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 Haemoglobinopathy Coordinating Centre

Guy's and St Thomas' NHS Foundation Trust including

Evelina London Children's Hospital

Visit date: 25th January 2024

Report date: 11th July 2024

Contents

Introduction

This report presents the findings of the review of Guy's and St Thomas' NHS Foundation Trust that took place on 25th 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 Guy's and St Thomas' NHS Foundation Trust health economy. Appendix 2 contains the details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- Guys and St Thomas' 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 Guy's and St Thomas' NHS Foundation Trust health economy for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks, are also due to the visiting team and their employing organisations for the time and expertise 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

Guy's and St Thomas' 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 patients, parents and carers, and with staff providing the services and visited the day units and wards on the Evelina London Children's Hospital and Guy's Hospital and the Emergency Department at the St Thomas' Hospital

Guy's and St Thomas' 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 King's College Hospital NHS Foundation Trust, and South London and the Maudsley and 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 King's College Hospital NHS Foundation Trust and together were known as KHP Haematology and were appointed jointly as the South East London and South East Haemoglobinopathy Coordinating Centre (SELSE HCC).

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

a 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 Concerns

1 Emergency Department Pathway

Reviewers were concerned about the pathway in place for adults, children, young people and their families to access emergency care via the ED at St Thomas's hospital site..

There was one door and one queue to both the adult and paediatric emergency departments and all patients joined an undifferentiated queue. Reviewers were concerned that actions to address capacity issues in the emergency department had resulted in a tented corridor being put up outside to protect people whilst queuing to enter the department. Patients were expected to wait outside in this queue before being triaged or approached by a 'roaming triage' nurse.

Reviewers were told that patients could by pass this queue by showing staff their emergency alert card but this did not appear to be full proof in overcoming the issue of overcrowding especially as some of the patients and families who met with the reviewing team were not aware of this. Others , who were aware, did not feel comfortable bypassing the queue and were concerned about the abuse they may receive from others in the queue.

Reviewers who visited the ED were unsure why there was not a separate entrance to the paediatric ED especially as patients once through the main ED triage had to register at the PED reception.

Once in the ED patients who met the reviewing team complained about the departments being very cold.

In the Emergency Department, adult patients, who were often waiting in the department for a significant length of time for admission, were not offered any food or drink.

2 Access to Red Cell Apheresis Service:

a Children and Young People's Service

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.

b Adult Haemoglobinopathy Service

Reviewers were concerned that apheresis could only be provided Monday to Friday and not available 24/7 as expected. Senior clinical staff were spending large amounts of time constantly juggling the programme diary in order to get new patients and ad hoc patients into the service. There was also an informal good will rota whereby staff would be called out of normal working hours to undertake urgent apheresis. The SHT had submitted a business case to expand the service so that a weekend working model could be introduced but this had not been agreed by the trust.

At the time of the visit, reviewers were concerned that both the adult and children's apheresis provision was unable to meet the clinical needs of the patient population and unlikely to be resolved without additional funding and, support at trust level.

Trust-wide Further Consideration

1. The transition CNS post had been vacant since 2018 which both the children's and adult SHTs considered had resulted in a negative impact on the transition process. At the time of the visit, recruitment to the transition CNS post had commenced and reviewers commented that should recruitment be unsuccessful, then providing specialist support for transition would continue to add a significant workload for other members of the SHT.

Views of Service Users and Carers

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	Y

During the visit the visiting team met with service users and carers with sickle cell disease representing the adult and children services. The views of the users were wide-ranging and 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.

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Specialist Haemoglobinopathy Team (Children and Young People Services): Evelina London Children's Hospital (ELCH)

General Comments and Achievements

This was a well organised team who were flexible to the needs of their patients and families and had good relationships across the multidisciplinary team. Patients who met with the visiting team were extremely positive about the team, especially the Clinical Nurse Specialists (CNSs).

The haemoglobinopathy service at ELCH managed the care of 404 children and young people with a haemoglobinopathy diagnosis. Staffing consisted of two consultant paediatric haematologists, three full time haemoglobinopathy CNSs , one fulltime research nurse and 1 community based CNS. Psychology was provided by the CAMHS team and there was access to neurocognitive assessments. A data manager had recently been appointed who would be responsible for the NHR data entry and local database management.

A range of joint specialist sickle cell clinics were in place with respiratory, neurology, transition, endocrinology and nephrology and there were good links with other specialist services.

Nurse led Hydroxycarbamide monitoring clinics were well established and via telephone and face to face consultations.

