MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

Health Services for People with Haemoglobin Disorders

Lewisham and Greenwich NHS Trust

Visit date: 06th February 2024

Report date: 11th July 2024

Contents

Introduction

This report presents the findings of the review of the Lewisham and Greenwich Hospitals NHS Trust that took place on 6th February 2024. The purpose of the visit was to review compliance with the Health Services for People with Haemoglobin Disorders Quality Standards Version 5.1, November 2021, which were developed by the UK Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit was organised by the Nursing and Urgent Care Team (NUCT) at the Midlands and Lancashire Commissioning Support Unit (MLCSU). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

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

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

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

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

- Lewisham and Greenwich Hospitals NHS Trust
- NHS England - London
- NHS South East Integrated Care Board

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioners in relation to this report is NHS South 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 to optimal care for all individuals living with an inherited haemoglobin disorder or rare inherited anaemia. 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 the Lewisham and Greenwich 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.

Return to Index

Review Visit Findings

Trust-wide General Comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders at the Lewisham and Greenwich NHS Trust (LGT). In total, the Trust serves 793 patients with haemoglobin Disorders, mostly sickle cell disease (SCD). During the visit, reviewers attended both the University Hospital Lewisham (UHL) and the Queen Elizabeth Hospital (QEH), and visited the emergency departments, assessment units and wards on both sites; they met with patients and carers, and with staff providing services for the local health economy.

The adult and paediatric Specialist Haemoglobinopathy Teams (SHT) provided services to the regions of Lewisham, Bexley and Greenwich, and cares for the 6th largest Haemoglobinopathy population in the UK. Both Trust acute sites have an Emergency Department, an ICU providing level 2 and 3 care, a Maternity Unit and a Level 2 Haemato-oncology service. Laboratory services were provided by the NHS East and South-East London Pathology partnership while substantial laboratory services including a comprehensive transfusion laboratory remain at each hospital site.

Specialist Haemoglobinopathy Community Nurses were available to both the adult, and children and young people (CYP) of Lewisham, and the CYP living in Greenwich and Bexley who use the QEH site for acute services. There was no service for the adult patients cared for at the QEH.

Some issues in this report relate specifically to the Trust as a whole and have been included in the Trust-wide section of the report. Other issues that were the same for both the adult service and the children and young people service have been repeated in each section.

Trust-wide Good Practice

Trust-wide Good Practice – children and young people

1. Strong networking with South East London and South East HCC - The reviewers were positively impressed by the robust relationships and networking structures that the SHT maintained with the HCC.
2. Paediatric patients had access to a dedicated cross-site Psychology Service – the Clinical Psychologist specialising in Haemoglobinopathies actively participated in clinics and organising bi-monthly Multidisciplinary Team (MDT) meetings to address and manage complex cases.
3. There were strong collaborations and connections between the Trust and Community Service providers.

Trust-wide Good Practice – adults

1. The review team met with executives who were committed to developing the service - considering this a high priority alongside other key services. This commitment was evidenced by recent investments in the apheresis service, the third Spectra Optia machine and development of the Hyper Acute Sickle Cell Unit (HASCU) business case. The clinical team and divisional management worked closely together and communicated the needs of their patients well to senior managers and executives.

2. Patients received an excellent psychology service achieving a positive impact in caring for the mental health of the patients, teaching them coping skills and problem solving. Presence in clinics at UHL enabled direct and immediate support alongside group learning specific to those undergoing exam stress. Training was provided by the team to front line staff in how to support sickle cell patients in crisis. Although the

psychology establishment was not to that required for the patient numbers, the team prioritised and triaged demand.

Trust-wide Serious Concern

Trust-wide Serious Concern – children and young people

1. Consultant Staffing

The Paediatric Consultant team (consisting of general paediatricians with a vast experience and interest in haemoglobinopathies) worked extremely hard, and the service was sustained on an 'above and beyond' commitment. The medical workforce establishment fell below that required for this service and therefore impacted on the ability to partake in essential activity such as audits, research and updating protocols, alongside delivery of direct patient care.

2. CNS Staffing

The service had insufficient CNS staffing with only one CNS (1 WTE) employed to cover both UHL and QEH sites. There were no cover arrangements for the Paediatric CNS sickness or absence. Pre-covid, a business case to increase capacity was written, however this had not progressed at the time of the visit. The service plan to re-submit an updated business case which if approved, would allow the service to recruit to a cross-site lead ANP post to facilitate automated exchanges plus additional CNSs to provide a more robust service and teaching programme for nurses, ward, and Emergency Department (ED) junior doctors. Without the approval of this business case, the service is extremely vulnerable.

Trust-wide Serious Concern – adults

1. Consultant Staffing

The reviewers observed that the service was driven by a workforce that works extremely hard and sustained on an 'above and beyond' commitment: the Lead Consultant PA allocated had been reduced from 1 to 0.5PAs. The medical workforce establishment fell below that required for this service and therefore impacted on the ability to partake in essential activity such as audits, research and updating protocols, alongside delivery of direct patient care. If the bid for the HASCU is successful, the availability of senior medical staff will need to be carefully considered.

2. Use of General Medical Wards – Adults

A high number of patients were admitted to non-haematology wards. The emergency pathway on both sites directs admissions via the Medical Admissions Unit (MAU) and often patients have been subsequently admitted to general medical wards due to no haematology beds being available.

It is recommended that the Trust undertakes a review of the haematology bed base capacity and demand and considers the implementation of electronic observation system in ED and MAU ward areas to support early identification of the deteriorating patient. This review is also timely in relation to moving sickle cell admissions to UHL as the opening of the proposed HASCU will further increase pressure on haematology bed capacity and challenge the successful implementation of this development.

Trust-Wide Concern

Trust-wide concern – children and young people

1. **No paediatric specialist pain team**

   There was no Paediatric Pain Service at either site within the Trust, and Patient-Controlled Analgesia (PCA) is unavailable. Patients in need of PCA are consequently transferred to Kings College Hospital NHS Foundation Trust (KCH) for the service.

