'walk-ins'. From December 2023 the HSTU had been able to extend their opening hours to 8am to 5pm on weekends and Bank Holidays to both emergency and elective cases.

Patients presenting to the ED were assessed by ED staff and then the on-site haematology SpR would admit them directly to a ward or to the HSTU, from where they could be discharged home or admitted to a ward bed. Acutely unwell patients requiring resuscitation were admitted to the ICU or HDU. SHT staff reported good relationships with the ED, there was a link consultant and senior ED nurse who provided teaching alongside their red cell colleagues.

The lack of capacity in the Haematology Supportive Therapy Unit HSTU was well recognised and there were plans to relocate the services to another larger location and develop an expanded and co-located Haematology Outpatient Department, Supportive Therapy Unit, expanded Apheresis Unit, Transplant Ambulatory Support Unit and a designated 4-6 bedded sickle support unit.

Inpatient Care

The inpatient care was split across the haematology wards (Elf and Libra, Waddington, Davidson and Dereck Mitchell), with outlying patients in renal (Fisk and Cheere), liver (Todd and Howard), maternity (Nightingale Birth Unit and William Gilliat post-natal) or general medical or surgical wards, usually only if their primary current problem was best managed under these specialties.

There were daily consultant led ward rounds Monday to Friday and Specialist trainee led rounds on Saturday and Sunday, with all newly admitted or unstable patients being reviewed by a consultant, including at the weekend.

The inpatient team consists of a haemoglobinopathy specialist nurse, a specialist trainee, an ACP, one FY3 grade doctor and a consultant on a 1 in 3 consultant attending rota, with each consultant usually attending for a two week period.

Apheresis

The service had a large and expanding red cell exchange programme for patients with a haemoglobinopathy diagnosis, with 130 patients on the programme in December 2023. This service was run out of the Apheresis Unit where there were 5 apheresis machine and also performed stem cell collections and plasma exchanges including for neurology patients. At the time of the visit, the specialist apheresis nurses were not able to insert femoral lines, so these cases were booked with interventional radiology, resulting in some limitations to

availability of apheresis for those with poor vascular access. The recently appointed ACP was training to insert femoral lines with the vascular access team with the view they would be inserting lines from March 2024. Peripheral access was utilised where possible and some patients had indwelling Portacaths inserted by our vascular surgeons. The apheresis nurses were trained to access veins with ultrasound.
The service had a small cohort of transfusion dependent thalassaemia patients and seven adult sickle cell disorder patients who were additionally managed on a regular top up transfusion program via the day unit. The team held a monthly MDT to discuss 10-15 patients on the current programme, any patients to add or remove from the programme, and to ensure that that their apheresis treatment is optimised and meeting transfusion targets, and to discuss access or compliance issues.

Haematology Outpatients:
There were two weekly general haemoglobinopathy outpatient clinics held on Thursday and Friday afternoons and additionally run regular joint specialist clinics.
A weekly local face to face adult red cell MDT meeting was held to discuss complex cases, receive feedback from psychology, social work, community and CNS teams and to plan and document peri-operative management.
The haematology outpatient department (HSTU) was housed in inadequate and crowded premises, with inadequate numbers of clinic rooms to allow all members of the team to function to their full capacity.

Views of Service Users and Carers

A long-standing monthly adult sickle support group ran a mixture of online and face to face meetings. More recently the red cell team had empowered the patients to run the group themselves with clinical team support. The active patient support forum had also been engaged in discussing, planning and disseminating service changes, patient information, social and financial issues (PIP, DSA, Discretional Freedom Pass and other applications), novel and existing therapies and disease education including in specific scenarios such as pregnancy, stem cell transplantation, and involvement in research, as well as for peer to peer support, sickle advocacy and awareness events and for celebrations including annual winter parties.
The SHT actively involved patients in service design and there were a number of quality improvement projects where patient experience and co-design was part of the development.