Regular transition clinics and workshops were provided for young people transitioning to adult care. The transition CNS post had been vacant since 2018 which both the children’s and adult SHTs considered had resulted in a negative impact on the transition process. At the time of the visit, recruitment to the transition CNS post was in progress. Some work had been undertaken to alter the pathway and the transition clinics were now held with the adult service at Guys Hospital site to enable young people to familiarise themselves with the facilities and meet with a wider range of staff

A combination of local, regional, and national MDT structures were in place. Local MDTs with the acute and community haemoglobinopathy team took place fortnightly with a psychosocial MDT held on a monthly basis with the neuropsychologist and social worker. On a quarterly basis a local transfusion MDT was held to review all transfusion patients. The team were also involved in the monthly HCC multidisciplinary meetings.

The SHT provided training to all groups of staff and had started a monthly paediatric haematology teaching which referring regional hospitals were able to attend.

The paediatric service had a strong commitment to research and at the time of the visit an active research programme.

SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE	
Evelina London Children's Hospital	**Linked Haemoglobinopathy Coordinating Centres (HCC)**
	South East London and South East Sickle Cell HCC (Joint HCC with Kings College Hospital NHS Foundation Trust **Thalassaemia and Rare Inherited Anaemias HCC - East London, Essex, Southeast London and the Southeast of England**
	The Trust provided in reach model providing the care with the following Trusts
	Dartford and Gravesham NHS Trust - Darent Valley Hospital
	Medway Maritime Hospital NHS FT
	University Hospitals Sussex NHS Foundation Trust - Royal Sussex County Hospital
	NHS Frimley Health Foundation Trust
	Croydon Health Services NHS Trust
	East and North Hertfordshire NHS Trust
	East Kent Hospitals University NHS Foundation Trust
	Lewisham and Greenwich NHS Trust
	Epsom and St Hellier University Hospitals NHS Trust

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**
Sickle Cell Disease	**386**	**361**	**171**	**39 (9 of which on RCE[2])**	**147**	**84**
Thalassaemia	**18**	**17**	**6**	**8 (TDT)**	**N/A**	**0**

Staffing

Specialist Haemoglobinopathy Team	Number of patients	**Actual PA/WTE (at time of visit)**

[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 .

[2] RCE- Red cell exchange

Consultant haematologist/paediatrician dedicated to work with patients with hemoglobinopathies	404	Two consultants with 8 and 7 PAs =15 PAs
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with hemoglobinopathies	404	2.8 WTE CNS - Band 7 1.2 WTE Research Nurse 1 WTE Community CNS - Band 7
Clinical Psychologist for paediatric patients dedicated to work with patients with hemoglobinopathies		2 WTE provided by CAMH Team

Emergency Care

Patients attended the Evelina Paediatric Emergency Department (PED) based at the St. Thomas' hospital site. The department saw approximately 24,000 children each year.

All patients would queue to be triaged at the main Emergency Department (ED) desk, and then directed towards the PED entrance, where they registered at the PED reception. For patients with haemoglobin disorders, changes had been made to the pathway following feedback about long waiting times for triage and delays in patients receiving their first does of analgesia, the reception staff were now instructed to request an immediate review by the triage nurse, although the process was not robust; see concerns section of the report about the Emergency Department pathway. Parents had been provided with electronic sickle cell alert cards, to be saved on their mobile devices to show to reception staff, highlighting importance of a prompt review and patients were also being provided with the NHS hand held physical cards for sickle cell disease patients.

When there was a long queue, the paediatric ED triage nurse would take children out of the long queue to direct them towards the paediatric ED. Once seen by the triage nurse patients were reviewed and assessed and analgesia administered. The new EPIC system had a built in sickle cell alert card that was visible on the screen to prompt review, blood tests and analgesia as per NICE guidance. The EPIC system also held the patient specific care plan if available.

Patients that required admission would either remain at the children's short stay unit (CSSU) within PED for up to 24 hours. For those requiring intravenous PCA, blood transfusion, or anticipated to be admitted more than 24 hours, were transferred to Mountain Ward at the Evelina Hospital(collocated on the St Thomas' Hospital site).

Following triage and initial management, patients were reviewed by a haemoglobinopathy consultant/ or haematology SPR in PED in normal working hours. Those presenting out of hours would be seen by the haemoglobinopathy consultant the next morning.

Monthly haemoglobinopathy teaching sessions were provided for the staff in the PED and feedback received was that the short and regular teaching sessions were well-received by those attending.