2. **Vulnerability in the Transition Pathway at QEH**

   There was vulnerability of the transition pathway at QEH due to an existing vacancy for an adult consultant haematologist. Although plans were in place to establish joint transfer of care clinics similar to those at UHL, the reviewers were apprehensive that the challenges in recruiting for this position could impede the smooth transition of paediatric patients to adult services. This is covered in more detail in the adult section as the CYP directorate does not have influence over the adult posts.

3. **Emergency Care**

   Concerns were raised by patient representatives in relation to the effectiveness of the 'green card' flagging status when attending the Emergency Department at both sites. There was a perception that knowledge of this by reception staff was variable and in some instances reception staff were assessing the priority status of patients leading to prolonged waits to be seen. Also, there were concerns raised by patients regarding the communication of plans in the ED at QEH.

Trust-wide Concern – adults

1. CNS workload

The CNS establishment of 3 WTE was inadequate for the size of the population served. Some activities such as writing support letters for schools, disability badges, universities etc were undertaken by the CNS, consultant, or psychologist because of a lack of MDT support for such areas, this impacted on their capacity for direct clinical care. More significantly, the CNSs were providing the elective apheresis service at the expense of their main role. The reviewers heard that this will be addressed soon, as 2 band 6 nurses have been appointed (and are currently being trained) to deliver the elective apheresis service. The review team also heard that the Chief Nurse was completing a Trust wide CNS review, which will hopefully explore alternatives such as skills mix to support delegation of appropriate tasks to release clinical time.

2. Divisional moves

The service described how they had moved divisions quite a lot which then entailed a new management team having to learn the service to understand the challenges and complexities. The service reported feeling supported and listened to by the current division; a sustained consistency of management would be helpful to aid and maintain the progress of the team.

3. Disparity of Services

There was a disparity of services between the UHL and QEH sites. Examples of this disparity included the lack of a Haemoglobinopathy (HBO) specialist consultant at QEH, provision of automated apheresis only at UHL with QEH patients transferred across, inability to see the psychologist face to face at QEH, and lack of access to community HBO services at QEH. If the HASCU bid for UHL is successful, the Trust should ensure this does not further increase these disparities.

Trust-wide Further Considerations

Trust-wide Further Considerations – children and young people

A long-term strategy for the provision of the service needs to be developed and the business case that the service plan to submit to address the Nursing and Admin workforce challenges requires close consideration to ensure sustainability and mitigate service vulnerability.

Trust-wide Further Consideration – adults

1. The required estates provision at QEH should be reviewed to support the HBO patients to attend clinic consultations with all MDT members with access to services in line with those at LUH.
2. Staffing levels and the junior nursing skill mix specifically in ED has made dedicated training challenging for the practice education nurses and CNS teams. The introduction of sickle cell link nurses and a sickle cell disease acute admission training tool will support this, alongside a more formalised nursing competency framework.
3. The Trust's implementation of a new Electronic Patient Record System (EPR) as part of the wider digital strategy should provide dedicated templates to support the generation of letters to schools etc, which will release CNS time for direct clinical care.
4. A long-term strategy for the provision of the service needs to be developed and agreed across the system by commissioners, Trust executive team, the speciality team, and service users. This should include both plans for expansion alongside clarity of what provision will be available on each acute site with full consideration of the future population health need.

Views of Service Users and Carers

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

During the visit the visiting team met with 11 adults, 10 had sickle cell disease, and 1 adult with thalassaemia. From the children's perspective the review team met 3 families with sickle cell disease and 2 families with B thalassaemia major.

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

The views of the users were extensive and wide-ranging and are documented in the children's and adult specialist haemoglobinopathy team sections. The review team would like to thank them for their openness and willingness to share their experiences.

Specialist Haemoglobinopathy Team (Children and Young People Services)

General Comments and Achievements

The LGT SHT was split between two hospital sites (UHL and QEH) with a shared management structure, policies and procedures and key staff including CNSs, Psychologists, Transition Team, and data managers as well as equal access to the elective automated exchange blood transfusion program (EBT) sited at the UHL. Medical staff were site specific as were non-specialist nursing staff, although the Haemoglobinopathy consultants were available for advice cross sites.

Haemoglobinopathy services for adults and young people post transition aged 16 and above were run separately to Paediatrics services, with transition straddling both services.

The Lewisham (UHL) site and the Queen Elizabeth (QEH) site had co-leads. The QEH site, which covers both Bexley and Greenwich areas, had an additional Paediatric Consultant who also ran Haemoglobinopathy clinics and supported with broader care delivery. The lead at the QEH site was appointed 5 months before the review team visit following the retirement of the previous lead. During the interim period, the service was covered solely by the deputy lead, posing challenges to an already limited workforce. Additionally, there was one acute CNS and one psychologist who provided cross-coverage, which was demanding given the patient volume at each site.

Although there were operational differences cross sites, the service was managed as a single unit.

There was access for older teenagers to the apheresis service currently run at Lewisham hospital but available to patients from both sites.

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

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM

Condition		Registered patients	Active patients *[1]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Children & Young People	384	411	346	11	197	290
Thalassaemia	Children & Young People	4	4	4	4	.	0

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual WTE/PA (at time of visit)
Consultant Haematologist/Paediatrician dedicated to work with patients with haemoglobinopathies	411	7.5
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with haemoglobinopathies	411	1.0
Clinical Psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies	411	1.0

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

Urgent and Emergency Care

UHL

At the UHL site, children with acute problems attended Paediatric A&E (under the CYP directorate), where they were assessed and treated before being discharged or admitted to the Children's in-patient unit or Paediatric short stay unit if deemed appropriate. All children were attended to by staff employed in the CYP directorate.