The visiting team met seven adults with sickle cell disease. Reviewers did not meet any patients living with thalassaemia during the visit. See their feedback below about the services provided by the Trust: -

- HSTU /clinic feedback was that the facilities that they attended were overcrowded and did not afford much privacy and dignity. Patients reported that other patients could see their details due to the placement of computer screens when they were being assessed
- There were mixed views about the access of information with some commenting that they knew where information could be accessed and others who did not.
- Patients unanimously agreed that the care they received from the consultants and CNS was very good and that they had good links with core staff members of the MDT and with community staff. Patients very happy with consultant and CNS who knew about them.
- They would be happy to have telephone consultations.
- One patient commented about their “fantastic” maternity experience, saying that every step of the way felt they felt safe, secure and informed in pregnancy and had easy access to the teams.
- All said that other wards were not as courteous to them and experience less than favourable attitudes. One patient had overheard arguments between professionals and heard comments that patients were only attending to receive ‘pain killers’.

- The experience in the emergency department was not pleasant with patients saying that they often waited overnight in the department, and it was not calm, very noisy and cold.
- Some reported their pain management was an issue if they were not admitted on to a haematology ward.
- One patient reported and episode when a subcutaneous prescription was offered intravenously and as they had some knowledge they were able to say and decline this route of administration.
- They reported a lack of staff knowledge in general education of their condition when admitted to outlying wards but reported that staff were knowledgeable on ELF ward.
- In general, the transition process had worked well, the transition clinic was good although one 19 year old commented that they had not been offered any transition meetings before he transitioned to the adult service.
- Patients felt comfortable and could trust the team and that equality and diversity and inclusion was evident, and they thought it was helpful to see that staff represented their local community.
- When they attended their annual review clinic appointment there was often no space for them to wait.
- Those who were linked to another trust which was more local for them commented that care seemed fragmented.

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Good Practice

1 The individual care plans that were seen on the EPIC patient record system were excellent. The patient alert and care plan had been developed by the team and included a mechanism whereby the record would show a 'flagged' alert so that staff could not proceed to the patient care plan until the alert had been acknowledged. The care plan was very well structured, easily accessible, and easy to read.

2 "Transition packs" including equipment was provided for all young people transitioning to adult care. The packs were individualised with key information and helpful equipment such as a dosette box, heat pad, and pulse oximeter. The information and contents provided were clearly designed to promote the young person's self-care.

3 The Transition Teenage Workshop Programme included representation from the psychology service, CNS and social work. As part of the programme young people were able to have a tour of the adult pathway including visiting the wards, the haematology supportive therapy unit and ED.

4 The team had good relationships with the nursing and medical teams working in the Emergency department and Maternity services. Bitesize education was provided on a weekly basis and as part of the staff induction had developed simulated scenario based training.

5 Previously the SHT had held a face to face pain MDT clinic with representation from members of the pain team. The team reported that these MDTs had resulted in patients with chronic pain receiving a more holistic approach to pain management. As part this approach they had seen patients being less dependent on long-term opioids and they had been able to work with patients following discharge to ensure a return back to their pre-admission baseline opiate intake. It was hoped that these MDTs would be re -established with the recruitment to the psychology post vacancy.

6 The SHT had created and launched, with support of the KHP haematology team and their Sickle Centre of excellence working group a co-produced e-learning tool which has patients educating staff using first person experience in an approachable and interactive manner. The trust had made the training mandatory for some staff groups. Once established there were plans to expand access to the LHTs.

7 Reviewers were impressed with the work undertaken with patients to co-produce videos for educational purposes, which would be shared initially via the KHP e-learning hub and then once available published on the Sickle Centre of excellence website. The videos covered "How a sickle cell crisis presents", "Managing

pain" and "Being heard" and the videos were also used as part of study days. There was also an excellent animated short educational video about priapism.

8 The breadth of sub specialist clinics and MDTS in place for patients was impressive. Clinics ranged from joint orthopaedic hip, neurology, obstetric, teenage transition, chronic pain, respiratory, renal, liver and specialist pulmonary hypertension clinics which were all available for clinicians across the network to refer patients into. Arrangements were in place for Urology (priapism) and ENT cases to be referred to clinics at GSTT.