In-patient Care

The inpatient team consisted of a haemoglobinopathy consultant and clinical nurse specialist and the haematology specialist registrar. A child and adolescent mental health psychologist (CAMHS) could join the ward round if required. on demand. A haematology SPR and a paediatric SPR were on call, and onsite 24/7 and there was access to a paediatric haematology consultant at all times

Surgical admissions (emergency or elective) were admitted to Savannah ward or Beach ward. Elective surgical patients were predominantly admitted for ENT, complex dental and general surgical procedures. A large proportion of those patients are referred from other haemoglobinopathy services in the region (SE England). To streamline this process, the haemoglobinopathy team were alerted directly by the surgical team or pre – assessment team with a TCI date, and 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 and outpatient care

Haemoglobinopathy outpatient clinics took place every Friday morning (once a month was reserved for telemedicine). The clinic was located in the Ocean outpatients department at the Evelina Main building. The clinics were attended by the core haemoglobinopathy team, CAMHS psychologist. A neuropsychologist was available and attended the morning teaching and patient list review. Community input at the clinics was not possible due to community staff shortages. Transition clinics were run once a month for all young people aged 12 years and above. In the absence of a substantive transition nurse, the transition workload was shared between the paediatric CNSs and one adult ANP. All children who were 12 years of age were supported and coached through transition passports by the existing paediatric CNSs. The adult ANP, if possible, would attend the paediatric clinic once a month to review and support all children over 12 years of age.

The trust used the EPIC system which enabled al patient data including vital signs, immunisation, and imaging to be immediate available.

Patients had access to written information, patient information leaflets, all information on haemoglobin disorders was also accessible via a scanned QR code. Annual reviews were completed in 30-minute outpatient clinic slots. For patients that attended for regular blood transfusion, then staff were able to conduct their annual review during their attendance to the day unit.

Elective blood transfusions took place in the Snow Fox Ward (day unit) located at St Thomas'. The unit was open Monday to Saturday between the hours of 8am and 7 pm.

Apheresis was undertaken on Snowfox day unit and available Monday to Friday 8 am to 5 pm, for elective transfusions and if required, acutely unwell inpatients. There was limited capacity for red cell apheresis due to staffing and available space. The day unit had two apheresis machines and one new machine expected from capital funding. Nine patients were on the programme and the service was entirely managed by the haemoglobinopathy CNS who could undertake ultrasound guided cannulation. *See concerns section of the report.*

Transcranial Doppler Scans (TCD) were undertaken in the ultrasonic angiography department at both hospital sites (St Thomas' and Guy's hospitals). A parallel TCD clinic to coincide with the main haemoglobinopathy clinic was planned for later in 2024 which would enable TCD scans to be undertaken when the patient attended for their clinic appointments.

Community-based Care

The community team was based at Wooden Spoon House, Elephant and Castle and hosted by the Evelina Childrens 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. There was no access to social, immigration or benefits advice.

Views of Service Users and Carers

The visiting team met with a group of parents and carers, caring for children and young people with sickle cell disease and thalassaemia during the visit. Their views were as follows:-

- The parents spoke highly about the support they received from the CNS team
- All Parents who spoke to the reviewers knew about the school care plans and were complimentary on the work the team did with schools to educate school staff about haemoglobin disorders. Video

conference meetings could also be arranged so that staff could provide advice and talk through the care plans with school staff.

- The carers praised the teams referral process and communication with local hospitals which meant their children were promptly transferred or referred to services at ELCH.
- Parents commented about how cold the ED and ward environments were and that they would bring extra blankets.
- None of the patients spoken to were aware of the 'pass' that would allow them to move up the queue in ED and be seen more quickly by the triage team.

Good Practice

1 Reviewers were impressed that as part of the setting up of the EPIC system a best practice advisory (BPA) had been implemented as a hard stop flag on the system which meant staff would need to acknowledge key information before they could proceed to the patient record. The care plan was very well structured, easily accessible and easy to read.

2 QR codes on the walls provided easy access to information and videos about sickle cell disorders. Patients and their families were able to access the information leaflets and click onto video links which provided additional information in a child friendly format.

3 The trust had implemented a 'Clin Bee' App which provided easy access to condition specific guidelines and policies for all medical and nursing staff.

4 Nurse led hydroxycarbamide had been in place since 2019 and reviewers were impressed with how the clinics had been developed based on feedback. A flexible approach had been implemented which enabled patients to book a slot to have their blood samples taken between the hours of 7.30 and 5pm, reducing the time they had to wait when attending. The service had also improved the pathway by the implementation of nurse led prescribing and agreed service level agreements with local prescribers.