The UHL Paediatric A&E area underwent redesign after COVID-19-related changes to the environment/paediatric space available.

QEH

At QEH, patients were seen in A&E (under Adult A&E directorate) in the designated Paediatric area. Sickle cell patients had a fast-track pathway and were seen by paediatric staff as opposed to ED staff unless it was in the case of trauma. Patients also reported being issued with a 'green card' to enable prioritisation, however they stated that reception staff were not always aware of this or knew what it meant, highlighting a requirement for education of non-clinical staff. If experiencing a painful crisis, analgesia was administered at triage. If the patient was deemed stable, there was a fast-track pathway to Happy Hippo Day Unit (HHDU) for assessment by paediatric staff. Assessment of all vitals were used to triage patients and select patients who were deemed to be stable enough for transfer to the HHDU. Patients requiring oxygen or scoring 3 or more on PEWS (Paediatric Early Warning Score) were seen in the ED. For younger children who were unable to use a numerical pain scale, the FLACC tool (Face, Legs, Activity, Cry, Consolability scale) was used. The service reported that the average length of wait to see a doctor on HHDU was 1 - 2 hrs. During this time, the nursing team assessed the child and gave appropriate analgesia.

A Paediatric Consultant was available 24/7 on both sites. The Lead Consultant on each site was informed of admissions. If there were significant concerns the patients were be discussed with Adult Haematologists on site or Paediatric Haematologists at KCH or Evelina London Children's Healthcare (ELCH) out of hours.

There are no facilities currently for direct admission to the inpatient wards on either site.

In-patient Care

UHL

The children's ward (Orchard ward) was an in-patient area with 20 beds (3 bays of 4-6 beds, 5 cubicles and 2 other isolation areas). In Paediatric ED, there was also a Paediatric Short Stay Unit with up to 4 beds. There was a 4 bedded HDU bay on Orchard ward which was used for patients on IV morphine and Opti flow.

QEH

The children's ward (Safari ward) was a 20 bedded ward with 15 cubicles and a 5 bedded bay.

The ward cared for a variety of general paediatric cases, orthopaedic and general surgical cases. The ward was generally very busy with 85-90% occupancy of beds on most days.

Regular blood transfusions were given via Porta Cath or peripherally on Safari ward.

In December 2022, a 4 bedded level 2 High Dependency Unit (HDU) within Safari Ward became fully operational at QEH. There was facility to provide non-invasive respiratory support for children with CPAP and BIPAP as well as enhanced physiotherapy. There was regular input in management for admitted patients from the Paediatric Intensive Care Unit (PICU) consultants at ELCH, as well as daily reviews from a Paediatric Consultant with HDU special interest.

At both UHL and QEH, a dedicated school room was available in the wards for children during their admission. Overnight accommodations were provided with beds for parents, and each in-patient ward had a designated play specialist. Additionally, interactive sickle cell education was facilitated through board and card games supplied by the Sickle Cell Society.

Collaboration between nursing and administrative staff on the ward and the acute CNS and community teams ensured seamless communication. This coordination ensured that the haemoglobinopathy clinical nurse specialist remained informed about the child's hospital admission and discharge process.

Day care

UHL

At UHL, the Children's Day Care Unit had 16 beds and was open from 07:30-20:30. It was used for regular blood transfusions as well as elective paediatric surgery and drug infusions. There was a dedicated play specialist for the Unit.

QEH

At QEH, the Happy Hippo Unit was open from 09.30-24:00 with a supervising Paediatric Consultant (last referrals accepted at 20:00). The Day Unit had many functions including an observation unit, primary and secondary assessment of patients presenting as emergencies, out-patient reviews, investigations including some phlebotomy, drug infusions and blood transfusions.

Outpatients

UHL

At UHL all children's outpatients' clinics were held in Kingfisher, a dedicated children's area, open from 09:00-17:00 5 days a week. There were 11 main consulting rooms and treatment rooms for weighing and measuring children as well as blood pressure and oxygen saturation measurements and urinalysis.

The Lead Consultant held 6 outpatient clinics per month in the children's outpatient department alongside the community and acute Sickle Cell Nurse Specialists. The Paediatric Psychologist sat in 2-3 clinics a month alongside the consultant.

Once a month visiting sonographers from the Vascular team at KCH performed Transcranial Doppler Ultrasound scans in the outpatient Clinic before the children were seen by the consultant or CNS.

There was a total of 4 joint clinics a year led by visiting paediatric haematologists from KCH. Children on regular blood transfusions were seen every six months in a dedicated joint transfusion clinic.

Teenage clinics took place on alternate Wednesday afternoons in the UHL paediatric outpatient clinic area for young people aged 11-17. Transition education and skills development were guided by the age-appropriate Ready Steady Go questionnaire responses in a stepwise fashion, alongside routine medical care and surveillance.

The transition to adult care pathway included a single joint transfer of care clinic which was arranged for those who were ready to move up to the adult services. This was attended by members of both the adult and paediatric staff including community-based nurse specialists, hospital-based nurse specialists, psychologists, and medical staff. They were arranged approximately 3 times per year on a Wednesday morning and took place in the adult outpatient area (suite 4).

Phlebotomy at UHL is based in Suite 1, open Monday to Friday, 08:00-16:00, for all ages. There was an imminent plan for paediatric phlebotomy to be co-located in children's day care.

QEH

At QEH, there was a dedicated paediatric outpatient department, Dolphins, open 5 days a week. There were 7 main consulting rooms and treatment rooms for weighing and measuring children as well as blood pressure and oxygen saturation measurements and urinalysis.

The Paediatric clinics in QEH were held weekly on Thursdays in the Dolphin outpatient department. There were 16 appointments in total including 2 "new" appointments for newly diagnosed children detected on new-born

screening who would be seen before reaching 3-months of age, and for patients who had moved into the area. New patient appointments were 30-minutes long and follow-up appointments 25-minutes long. The acute and community CNS and psychologist attended clinic. Twice a month visiting sonographers from the Vascular team at KCH performed Trans-cranial Doppler screening scans in the outpatient clinic before the children were seen by the consultant or CNS.