9 The SHT had an impressive and active research program, both SHT initiated and led and commercial, with patients being considered for and having discussions about available clinical trials and some actively participating in current trials. The visiting team were told about the Natural History and Clinical Outcomes database study, which was an observational study. Recruitment at the time of the visit had exceed over 500 patients and the team reported that initial data analysis had already yielded valuable data and evidence in adults with sickle cell disease.

Immediate Risks None were identified during the visit. See Serious Concern section.

Serious Concern

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 for the 1114 patients under their care.

a At the time of the visit, the three consultants had only 25.5 programmed activity (PA) sessions rather 40.5 PAs for work with the service which included work with the SHT network, research and leadership of the HCC.

b The consultant attending rota was 1:3 and the on-call consultant rota was 1:7. Reviewers considered this was not sustainable due to the frequency of attending and on-call commitments, outreach commitments to LHTs, and that clinicians were unable to reduce other planned activities when on call. One of the consultant described regularly working late into the night to complete clinics and data submissions when attending one of the outreach hospitals.

c There was limited time available due to clinical commitments to develop and support the local haemoglobinopathy teams (LHTs). The LHTs were also experiencing a significant increase in patient numbers and reported the increasing pressure of trying to care for this cohort of patients with the limited staff with experience in caring for patients with haemoglobinopathies.

The Trust was aware of the situation; however, reviewers were concerned that the lack of capacity will become more pronounced with the increase in the number of service users within likely to continue year on year. There was no evidence of a plan in place to remedy the situation.

2 Clinical Nurse Specialist Workload

At the time of the visit the one wte CNS for the SHT and one wte CNS post for lead nurse and transition lead were either were absent due to long-term sick leave. This had left the remaining nursing staff overstretched and had impacted their ability to provide some services e.g. transition, haematology nurse education and full establishment of haemoglobinopathy competencies.
Reviewers were concerned in particular that one acute CNS was trying to cover all aspects of the service for 1114 patients with no cover for absences which they considered not sustainable.
Reviewers were also told that due to the overall financial position of the trust there would be no recruitment to any vacancies until April 2024.

Concern

1 Poor patient environment

The environment in the emergency department, outpatient clinic and apheresis areas were extremely crowded and cramped with insufficient space and not fit for purpose for the number of patients attending and for staff working in these areas.

In the outpatient and apheresis unit it was clear that patients privacy and dignity was being compromised, with inadequate numbers of clinic rooms to allow all members of the core team to function to their full capacity (esp. rooms for psychology counselling, social work interviews and case work management, and rooms for community and hospital red cell nurses to see patients in clinic, perform vaccinations and phlebotomy/line access and assessment, annual reviews, analgesia/care plan preparation with patients, and have face to face nurse-led clinics).

The waiting room was small and windowless, and despite recent refurbishment, was not well suited to its purpose. Reviewers observed and were told by patients that they could hear other patients confidential information and due to the cramped conditions they could see other patients information on the staff computer screens.

The lack of appropriate facilities in which to see patients was severely impacting the psychology service and it had limited the number of face to face and virtual appointments for patients that could be provided as privacy and confidentiality could not be assured. Some work had been undertaken to mitigate the issue by the use of a counselling room on DMU by social work and psychology team members, and virtual nurse clinics.

2 Access to Red Cell Exchange Programme

The service had a large and expanding red cell exchange programme for patients with a haemoglobinopathy diagnosis, with 130 patients on the programme in December 2023. New patients who needed to start on the automated red cell exchange programme and who required access via in/out femoral vascath experienced delays to starting and extended intervals between apheresis procedures. This was due to the lack of availability of staff to perform venous access by femoral vascath insertion. At the time of the visit, the specialist apheresis nurses were not able to insert femoral lines, so these cases were booked with interventional radiology, resulting in some limitations to availability of apheresis for those with poor vascular access. Some work had been undertaken to mitigate the issue with to reduce the time between procedures, and for patients to meet their transfusion targets by the recruitment and training of additional apheresis nurses, development of the ACP role to undertake insertion of femoral lines and expanding of the service from 5-6 day working to 7 day working, as well as extended hours. However, reviewers remained concerned that the capacity of the service, especially space and equipment access would remain challenged with the increasing number of new patients likely to require apheresis in the future.