5 Most pneumococcal vaccinations were administered by the CNS team when the patient attended their clinic appointment which meant that they would not need to remember to make an appointment for vaccine administration with their GP.

6 There was a good range of surgical pathways in place. For children requiring surgery the haemoglobinopathy team were alerted when the patient was provided with their admission date or attended their pre assessment clinic appointment. This meant that all patients booked for planned surgery would have their cases discussed at the haemoglobinopathy MDT and a consultation held with the family to ensure a peri operative plan was developed. Patients were then routinely reviewed at the time of admission and post operatively.

7 The psychology service had a low threshold for referral which meant that if parents, schools of other professionals had concerns they could refer for neuropsychology assessments. Once assessed they could be referred to the child and adolescent mental health team who would be able to liaise with the patient and their family in the community.

8 The review team were impressed with the excellent IV access provision which meant patients whose venous access was complex could easily be referred to the IV team.

9 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. In addition to a wide range of training provided to staff

in the care of patients with haemoglobin disorders the team were in the process of developing a module on sickle cell disease for all staff via the cancer academy.

10 The team had developed a number of sub specialist clinics for patients. Clinics ranged from neurology, transition, respiratory, renal, and endocrinology. The SHT were also working with the HCC to develop a network wide sickle cell disorder priapism pathway.

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

Serious Concern

1 Consultant staffing

Reviewers were concerned that the service had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders. The lead consultant had 9PAs for direct clinical care and 1 SPA which did not meet the minimum requirement of 1.5 SPA required for their appraisal and to maintain professional registration. Neither the lead consultant or the deputy had allocated time for supporting activities or for geographical leadership for the SHT or HCC. The Consultants were providing a 1:2 rota for their hemoglobinopathy work and a 1:3 on call out of hours rota which reviewers considered was not sustainable.

Concerns

1 Access to 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 SHT was 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 Analgesia

The most recent service audit of compliance with the NICE clinical guideline on the management of acute pain showed that only 44% of patients had received analgesia within 30 minutes of arrival to the Emergency Department. Reviewers were made aware of a range of actions being taken by the SHT to improve the urgent and emergency pathway to improve compliance with the time to first does of analgesia however the results of 44% were suboptimal.

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.

4 Access to welfare and benefits support

Patients with haemoglobinopathy disorders did not have easy access to social, immigration or benefits advice which resulted in clinical staff spending a considerable amount of time supporting patients and their families with welfare issues. The reviewers were told that this issue would be addressed once the new community hub was in operation.

Further Consideration

1 The SHT has a range of projects and service improvements project underway and from discussion during the visit it was not clear to reviewers how all the different groups were collaborating to meet the teams priorities and the work plan.

2 Preparation for transition to adult care started around the age of 12 years and in the last two years 69 young people had transitioned to adult services. As the Transition CNS post had been vacant since 2018 it was not clear who within the team had oversight of the young people to ensure that their transition passports were completed. At the time of the visit the recruitment to the vacant transition nurse post had commenced and reviewers commented that should recruitment be unsuccessful, then providing specialist support for transition would continue to add a significant workload for other members of the SHT.

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Specialist Haemoglobinopathy Team (Adult Services):

Guy's and St Thomas' NHS Foundation Trust (GSTT)

General Comments and Achievements

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

The adult haemoglobinopathy service at GSTT managed the care of 1025 adults with haemoglobinopathy diagnoses who were registered on the National Haemoglobinopathy Register. Over the past 10 years patient numbers had increased from 580 in 2012 to approximately 1119 at the time of the visit.

Staffing consisted of three consultant haematologists with dedicated 21.5PAs for haemoglobinopathy work alongside three general haematology colleagues who jointly managed the inpatient work. The SHT had 1.5 WTE Advanced Nurse Practitioners (ANP) and two clinical nurse specialists (CNS). The haematology psychology service, consisting of 0.6 WTE Consultant Psychologist, one WTE highly specialised psychologist, two psychologists and a pre-qualified assistant psychologist supported haemoglobinopathy patients but also those patients with haemostasis and myeloproliferative diagnoses. The SHT had administrative and data management support.

Nurse led Hydroxycarbamide telephone and face to face monitoring clinics were well established and a range of joint specialist sickle cell clinics were in place with respiratory, neurology, transition, orthopaedic, obstetric, pain, endocrinology and nephrology and there were good links with other specialist services.