The number of children on hydroxycarbamide in QEH had almost doubled since the last review (129). This increase had been accommodated in a nurse-led hydroxyamide clinic which ran every 2 weeks (6 patients per clinic). The majority of these appointments were conducted via video to reduce disruption to families. Any concerns raised were discussed with the Lead Consultant with further review in consultant clinic arranged if needed. As the numbers of patients on hydroxycarbamide continue to increase, the team were looking to expand the nurse-led clinics.

There was a total of 18 joint clinics a year led by a visiting paediatric haematologist from KCH. Children on regular blood transfusions were seen every six months in a dedicated joint transfusion clinic. The joint clinics were also attended by the dedicated psychologist along with both acute and community paediatric specialist nurses.

Phlebotomy services at QEH ran alongside the clinic to reduce the number of planned attendances. Children over 3 years were bled in adult phlebotomy areas but were seen with priority as soon as they arrived. Children under three years had blood tests in the Dolphin Outpatient Department.

There was a trained children's nurse running both departments and both had toys and books for all ages however the visiting team recommended that further consideration could be given to the outpatient phlebotomy areas where adult and paediatric patients are mixed at both sites. The review team were informed that at Lewisham there was a plan for paediatric phlebotomy to be co-located in children's day care.

At QEH, teen clinics (from age 15) had been introduced every month for the last 3-4 years. These clinics were overseen by a qualified adult and paediatric haematologist with a special interest in Transition. The clinic took place in the adult OPD with variable attendance by the over-stretched Paediatric Consultant. At the time of the peer review, this clinic had just been replaced by a Ready Steady Go clinic run in the Paediatric OPD in conjunction with the Paediatric team to reflect the UHL model. The cross-site transition nurse coordinator was helping to formalise the transition pathway, starting early transition preparation using the Ready, Steady Go questionnaire in a step-wise manner.

During the visit concerns were highlighted by individuals at the patient focus group in relation to this pathway working in practice at QEH. Feedback from one 17-year-old patient was that they hadn't heard from anyone in relation to the transfer to adult services.

The handover clinic to adult services in QEH had been challenging in the absence of a QEH based adult haematologist with an interest in Haemoglobinopathies, so that the more complex patients were being transitioned to UHL adult team. A solution had been agreed to add quarterly handover slots to the monthly clinic run by an adult haematologist from KCH, that would be attended by the Transition Lead Consultant, deputy Lead Consultant and CNSs.

Throughout the paediatric department, there were leaflets available and patient and staff information boards covering sickle cell disease, but no information about thalassaemia.

Community-based Care

The Community Haemoglobinopathy Nursing Team for UHL operated from the Mary Sheridan Centre in Lambeth. A single full-time Community Clinical Nurse Specialist (CNS) was responsible for antenatal counselling, conducting visits for new births, home visits, and managing out-patient clinics. The review team acknowledged the nurse's exceptional dedication to her role, noting her passion and the development of strong relationships with her patients. She consistently went above and beyond her duties to ensure the best possible care for her patients.

It was acknowledged that the current community CNS had extensive knowledge and had built lifelong relationships with patients therefore as she approached retirement age reviewers were concerned about succession planning for this role. The service provided assurance that this role would be replaced however it was acknowledged that it will take time for a new CNS to build relationships with patients.

Lewisham Community nursing team based at Kaleidoscope, accessed Portacaths for regular transfusion patients and administered ambulatory antibiotics for all patients.

There were plans in place for the introduction of a new haemoglobinopathy community hub for Lewisham, Lambeth, Southwark and Oxleas, including extra paediatric and adult nurses. The plan was for this service to run alongside the existing team of 8 paediatric community nurses at Wooden Spoon House, and to support Oxleas and Bromley. These developments would enable community nursing cross cover ensuring there is no gap in service during times of sickness/ absence.

New welfare advisors had also been appointed and there were plans for a dietician and physiotherapist post in the hub.

Oxleas provided the Community Services for QEH, facilitated by two part-time Specialist Children's Community Nurses. There were 2 x 0.5 WTE community CNSs covering two large boroughs which was insufficient to meet the need. In addition, they were also covering general paediatrics and were not always able prioritise sickle/thalassaemia patients. These nurses were responsible for conducting new birth home visits, home and school visits, and managing outpatient clinics. In response to their demanding schedules, they often conducted care planning appointments with patients online. Unfortunately, the substantial workload hindered their active engagement with the Multidisciplinary Team (MDT) and attendance at MDT meetings.

The planned developments of the community hub would however improve haemoglobinopathy community care capacity for patients under Oxleas.

The review team expressed apprehension regarding the limited contribution of the Oxleas community nurses to the broader team. They recommended exploring strategies to enhance collaboration and involvement, emphasising the importance of improving the connection between the community nurses and the wider MDT for more effective coordination of care.

Antenatal counselling was provided by the Mary Sheridan Centre.

Views of Service Users and Carers

Service user Feedback

The review team met with three families caring for children with sickle cell disease and 2 families caring for children with B thalassaemia major.

UHL Service User Feedback

1. In the Emergency Department (ED), parents perceived that receptionists were making judgments on the acuity of their child's crisis, affecting their priority for care. Instances of prolonged wait times were cited.
2. Knowledge of Haemoglobinopathies varied among ED staff, resulting in encounters with clinicians possessing limited understanding of the conditions.
3. The commendable support and expertise of the Lewisham Lead Consultant, and the two Paediatric Clinical Nurse Specialists (CNSs), were acknowledged by all representatives. The Paediatric specialty team's care was highly appreciated.
4. Despite existing school care plans established by the Community CNS, concerns were raised about schools lacking sufficient knowledge of Haemoglobinopathies, especially Thalassaemia.