3 Access to Psychology

Access to psychology was insufficient for the 1114 pts registered with the service. There was only 1 wte postholder in place and the 0.8 WTE post was vacant and reviewers were told that recruitment to the post had not been successful on three attempts. If recruitment was successful the level of psychology support would still not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one wte psychologist for every 300 patients. Reviewers were concerned as without sufficient dedicated psychologist 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 Guidelines for the care of patients living with Thalassaemia

Very few guidelines were in place for the care of patients with Thalassaemia which may result in the latest national guidance not being implemented and the potential to obscure variation in practice.

5 Patients on outlying wards and length of stay

Reviewers were told during the visit that patients with haemoglobin disorders were often admitted to outlying wards. Patients who met with the reviewing team commented that the staff were less courteous in these areas and had limited knowledge of their conditions. Pain management was an issue if they were not admitted to a haematology ward. Reviewers were told of time when a patient overheard arguments between professionals believing that the patient was only attending to access analgesia. One patient reported and episode when they had to stop a nurse delivering sub cutaneous medication intravenously.

An audit of acute admissions to inappropriate settings had not been completed which if undertaken would help with identifying pathway issues and identifying educational needs in these areas, planning patient management and support to areas as well as identifying if there were any specific training needs for staff An audit would also enable a review of the patients length of stay in these areas and targeting of any actions to ensure timely assessment, treatment, and discharge of patients.

6 Care in the Emergency Department

Patients did not consider that they had a good experience when attending the ED. Patients believed that care was less than optimal. The ED was extremely busy and they waited long times for analgesia and were often in the department overnight which was very noisy and cold.

7 Potential of patients to be lost to follow up

The process for oversight of patients who had not attended appointments or who had not had an annual review was not robust and dependant on the clinical staff to implement checking process which was impacting on their clinical time. Reviewers were told there was a large backlog of clinic patients who had not been allocated an appointment and there was an incomplete oversight of patients lost to follow-up, and a failure in process to re-appoint and close clinics at the end of each clinic session

Further Consideration

1 Access to specialist teams for example endocrinology and orthopaedic (other than for hip surgery) were often provided on a case by case via an email and whilst this informal approach was working well, reviewers considered that access to speciality teams would benefit from being provided on a more formal basis.

2 Parents reported that when they attended for blood tests the request forms were often not completed which meant that they were spending a significant amount of time waiting for the forms to be completed before their samples could be taken. This most likely reflects the inadequacy of clinician time and the new IT system.

3 The transition pathway was not being consistently implemented. Reviewers considered that this was important to address to ensure adequate transition planning took place, particularly as reviewers were told that some patients did not start transition till the age of 16 by which time they would be admitted to adult wards for inpatient care.

4 Governance of documentation seen would benefit from review, some documents did not have review dates, where out of date and the information of the website was not always accessible. The information seen covering chelation was from 2015 and was out of date.

Commissioning

The review team had discussions with a local commissioner from NHS South East London Integrated Care Board and NHS England – London. Several of the issues in this report will require the active involvement of the Trust and commissioners in order to ensure that timely progress is made.

Good Practice

1 There was good engagement and collaboration on projects from South London ICB and NHSE London commissioners with the HCC. Reviewers were told of the work to develop a community hub. The community hub once implemented would be available to all patients across the SELSE HCC network boundaries and the work was also being undertaken across the HCC to develop an Emergency department admission bypass pathway.

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Membership of Visiting Team

Visiting Team		
Ryan Mullally	Consultant Adult Haematologist	Whittington Health
Sandy Hayes	Adult Haemoglobinopathy Senior Specialist Nurse	
Kelsey Hunt	HCC Network Manager	Sheffield Teaching Hospital NHS Trust
Emmy Dickens	Consultant Paediatric Haematologist	Cambridge University Hospital NHS Trust
Clare Clark	Paediatric Haematology Clinical Nurse Specialist (CANP)	Cambridge University Hospital NHS Trust
Hannah Coyle	NHS England Quality Manager (Specialised Commissioning)	NHS England
Carol Burt	User representative	Midlands Sickle Cell Patient Voice Group
Ira Jankowski	User representative	UK Thalassaemia Society
Roanna Maharaj	User representative	UK Thalassaemia Society