The results of the network wide survey undertaken in 2023 had shown some changes in experience and care. The SHT had an action plan to address these and had applied to the ICB health Inequalities fund to optimise the urgent and emergency care pathway to improve access and for the development of patient information.

Regular transition clinics and workshops were provided for young people transitioning to adult care. The transition CNS post had been vacant since 2018 which both the children's and adult SHTs considered had resulted in a negative impact on the transition process. At the time of the visit, recruitment to the transition CNS post was in progress. Some work had been undertaken to alter the pathway and the transition clinics were now held with the adult service at Guys Hospital site to enable young people to familiarise themselves with the facilities and meet with a wider range of staff. There was also a new Teenage and Young Adult (TYA) ward being commissioned at the Guy's hospital site which would be accessible to teenagers and young adults with haemoglobin disorders.

The team was committed to teaching and training with teaching and training undertaken by all team members across the breadth of the MDT within the hospital and beyond. *See good practice section of the report.*

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 Steadfast, Hope, Hibiscus, TAPS 2, and Natural history studies actively recruiting.

An active support group was in place for patients with sickle cell disorders and thalassaemia, facilitated by the psychology service, and patients were often involved in strategic and operational issues, and research.

SPECIALIST HAEMOGLOBINOPATHY TEAM - - ADULTS			
Guy's and St Thomas' 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	**Thalassaemia**
	Dartford and Gravesham NHS Trust - Darent Valley Hospital	74 (58 attend GSTT & 16 attend KCH)	2
	Maidstone and Tunbridge Wells NHS Trust	0 on NHR Appx <20	0 on NHR 1 shared care GSTT
	Medway Maritime Hospital NHS FT	97	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- ADULTS						
Condition	**Registered patients**	**Active patients *[3]**	**Annual review ****	**Long-term transfusion**	**Eligible patients - hydroxycarbamide**	**In-patient admissions in last year**
Sickle Cell Disease	988	Data not provided	563	222	279	708
Thalassaemia	31	Data not provided	Data not provided	Data not provided	N/A	

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

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant haematologist dedicated to work with patients with hemoglobinopathies	1119	3 Consultants with 21. PAs for Haemoglobinopathy work
Clinical Nurse Specialist (CNS) for adult patients dedicated to work with patients with hemoglobinopathies	1119	1.5 WTE ANP 2 WTE CNS 1 WTE Community CNS
Clinical Psychologist for adult patients dedicated to work with patients with hemoglobinopathies	1119	4.48 WTE qualified psychologists + 1.0 Assistant Psychologist covering all adult non-malignant haematology plus myeloproliferative neoplasms and including dedicated support to haemoglobinopathies.

Emergency Care

Patients presenting to the ED at ST Thomas' hospital, were assessed then transferred either directly to an inpatient ward at Guys Hospital or to the multi-speciality unit (MSAU) from where they can be discharged home or admitted to a Guy's hospital in patient ward. Acutely unwell patients requiring resuscitation were admitted to the ICU or HDU at the St Thomas site.

Inpatient Care

inpatient care was provided at both the Guy's and St Thomas' Hospitals. Patients were admitted mostly via the emergency department but could also present to the haematology day unit Mon – Fri to access the pain service and may be admitted via this route. Daily consultant led ward rounds were in place Monday through Friday and Specialist trainee led rounds on Saturday and Sunday, and all ward rounds would cover patients admitted to both hospital sites.

Outpatients

Twice weekly general haemoglobinopathy outpatient clinics were held on Tuesday afternoon and Friday mornings and additionally the team ran monthly joint specialist clinics in these areas. The clinics were supported by between 1-3 sickle consultants, a specialist trainee, an ANP and members of the MDT including the psychologist for the pre-clinic meeting and for select joint patient review.

The ANP team held dedicated Nurse led Hydroxycarbamide clinics on Wednesdays and Thursdays.

Apheresis

The service had a large and expanding red cell exchange programme for patients with a haemoglobinopathy diagnosis, with 222 patients on the programme in November 2023 and a small waiting list of patients due to join. This service was run from the haematology day unit on the Guy's hospital site, where there were five apheresis machines with an additional machine due to be commissioned. The service was able to perform 6 -7 procedures per day but could increase to 8 if required. The two specialist apheresis nurses, both band 7 were also CVAD trained and able to insert femoral lines in the patients who require this access, although in general

peripheral access was preferred in as many patients as possible. All the apheresis nurses were trained to access veins with ultrasound. There was good collaboration with the renal vascular access team and the team were working on case to develop a fistula service specifically for thier transfusion cohort, at present this was done on an ad hoc basis.
A small cohort of transfusion dependent thalassaemia patients, three adult sickle patients and one PKD patient who were additionally managed on a regular top up transfusion program via the day unit.
During the Covid -19 pandemic the team reviewed all regularly transfusion patients on the day unit whilst they attended for transfusions, but due to the total numbers, low availability of private spaces on the day unit to maintain clinical confidentiality be reviewed opportunistically during their transfusion episode to ensure they received their annual reviews.