5. Ward care exhibited variability, with positive experiences of helpful and responsive staff contrasted by poor experiences and apprehensions regarding staffing shortages. Limited bed capacity led to frequent patient relocations. Some reported extended stays attributed to staffing issues and delayed treatment, while others mentioned premature discharges resulting in readmission.
6. Day care received commendation, with parents feeling exceptionally well-supported during transfusions.
7. Patients and carers expressed a desire for increased support through a dedicated support group.

QEH Service User Feedback

1. Service users who spoke to the reviewers had been issued with a 'green card' to enable prioritisation for triage in ED when they attended however they stated that reception staff were not always aware of the need to prioritise them and they felt non- clinical staff would benefit from some training about the process.
2. Service users noted an improvement in the care provided in the Emergency Department (ED) and appreciated that the staff consistently notified the Clinical Nurse Specialist (CNS) about their attendance. However, concerns were raised about the communication of plans to parents during ED visits.
3. Carers perceived quicker prioritisation when arriving with an ambulance rather than as individual parents.
4. Despite existing care plans that were implemented by the community CNS, schools lacked education on Haemoglobinopathies, particularly Thalassaemia.
5. Representatives reported challenges in accessing the specialist team but praised the supportive care and positive relationships when contact was established.
6. Confusion arose regarding phlebotomy, with uncertainty about whether the blood tests were conducted by the specialist team or the phlebotomy service.
7. Day care received positive feedback, with patients and their carers expressing satisfaction with their experiences during transfusions. However, some aspects of care, such as transfusions and managing iron overload, highlighted a perceived need for enhanced education and understanding among service users.
8. Patients and carers fed back positively about having access to a youth board however patients and carers of younger children expressed a desire for increased support through a dedicated support group.
9. Transitional care is showing signs of improvement; nevertheless, a 17-year-old patient revealed that there had been no discussion regarding the transition to adult services in their case.

Good Practice

1. Exceptionally hard working and dedicated team - The team were evidently working hard and are committed to providing high-quality services and making progress towards achieving the national quality standards. Individuals within the team went above and beyond the remit of their role to support patients and ensure safe and effective care.
2. Transition Service at UHL - There was an impressive transition service set up at UHL with the provision of Teens and Tween and Ready Steady Go clinics. There were plans for these joint clinics to be enhanced and improved at QEH.
3. Implementation of a cross-site Psychology Service – A dedicated Clinical Psychologist specialising in Haemoglobinopathies was in post, actively participating in clinics and organising bi-monthly Multidisciplinary Team (MDT) meetings to address and manage complex cases.
4. Strong networking with South East London and South East Sickle Cell HCC -. The reviewers were positively impressed by the robust relationships and networking structures that the SHT maintained with the HCC.

5. Positive Collaborations with consultants/community/CNS – The reviewers noted the commendable close collaboration between the consultants, CNS and community staff, particularly at UHL. Despite acknowledging workforce challenges, patients and their caregivers perceived a genuine sense of care.
6. Youth board at QEH - The reviewers identified the youth board in Greenwich as an exemplary area of best practice.

Immediate Risk

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

Serious Concerns

1. Consultant Staffing

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

b) At the time of the visit the Lead Consultants (general paediatricians) had a total of 6.5 PA's for 456 patients, plus 1 PA by the deputy lead consultant. There are also 0.75 PAs provided by the dual qualified adult and paediatric haematologist with interest in transition cross site. Based on the UK Forum recommendations, the consultant staffing was significantly under-resourced.

2. CNS Staffing

a) At the time of the visit, reviewers were concerned that the service had insufficient CNS staffing with only one CNS (1 WTE) employed to cover both UHL and QEH sites.

b) There were no cover arrangements for the Paediatric CNS sickness or absence. The CNS was completing specialist academic study which took her out of practice 1 day per week leaving CNS cover 3 days per week for two sites at the time of visit. (The 1 WTE is worked in 4 days with longer hours). This was highlighted by the review team as a serious concern. Pre covid-19, a business case to increase capacity was written however this has not progressed. The service planned to re-submit an updated business case which if approved, would allow the service to recruit to a cross site lead ANP post to facilitate automated exchanges plus additional CNSs to provide a more robust service and teaching programme for nurses, ward and ED junior doctors. Without the approval of this business case, the service is vulnerable.

Concerns

1. Vulnerability in the Transition Pathway at QEH

Reviewers expressed concern regarding the vulnerability of the transition pathway at QEH due to the absence of an adult Consultant Haematologist with an interest in haemoglobinopathies. Although plans were in place to establish joint transfer of care clinics similar to those at UHL, the reviewers were apprehensive that the challenges in recruiting to this position could impede the smooth transition of paediatric patients to adult services. These concerns were also highlighted by patients and carers at the service user focus groups, where one 17-year-old patient had not been spoken to about transition.

2. No paediatric specialist pain team

No Paediatric Pain Service is currently in place at either site within the Trust, and Patient-Controlled Analgesia (PCA) was unavailable. Although the anaesthetic team had recently formulated new PCA guidelines, no training sessions had been conducted. Patients in need of PCA were consequently transferred to KCH for the service.

3. Emergency Care

Concerns were raised by patient representatives in relation to the effectiveness of the 'green card' flagging status when attending the Emergency Department at both sites. There was a perception that knowledge of this by reception staff was variable and in some instances reception staff were assessing the priority status of patients leading to prolonged time they waited to be seen.