Clinical Leads		
Josh Wright	Consultant Adult Haematologist	Sheffield Teaching Hospital NHS Trust
Sabiha Kauser	Consultant Paediatric Haematologist	Manchester University NHS Trust

MLCSU Team		
Sarah Broomhead	Professional Lead	MLCSU
Samantha Singh	Clinical Lead	MLCSU

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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
Haemoglobinopathy Coordinating Centre (HCC) Sickle Cell – All Ages	13	5	38%
Specialist Haemoglobinopathy Team (SHT) Children and Young People	49	34	69%
Specialist Haemoglobinopathy Team (SHT) Adults	45	23	51%

South East London and South East (SELSE) Sickle Cell Haemoglobinopathy Coordinating Care Centre - All Ages

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-198S	**Network-wide Involvement of Children, Young People and Families (SCD)** The Sickle Cell Disorder HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702).	N	From the evidence seen it was not clear if patients and carers of all ages were represented at HCC business meetings. The HCC produced a Red Cell Newsletter quarterly which included patient testimonials and awareness days had been held.
H-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The HCC nominated lead had insufficient time for their HCC leadership as well as other clinical commitments.
H-202	**Lead Nurse** A lead nurse should be available with: Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders a. Responsibility for liaison with other services within the network b. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	There was no lead nurse with responsibility for leadership across the HCC. There was a nurse educator in post.
H-202A	**Lead Manager** A lead manager should be available with: a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs b. Responsibility for liaison with other services within the network The lead manager should have appropriate time for their role.	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-203	**Lead for Transcranial Doppler Ultrasound** The HCC should have a nominated lead for Transcranial Doppler Ultrasound screening.	Y	
H-602S	**HCC Service Organisation (SCD)** A Sickle Cell Disorder HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including: a. Telephone or email advice for outpatient and inpatient care b. Advice on emergencies outside of normal working hours	N	Advice on emergencies outside of normal working hours to all linked SHTs and LHTs was not yet in place. Reviewers were told that achieving this was part of the work plan for 2023/24.
H-605S	**HCC Multidisciplinary Discussion (SCD)** MDT meetings for the discussion of more complex patients with sickle cell disorder should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use.	Y	
H-609	**NHS Blood and Transplant Liaison** The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies.	N	Reviewers did not see any evidence to show that the HCC has met annually with NHSBT.

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-702S	**HCC Business Meetings (SCD)** The Sickle Cell Disorder HCC should organise at least two meetings each year with its referring SHTs and LHTs to: a Agree network-wide information for patients and carers of all ages b Agree network-wide policies, procedures and guidelines, including revisions as required c Agree the annual network education and training programme d Agree the annual network audit plan, review results of network audits undertaken and agree action plans e Review and agree learning from any positive feedback or complaints involving liaison between teams f Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams g Review progress with patient experience and clinical outcomes (QS H-797) across the network and agree any network-wide actions to improve performance h Consider the TCD annual monitoring report and agree any actions required (QS H-704)	Y	Including everyone's roles and organisation to the attendance lists would make it clearer about who was representing each team/organisation. .
H-703	**HCC Annual Programme of Work** The HCC should meet with their commissioners at least annually in order to: Review progress on the previous year's annual programme of work a. Review progress with improving patient experience and clinical outcomes across the network (QS H-797) b. Agree the annual programme of work for the forthcoming year	N	Evidence of a mid-year summary was seen but not evidence demonstrating a review of the previous years agreed programme of work.

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-704	**Transcranial Doppler (TCD) Monitoring Report** The HCC TCD lead should monitor and review at least annually: a. The list of staff undertaking TCD ultrasound and whether they have undertaken 40 procedures in the last year (QS HC-209) b. Results of internal quality assurance systems (QS HC-504) c. Results of National Quality Assurance Scheme (NQAS) for TCD ultrasound (when established) or local peer review arrangements (until NQAS established) d. Number of TCD ultrasounds performed and the number of abnormal TCDs across the network e. Whether any changes to the TCD Standard Operating Procedure (QS HC-504) are required	Y	
H-707	**Research** The HCC should have agreed a list of research trials available to all patients within the network and SHTs should actively participate in these trials.	Y	
H-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Some documentation seen did not have version or review dates included. Minutes of meetings had signatures but it was not clear of their role and organisation. Some of the minutes seen appeared to be a completed transcript of the conversations held.