Community services

The community team was based at Wooden Spoon House, Elephant and Castle and hosted by the Evelina Childrens 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. There was no access to social, immigration or benefits advice except via local Citizens Advice Bureaus. Help with housing, personal individual payment, immigration, benefit, and financial burden was due to be taken on by the Southwark Law Centre and the community service were recruiting to two new benefit advisor posts.

Views of Service Users and Carers

The visiting team met with five adults with sickle cell during the visit. Reviewers did not meet any patients living with thalassaemia or anyone who had recently transitioned to the adult service.

Of note was that none of the patients who met with the reviewing team had experienced a sickle cell crisis requiring admission in the last 4 – 5 years so they were not able to comment on how inpatient care was being delivered at the time of the visit and that some of the experiences recounted may no longer be valid. See their feedback below about the services provided by the Trust:

- Patients who met with the visiting team commented that whilst they had care plans they were not always acknowledged or used by health professionals.
- Patients were not aware that they could have a patient controlled analgesia system for control of acute pain when an inpatient.
- Patients would like access to a blood transfusion service on a Saturday
- Patients were aware that they needed to visit their nearest hospital in an emergency, which may not always be at Guys and St Thomas' NHS Foundation Trust.
- They commented that their experience of the Emergency Department and wards was that they were always cold, and they had to ask for more blankets and food and drink was not available if they were awaiting admission.
- Patients commented that they often had multiple moves to different wards when an inpatient and felt that staff could be more understanding of the nature of their symptoms and their susceptibility to the cold.
- The day unit only had space for four beds and the patients who met with the visiting team said access to these was on a first come first served basis and that patients with other treatments and conditions took priority.

- Those who met with the reviewing team talked about young people when admitted to adult wards often found it hard to be with the very sick and dying patients and would value access to the young person ward once operational

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. 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.
3. 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.
4. The SHT ran a monthly virtual pain MDT clinic with colleagues from the pain team and would accept referrals from other Haemoglobinopathy Coordinating Centres. The MDT had representation the wider SHT and representatives from the chronic pain team who had a particular interest in sickle cell disease and opioid management. The team reported that since the commencement of the MDTs it had resulted in patients with chronic pain receiving a more holistic approach to pain management. As part this approach they were seeing patients being less dependent on long-term opioids and they had been able to work with patient following discharge to ensure a return back to their pre-admission baseline opiate intake. They had also produced a leaflet that educates on opioid medications.
5. The psychology team had ensured that users were actively involved in the interviews for psychology staff. Involvement of users regularly in staff recruitment was also being considered.
6. The Lead Nurse was proactive in supporting other SHTs and had delivered study days for the SHT provided by Croydon Health Services NHS Trust and was planning to undertake similar activity for the SHT based at Lewisham and Greenwich NHS Trust
7. Reviewers were impressed with the excellent support the SHT received from the critical care team in terms of their advice and provision of emergency red cell exchange transfusions
8. Consultants on the attending rota had protected time outside of ward weeks and there was also a rota specifically to cover outpatient and day unit queries which enabled the other consultants to focus on their other direct care commitments. The consultants also had included in their programmed activity (PAs) time allocated to undertake research. The team were also impressed by the addition of other general haematologists to the ward cover rota which increased the resilience of the service and allowed the sickle cell disease focussed consultants time to improve and develop the service.
9. The breadth of sub specialist clinics and MDTS in place for patients was impressive. Clinics ranged from orthopaedic, neurology, obstetric, teenage transition, chronic pain, respiratory, renal, respiratory, and endocrinology.
10. 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. One of the consultant haematologists was the lead investigator for 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.

Concerns

1 SHT Leadership

Reviewers were concerned that the Lead clinician had only 1hr per week to provide leadership, service development and for their network role as SHT lead and for their deputy lead role in the HCC. Support to the LHTs was particularly important as they were experiencing a significant increase in patient numbers and reported the increasing pressure of trying to care for this cohort of patients with limited staff time and experience in caring for patients with haemoglobinopathies.