Further Considerations

1. It is recommended that a comprehensive nursing competency framework for haemoglobinopathies, incorporating routine cross-site training to ensure that all nurses attain the required competencies, is developed.
2. With the exception of the youth board at QEH, there is lack of awareness that the monthly support group is open to carers and young people aged 16 and above.
3. Reviewers suggested that further consideration could be given to the outpatient phlebotomy areas where adult and paediatric patients are mixed at both sites. Consideration of introducing finger prick blood tests is also recommended.
4. Many of the Clinical Guidelines were available through the network. Consideration should be given to local availability and Trust ratification.
5. Patient information leaflets were impressive for complications and management of sickle cell disease, however there was a marked absence of patient information regarding transfusion dependant thalassaemia.
6. Patients reported being issued with a 'green card' to enable prioritisation for triage in ED however they stated that reception staff were not always aware of this or knew what it meant, highlighting a requirement for education of non-clinical staff.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

The LGT SHT was split sites between QEH and UHL with shared structure, policies and procedures and key staff including CNSs, Psychologists, Transition Team, and data managers as well as equal access to the elective automated red cell exchange sited at the UHL site. Medical staff were site specific as were the non-specialist nursing staff although the Haemoglobinopathy consultants were available for advice cross sites. Haemoglobinopathy services for adults and young people post Transition aged 16 and above were run separately to paediatrics services, with Transition straddling both services.

Since the last Peer Review, the Haematology and Cancer Services Directorate had undergone a further managerial restructure and has since joined the Allied Clinical Sciences Division. A business case was in progress to develop a Hyper Acute Sickle Cell Unit (HASCU) on the UHL site, if funding is successful this would provide centralised triage and assessment for sickle cell patients across Lewisham, Greenwich and Bexley therefore offering a direct access pathway. Within the business case, it is proposed that automated red cell exchange will be provided within LGT during normal hours and by an outreach service provided NHSBT for emergencies, particularly out of hours.

The lead consultant was based at the UHL and the deputy was based at the QEH. Both have led an extremely dedicated and hard-working team.

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

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[2]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Adults	445	445	336	72	Circa 62/220	304
Thalassaemia	Adults	11	11	8	7	NA	NA

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

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant Haematologist dedicated to work with patients with haemoglobinopathies	456	6.5 PAs
Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies	456	3 WTE plus 2 apheresis nurses
Nurse for adult patients dedicated to work with patients with haemoglobinopathies in the community	456	1 WTE employed by GSTT
Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies	456	1.1 WTE

Emergency Care

UHL

Patients with acute presentations including painful crisis attended the emergency department with UHL attendance being nearly 3 times that of QEH. On arrival patients are triaged as Category 2 and were treated according to their pain protocol on iCare under "Flags".

Those improving after 2 doses of analgesia were discharged and reviewed in a virtual clinic the following morning where a referral for social support or consultant follow-up appointment was made if required.

Admissions from ED were via the medical team to the Medical Admissions Unit and the General Medical Ward (Chestnut Ward) under the care of the medics with a plan for haematology review within 14 hours. The Clinical Nurse Specialists (CNS) were notified via email of ED attendances daily therefore the timeliness in which they are made aware of the patients' attendance was dependent on the time the patient presents.

There were no Day Unit assessment facilities and no direct haematology admissions available for Haemoglobinopathy patients. A HASCU bid was in progress for an ED bypass unit at the UHL site to treat all Trust patients. If successful, this bid will see a telephone triage service and a dedicated area on Laurel Ward staffed 24/7 with Advanced Clinical Practitioners.

QEH

The Triage area in the ED had a poster on the wall prompting the triage nurse to directly ask if the patient had SCD or Thalassaemia. If a Patient Group Directive (PGD) was in place, analgesia was provided by the nurse at triage, although the PGD did not cover all patients with SCD. All patients were directed to the 'Majors' pathway. Staff had access to the analgesia care plan of sickle cell patients though the Flags system on iCare. The related guidelines were referenced and available via the ED handbook available electronically and signage prompting adherence to the SCD and Thalassaemia guidelines was present on the department walls.

Dedicated training to nursing staff was provided within the Foundation Emergency Nursing (FEN) Course with additional training available for nurses completing the level 2 course. Topics of focus training weeks were also conducted March to November with a break in the winter months. Training was available on the e-learning for health portal as part of a wider Quality Improvement programme with plans to incentivise completion by award of a Sickle Cell Society Badge.

The ED had dedicated nurse educators however these nurses could often be utilised within nurse staffing numbers due to nurse staffing pressures and an establishment of junior nurses.

Admitted patients were transferred to the Acute Medical Unit (AMU) and then to an inpatient ward as soon as possible with daily reviews in the intervening period with notification of the haematology team within 14 hours or sooner if there were concerns about the patient's condition.

Inpatient Care

UHL

Daily reviews of all admitted haemoglobinopathy patients were in place by the Haematology team, whether the patient was on the Haematology or other ward. This included twice weekly consultant ward rounds as a minimum. Consultant ward rounds were preceded by an MDT meeting and attended by Community CNSs and the Housing Officer whenever possible as well as the core clinical team (doctors, nurses, and psychologist).

Laurel Ward, the main ward for haemoglobinopathy patients at UHL was not a dedicated haematology ward and managed by another division within the Trust (Lewisham Medicine and Community). The case mix on the ward was made up of a mixture of gastroenterology, acute medicine, and haematology. Staff reported that haemoglobinopathy patients were regularly placed on non-haematology wards.

A doctor of ST1 equivalent grade had recently been temporarily added to the haematology staffing at the UHL site to reflect the high in-patient workload at the UHL site with a plan to make this permanent, subject to a business case.

QEH

Ward 21 was the dedicated ward under the care of the Haematology Team in QEH. Wards 1, 22 and 23 were general medical wards managed by the general medical team. Haemoglobinopathy patients were transferred to these if no beds were available on ward 21. Staff reported that haemoglobinopathy patients were regularly placed on non-haematology wards.

On visiting ward 1, a general medical ward at QEH, reviewers observed both SCD and Thalassaemia information available on the walls and the nurses described a rolling programme of education although no formal competency framework was in place.

Ward 21 staff reported that young people were able to have a parent or carer stay with them overnight alongside being supported by a paediatric haematology transition nurse up to the age of 24.