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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	N	Reviewers did not see any information for patients with thalassaemia. This QS was met for those with sickle cell disease.
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.	N	See main report.
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	Y	The transition pathway was well designed and workshops were held with young people. From discussions the transition pathway was not consistently implemented and reviewers were told that some young people had not started transition until the age of 16.
HC-197	**Gathering Views of Children, Young People and their Families** The service should gather the views of children, young people and their families at least every three years using: a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder' b. UKTS Survey for Parents of Children with Thalassaemia	Y	

Ref.	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	N	There was a paediatric forum but it was not clear about the arrangements for involvement for those living with thalassaemia.
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The nominated lead had insufficient time allocated in their job plan for service development and their network role.
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 sufficient time for leadership of the SHT as defined by the QS.

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	Four consultant haematologists and two paediatricians with a specialist interest in haematology / oncology interest. All consultants provided outreach clinics It was not clear from the evidence the time in terms of PAs that each of the consultants had for the allocated for the care of the 462 patients with haemoglobinopathies.
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.	N	In practice the on call consultant rota was 1:2 and reviewers considered this was not sustainable due to the frequency of on call commitments and that clinicians were unable to reduce other planned activities when on call.
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	Two CNSs were in post covering acute and community services. 0.6wte CNS post was vacant. The day unit could not be staffed on Saturdays to provide day care due to lack of staff.

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.	Y	There were two wte psychologists but reviewers were told that the service capacity was hampered due to the lack of appropriate facilities in which to see patients.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	Y	
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	
HC-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required: a. Social worker / benefits adviser b. Play specialist / youth worker c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Child and adolescent mental health services	Y	

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	Access to automated exchange transfusions was not available 24/7 if required manual exchange would be undertaken.
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	Training for ED staff was provided every three months but a framework to assess staff competences in the urgent care of people with haemoglobin disorders was not in place. It was not clear if the KHP haematology study days included medical and nursing staff working in the Emergency Departments and admission units.

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	
HC-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for children, young people and their families.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-504	**Transcranial Doppler Ultrasound Standard Operating Procedure** A Standard Operating Procedure for Transcranial Doppler ultrasound should be in use covering at least: a. Transcranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Transcranial Doppler ultrasound (QS HC-209) d. Arrangements for ensuring staff performing Transcranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	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	Y	
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	Y	
HC-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred For children and young people with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration For children and young people with thalassaemia: l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-510	**Clinical Guidelines: Chronic Complication** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea f. Endocrine and growth problems, including endocrinopathies and osteoporosis g. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology h. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease i. Growth delay / delayed puberty j. Enuresis k. Urological complications, including priapism l. Dental problems	Y	
HC-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of children and young people with sickle cell disorder and thalassaemia during anaesthesia and surgery.	Y	
HC-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	

Ref.	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	Shared care agreements with LHTS were not yet in place.
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 service level agreement covering the role of the community service in the care of children and young people with haemoglobin disorder and two way exchange of information was not yet in place.
HC-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each SCD HCC Business Meeting (QS HC-702).	Y	
HC-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HC-702).	N	Evidence to demonstrate that representatives attended the Thalassaemia HCC was not available.
HC-608	**Neonatal Screening Programme Review Meetings** The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results, identify issues of mutual concern and agree action.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	
HC-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions	Y	
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS HC-702d).	Y	
HC-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	
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	All but 'c' was met as these audits had not been completed. A network wide survey had been undertaken for Sickle Cell Disease. There was no evidence to show results of the last Thalassaemia PREMS and whether a comparison of results with other services had been collated and shared.

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	Not all the documentation provided and polices had documented processes for ratification.

Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-102	**Information about Haemoglobin Disorders** Patients and their carers should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	Reviewers did not see information covering all aspects of the quality standard. Some information was accessible on the website. The information seen covering chelation was from 2015 and out of date.
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	The individual care plans that were seen on the EPIC patient record system were excellent.
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	N	See main report
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	Y	The transition pathway was well designed although not consistently implemented. From discussions it appeared that some young people had not started transition until the age of 16.

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	Y	
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	Y	An active support group was in place for any patients with a haemoglobin disorder. Patients were involved in decisions about the service.
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	Two clinical leads shared the leadership of the SHT. The lead did have time allocated but in practice had limited time due to inadequate time for other activities
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	Thee was no lead nurse in post and the other CNS did not have time for leading the SHT.

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 insufficient medical staff (25.5PAs) to care for 1114 patients
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	In practice the on call consultant rota was 1:3 and reviewers considered this was not sustainable due to the frequency of on call commitments and that clinicians were unable to reduce other planned activities when on call.
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.	N	The SHT had a total of one ACP and three CNSs. At the time of the visit 50% of this workforce was absent with a high workload caring for 1114 patients and no time for leadership of the SHT. A community CNS (1 wte) had recently been appointed. Weekly teaching by the team was provided but competences following this were not measured. A training & competency check list for Haematology Nurses and those performing apheresis was in place. The RCN competency framework for nursing staff (2010 version) was used but it was not clear whether staff were updated on more recent published guidance Data from the network 'E' Learning package showed that 150 staff had attended the training overall but the data was not broken down by organisation or speciality. Regular network study days were held .
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	At the time of the visit, one wte psychologist was in post and one wte post was vacant. Even at full establishment the number of wte psychologists was insufficient for the activity of the team (1114 patients).

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	Some data support was available but the team did not have sufficient data support to enable timely recording of annual review data on the NHR. The data manager's time was divided between the HCC - 40% and the trust - 60%.
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	Y	
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	Access to automated exchange transfusions was not available 24/7. All other aspects of the QS were met.
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	N	An 'E' Learning package had been developed and study days held but there was no framework in place to assess staff competences. Bitesize training covering the urgent care of people with haemoglobin disorders was also provided to ED staff. Staff in the ED who met with the reviewing team were clear about how to access advice from the SHT.
HA-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HA-195)	Y	
HA-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for patients and carers.	Y	

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	Guidance was not seen covering transfusions for patients thalassaemia who were transfusion dependent.
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring of complications e. Indications for discontinuation	N	Guidance was not in place. A nurse led SOP for hydroxycarbamide monitoring was in place.
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	
HA-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. For patients with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision v. For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine	N	Guidance was not seen covering acute complications for patients thalassaemia..

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	The guidelines did not cover care of chronic complications for those with thalassaemia.
HA-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery.	N	The guidelines did not cover patients living with thalassaemia.

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	Evidence was not seen covering guidance for those with a sickle cell disorder or those who were transfusion dependent thalassaemia
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	Operational policy 2019 due for review 2022 and did not appear to reflect local practice. It was not clear about the mechanisms in place for oversight of those patients who did not attend appointments (c). There was limited detail about the transfer of patients to other areas and coordination and oversight of care within the LHTs (d), or the governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations (f).
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	Shared care agreements with LHTS were not yet in place. There was an SLA with Lewisham and Greenwich SHTS as the Trust provided some outreach support.

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 service level agreement covering the role of the community service in the care of adults with haemoglobin disorder and two way exchange of information was not yet in place
HA-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each Sickle Cell Disorder HCC Business Meeting (QS HA-702).	Y	
HA-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HA-702).	N	Evidence to demonstrate that representatives attended the Thalassaemia HCC was not available.
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	Some aspects of patient experience re transfusion and acute admissions had been asked as part of the PREMS but not an audit covering all aspects as required by the QS
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	All but 'c' was met as these audits had not been completed A network wide survey had been undertaken for Sickle Cell Disease. There was no evidence to show results of the last Thalassaemia PREMS and whether comparison with other services had been collated and shared.
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	Not all the documentation and polices had documented process for ratification