2 Red Cell Exchange Apheresis Service

Reviewers were concerned that apheresis could only be provided Monday to Friday and not available 24/7 as expected by an NHSE specification for specialist haemoglobinopathy teams.

The red cell exchange programme provided by the Trust was one of the largest programmes in England with 222 patients on the programme and a waiting list and with the increase in patient numbers likely to be an ever-increasing demand year on year.

Senior clinical staff were spending large amounts of time constantly juggling the programme diary in order to get new patients and ad hoc patients into the service. In addition, there was an informal good will rota whereby staff would be called out of normal working hours to undertake urgent apheresis. Reviewers were told that in addition to the informal arrangements, staff were not paid enhanced rates for attending out of hours. The SHT had submitting a business case to expand the service so that a weekend working model could be introduced but this had not been agreed by the trust.

At the time of the visit, reviewers were concerned that this service was unable 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 additional funding and, support at trust level.

3 Access to Analgesia

The most recent service audit of compliance with the NICE clinical guideline on the management of acute pain showed that only 55% of patients had received analgesia within 30 minutes of arrival to the Emergency Department. Reviewers were made aware of a range of actions being taken by the SHT to improve the urgent and emergency pathway to improve compliance with the time to first does of analgesia however the results of 55% were still suboptimal.

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. Due to the low prevalence of this group across the SHT catchment and with the number of thalassaemic patients in the transition process to adult care, the SHT may wish to consider identifying a lead for Thalassaemia who would be responsible for this group, including oversight for guidance and information and to ensure best practice is implemented.

4 Access to welfare and benefits support

Patients with haemoglobinopathy disorders did not have easy access to social, immigration or benefits advice which resulted in clinical staff spending a considerable amount of time supporting patients and

their families with welfare issues. The reviewers were told that recruitment for a social worker was in the progress and that additional support would be available once the new community hub was in operation.

Further Consideration

1 Patients who met with the reviewers reported that their care plans developed at GSST were not used when they attended their local hospital, which were often in the same network, as well as when they attended elsewhere.

2 Psychology support was approximately 3.4 WTE for 1119 patients and did not quite meet British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia recommendation of one WTE for 300 patients and likely to be insufficient as rise in demand for the service continues.

3 Governance of guidance and protocols should be more robust ensuring appropriate document control and updating. There was little indication in the published documents as to how they were being utilised by the SHTs and LHTs in the network as the documents did not include information about the local pathway or contact details.

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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 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
Andrea Leigh	Consultant Paediatric Haematologist	University College Hospital NHS Trust
Isabel Adams	Haemoglobinopathy Liaison Sister	Birmingham Women's and Children's NHS Foundation Trust -
Edith Aimiuwu	Paediatric clinical nurse specialist (ANP)	Whittington Health NHS Trust
Hannah Coyle	NHS England Quality Manager (Specialised Commissioning)	NHS England
Carol Burt	User representative	Midlands Sickle Cell Patient Voice Group
Elizabeth Caulley	User Representative	Manchester Sickle Cell Society
Romaine 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 TBA

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	37	76%
Specialist Haemoglobinopathy Team (SHT) Adults	45	35	78%

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: 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 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	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
	The lead manager should have appropriate time for their role.		
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.

Specialist Haemoglobinopathy Team for Children and Young People with Haemoglobin Disorders

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-102	**Information about Haemoglobin Disorders** Children, young people and their families should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Parental or self-administration of medications and infusions	Y	Leaflets were available in paper form as well as QR codes on inpatient and outpatient areas. Information included short videos of patients experiences related to the information provided . Information was all in English but the team could print information for patients whose first language was not English.
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	Schools had care plans and the care plans were individualised for patients with sickle cell disorder or thalassaemia. Letters written were generic but when required was tailored to the individual's need. In some documentation seen the spelling of thalassaemia was not correct.
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	All Parents who spoke to the reviewers knew about the school care plans and were complementary on the work the team did with schools to educate about haemoglobin disorders . Teams meetings were also arranged with schools so that staff could provide advice and talk through the care plans with school staff

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	Y	Patients reported that the wards and ED areas were always cold and they had to ask for more blanket.
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	Young people had either a Thalassaemia or Sickle cell passports and a booklet explaining about transition. The team would also prepare a handover document. For young people with a sickle cell disorder this the handover include information about their analgesia plan
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	Y	
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The nominated lead had 9 PAs for direct clinical care and only 1 SPA and no time allocated in their job plan for service development and SHT 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.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The two consultant paediatric haematologists had 15PA in total for general haematology to care which included caring for 404 children and young people with haemoglobin disorders The two consultants did not have sufficient PAs for supporting activities (0.5 PAs per 50 patients) and the lead did not have any time allocated for their geographical leadership role (1PA).
HC-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of children and young people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	
HC-206	**Doctors in Training** If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders.	Y	
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.	Y	

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	Two WTE psychologist were in place for the haemoglobinopathy service via CAMHS team with access to neurocognitive assessment provided by a neuropsychologist based at ELCH.
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	N	Patients did into have access to a Social worker / benefit adviser. At the time of the visit the team were in the process of recruiting to two posts.