Day Unit

UHL

The automated red cell exchange transfusion program was situated on Suite 8 (Chemotherapy Day Unit) for both UHL and QEH patients, as was the transfusion service for the UHL transfusion dependent thalassaemia patients.

There were two apheresis machines at UHL that provided elective red cell exchange for both patients at UHL and patients transferred from the QEH site. Funding had been secured for a 3rd machine to be based at the QEH site. The apheresis service is currently run by the Haemoglobinopathy CNS at the expense of their other roles. 2 x apheresis nurse specialists training is in progress, to staff the elective service and enable the Haemoglobinopathy CNSs more time in their intended role.

QEH

One transfusion dependant thalassaemia patient was transfused on ward 21, where 2 in-patient beds were blocked for transfusions at weekends. Transfusion on Ward 21 (using the dedicated beds) was managed by the

haematologists using an excel spread sheet on a shared drive to add the patients that need transfusion. The administrative staff scheduled accordingly, and bloods were taken 2 days prior to avoid any delay on the day of transfusion. Due to bed pressures, these beds were sometime used for inpatients overnight, but such patients were prioritised for movement the following morning.

As part of a wider quality flow improvement programme, a new relocated ambulatory care unit had recently been opened at the QEH site and patients requiring regular transfusions during the working week were accommodated here.

Outpatient

Outpatient Care:

UHL

One large weekly adult Haemoglobinopathy clinic took place at the UHL site on a Wednesday which regularly lasted for 6-8 hours. The length of time required to run this clinic was not reflected in the consultant job plans. The planned transfer of caseload by the locum consultant from the lead consultant's oncology clinic will go a long way towards resolving this issue by allowing her 2 PAs of haemoglobinopathy clinic time weekly.

3 to 4 times a year, the adult Haemoglobinopathy clinic was cancelled and replaced by a "Transition" handover clinic run jointly by the adult haemoglobinopathy Lead Consultant and the Lead Consultant Paediatrician for the service, together with the extended team including adult and paediatric community nurses.

QEH

At the QEH, the main adult Haemoglobinopathy clinics were delivered within the Macmillan Brook Outpatient Unit. Staff expressed concern that the unit is often perceived as a provision for oncology patients rather than wider Haematology Disorders.

A weekly Monday afternoon haemoglobinopathy clinic was run by the locum consultant at the time of the visit. An all-day outreach clinic on the first Wednesday of the month was provided by a Consultant Haematologist at KCH and KCH/GSTT HCC lead on the first Wednesday of the month, where some of the more complex patients were seen.

The review team heard that often the CNSs struggled to support patients in the QEH outpatient setting due to the expansion on the oncology service and limited consultation rooms available within the site to access. The divisional management were aware of this challenge and worked to support as able within the physical constraints.

General

Specialist care for patients with thalassaemia, including access to iron quantification scanning (Ferriscan and T2* MRI), endocrinology and bone health services, was led by the teams at the KCH and The Royal London Hospital with some tests provided at the University College London Hospital (UCLH), who have traditionally looked after UHL patients with thalassaemia major.

There was an adult psychology service that provided 3 clinics a week. These were a combination of in-person and online appointments (Teams or Attend Anywhere) based on patient choice. Unfortunately, the service lost its clinic room at QEH, so any QEH patients who wanted an in-person appointment had to travel to UHL.

To mitigate medical staff resourcing difficulties and following recovery from the pandemic, many consultations were still being conducted by telephone, although the patients were strongly encouraged to attend in person if they wished to, particularly if they notice any changes in their health or had not been seen face to face recently.

Joint Obstetrics/Haematology clinics were run monthly at each site where pregnant haemoglobinopathy patients were seen.

Community-Based Care

Specialist Haemoglobinopathy Community Nurses were available to the Lewisham patients though the South-East London Sickle Cell and Thalassaemia Centre at the Mary Sheridan Centre in the Wooden Spoon House at the Elephant and Castle and hosted by Guy's and St Thomas' (GSTT). Lewisham patients also had access to benefits advice through the Southwark Law Centre, to a Housing officer based in UHL and to social prescribing. This progress had unfortunately not yet been extended to QEH adult patients, who remained without a Community CNS or access to benefits advice, although some access to the Southwark Law Centre had recently been granted.

A proposed Joint ICB/HCC project aimed to extend these facilities to patients in the boroughs of Bexley and Greenwich (the areas served by QEH) was in progress and the reviewers were pleased to hear about the plans for investment in these services to reduce the disparity of access.

Views of Service Users and Carers

Feedback from UHL patients living with sickle cell disease and thalassaemia meeting:

The visiting team met with 11 people representing patient views. 10 had SCD and one had Thalassaemia. The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences.

1. All spoke highly of the direct access they had to their consultants by email. By contrast, CNSs were not contacted by the patients for advice.
2. Admission via ambulance to ED ensured a faster track to triage, contributing to the preference to call an ambulance. They had been advised to tell ED staff that of their SCD status and not assume that this would be identified on their notes.
3. Many still found themselves having to explain what SCD is, and what their immediate needs were in presenting to ED. Their families also understood the necessity to advocate on their behalf when they were in a crisis.
4. The patients expressed that outliers were very high with a clear need to create a dedicated ward and fully address the nurse turnover crisis. If not on a haematology ward, there were concerns that their condition and needs were not understood fully. They also spoke of their concern for others if on a non-haematology ward, i.e. suppressing their feelings of pain so as not disturb elderly patients.
5. Not everyone had annual reviews. As such, many of the care plans are likely to be out of date.
6. They felt that when presenting as an emergency they had to advocate for themselves, and staff were unaware of their iCare plans. The ED staff the review team met at UHL expressed that "everyone gets timely pain relief". However, this is not borne out in the Trusts own audits i.e. Lewisham 55% and Greenwich 45%. This disconnect should be explored, as ED will not seek to improve on the current timeliness if they do not accept there is an issue.
7. Some patients being reviewed in telephone clinics stated they would prefer face to face appointments.