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	Automated red cell exchange transfusion was only available Monday – Friday 9am -5pm All other specialist support was available.
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.	Y	
HC-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HC-195)	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	
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	Of note was that the guidelines did not reflect the latest update from NHSBT on the use of <10day old blood.
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	N	The guidance due for review in 2022 and it was not clear how the BSH guidance had been adapted for use locally.

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	N	It was not clear in the guidance about acute changes in vision and indications for seeking advice from the HCC / SHT.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-510	**Clinical Guidelines: Chronic Complication** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea f. Endocrine and growth problems, including endocrinopathies and osteoporosis g. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology h. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease i. Growth delay / delayed puberty j. Enuresis k. Urological complications, including priapism l. Dental problems	N	Indications for discussion at MDT and cardiology guidance covering cardio myopathy relating to SCD and iron overload related heart disease was not included in the guidance. The guidance was comprehensive for the other areas of the QS.
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	N	Operational policy was due for review by April 2023; Some information had been updated in the guideline in December 2023.The policy was not clear about the following:- Failsafe arrangements in terms of who would be responsible for oversight for those who were referred especially as the TCD compliance rate was 50%. rate ('e') The policy mentioned DNA policy rather than the term 'were not brought ' for children and young people and did not include the criteria for referring to the safeguarding team ('g'). In practice, families would be sent a text reminder for appointments about a week before the clinic and would receive a reminder call from community nurse. Governance arrangements for providing consultation and assessment virtually was not explicit ('f'), apart from the nurse led telephone clinic which did have process for managing queries and for Hydroxycarbamide treatment.

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	No patients with thalassaemia had been admitted in the last year.
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	From the evidence seen it was not clear whether the SHT had reviewed 'a – c' with patient and carer reps 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.

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.	Y	

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	Y	
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	Y	Patients who met with the visiting team commented that whilst they had care plans they were not always acknowledged or used by health professionals
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	The Thalassaemia GP information seen included details about hydroxycarbamide and painful crisis.
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	Patients reported that the wards and ED areas were always cold and they had to ask for more blankets
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	Young people had either a Thalassaemia or Sickle cell passport and a booklet explaining about transition. The psychology team also were involved with young people when they first transitioned to the adult service.

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 SCD and Thalassaemia Patients were involved in strategy, operational issues, and research. The psychology service also ran patient group meetings
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The nominated lead had insufficient time allocated in their job plan (1hr) for service development and network role Deputy for lead consultant was in place.
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	There were insufficient medical staff (21.5PAs) to care for 1119 patients. The SHT had only been able to complete 50% of patient annual reviews and the lead did not have time for network leadership.
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	Y	The SHT had a total of 1.5 ANP and 2 WTE CNS and 1 WTE CNS who covered the community. 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	There were 4.48 WTE psychologists covering 1119 haemoglobinopathy patients and also those with haemostasis and patients with myeloproliferative diagnoses. Reviewers were told that about 70% of referrals were related to SCD and thalassaemia equating to approximately 3.4 WTE of qualified psychology service making a ratio of 1:330 patients.
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	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	Automated red cell exchange transfusion was not funded 24/7. In practice there was an unofficial rota and staff would undertake out of normal working hours. Reviewers were told that a business case to provide a service 24/7 had been developed but not agreed.
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HA-195)	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	Y	
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	Guidance was in the process of being updated. Existing guidance covered all aspects of the QS.

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	Y	STSTN Guidance seen but the guideline did not include a review date or version number.
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	Y	

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	Y	
HA-511	**Anaesthesia and Surgery** Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery.	Y	

Ref.	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	Y	
HA-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	

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	Y	The operational policy dated 2023 covered all aspects of the QS
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	The SHT did not have any formal SLAs with their LHTs. The SHT had plans to address this as part of their annual work programme.

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	
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	Y	
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	From the evidence seen it was not clear whether the SHT had reviewed 'a – c' with patient and carer reps 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	There was no standardisation of documents submitted.