Feedback from QEH patients living with sickle cell disease and thalassaemia meeting:

The visiting team met with 1 adult with sickle cell disease during the visit to QEH.

The patient described how they were happy with the support and care received from the team at the QEH. On pressing by the review team on what improvements they would like to see, the patient expressed that they would want to be cared for on the dedicated haematology ward instead of the general medical ward and they were not aware they had a care plan.

Good Practice

1. The clinical team and divisional management worked closely together to understand and provide for the needs of their patients and the future investment required. The apheresis team staffing had been expanded with the addition of 2 WTE new apheresis nurses which will release the CNS team to offer more support to in-patients and clinic patients. Funding for a third Spectra Optia machine had been granted for use at the QEH site, alongside support for the business case for a HASCU at UHL. Patients received an excellent psychology service achieving a positive impact in caring for their mental health, teaching them coping skills and problem solving. Physical presence in clinics at UHL enabled direct and immediate support alongside group learning specific to those undergoing exam stress. Training was provided by the team to front line staff in how to support sickle patients in crisis. Although the psychology establishment was not to that required for the patient numbers, the team prioritised and triaged demand.
2. There was a dedicated transition service with the provision of teens and tween clinics across both sites. Handover clinics were held jointly by the adult and paediatric haemoglobinopathy teams at UHL with a plan for similar clinics at QEH. The first of these clinics is planned for September 2024 when enough patients will be ready for handover. Parents could stay overnight on the adult ward for the young person's stay and teenagers and young adults requiring admission were also supported by a paediatric transition nurse.
3. Social support at the UHL site had been enhanced by the ICB with the appointment of a housing officer attached to the service, and access to the Southwark Law Centre for assistance with benefits and other relevant matters.
4. CNS attitude to patients was fully holistic. They understood and supported their patients' social, psychological, and physical well-being.
5. The QEH phlebotomy service provided the haemoglobinopathy patients with green cards that fast tracked them through the phlebotomy clinics. Green chairs were allocated so that fast-track patients were easily identified by staff and treated accordingly.
6. The ED training package at QEH was comprehensive for both medical and nursing staff through both formal training and weekly topic events. A quality improvement initiative with KCL was in progress to identify and support good practice with staff incentivised to complete the SELSE HCC e-learning for health training package "Sickle Cell Disease Training" by the award of the sickle cell society pin badge. This module concentrated on emergency care and stigma.

Immediate Risk

No immediate risks were identified.

Serious Concern

1. Consultant Staffing

a) The service was driven by a workforce that works extremely hard and was sustained on this 'above and beyond' commitment, without adequate reflection of the workload in job plans. The Lead Consultant PA allocation was reduced from 1 to 0.5 PAs. After an 18-month consultant vacancy, with all duties arising from the vacancy covered by the remaining consultants, a locum consultant had started at UHL on 08 January 2024. This had released some dedicated sickle cell and thalassaemia clinical consultant time. After a recent increase in establishment and due to past recruitment difficulties, the team are working with KCH to offer a more attractive role.

b) The medical workforce establishment fell below that required for this service and therefore has impacted on the ability to partake in essential activity such as audits, research, updating protocols and attending HCC meetings alongside direct patient care. If the bid for the HASCU is successful, the capacity of senior medical staff to provide specialist input will need to be carefully considered.

2. Use of General Medical Wards

a) A high number of patients were admitted to non-haematology wards. The emergency pathway on both sites involved admission to MAU and often patients were subsequently admitted to general medical wards due to a lack of haematology bed availability. It is recommended that the Trust undertakes a review of the haematology bed base capacity and demand.

b) Although there was a plan in place for haematology review within 14 hours of admission, in practice staff working on AMU reported patients often having to wait over 24 hours for an in-person review by a senior haematology decision maker. It is recommended that the Trust consider the implementation of electronic observations in ED and AMU ward areas to support early identification of a deteriorating patient.

3. Planned Apheresis

The review team were pleased to hear about the investment in a 3rd Spectra Optia machine to support patients to receive emergency exchange transfusion at the QEH site. However, inequalities across the 2 sites prevailed with no plans to make elective apheresis available at the QEH site in the immediate future in view of current staffing issues. QEH patients are currently referred to UHL to access this treatment option. The service should consider the best approach to provide equity at both sites while meeting the delivery needs of this highly specialised service.

Concern

1. Timely administration of analgesia

Audit data on the timeliness of analgesia were available and demonstrated a need for improvement which has been followed by a dedicated quality Improvement programme in this area. The Emergency Department staff who spoke with the visit team felt that analgesia was given in a timely manner; however, this view was not aligned with the reported experience of patients spoken to during the review. Regular and continued audits are required as part of this quality improvement approach to provide assurance of progress in the timeliness of analgesia administration.

2. Single Point of Contact

Whereas the patients are provided with the CNSs work mobile telephone numbers and the numbers of the haematology secretarial team, the current staffing situation whereby the CNSs are providing the apheresis service and their team have been affected by long term sick leave has meant that several patients have found it easier to contact the consultants through their direct email address for any queries. Whilst this is honourable and dedicated, there is concern as to the resilience of this approach. The best use of the existing service email address should be explored, alongside how the CNS team may support and triage any queries. If successful, the

HASCU development will facilitate a dedicated triage phone line available 24 hours a day, 7 days a week. However, in the meantime, patients should have access to a reliable way to contact their team when required.

3. CNS workload

The CNS establishment of 3 WTE was inadequate for the size of the population served. Some activities such as writing support letters for schools, disability badges, universities etc are undertaken by the CNS because of a lack of MDT support for such areas impacting on their capacity for direct clinical care. The CNSs are currently providing the apheresis service pending the training of 2 WTE dedicated apheresis nurses. The CNSs will have more clinical time once the apheresis nurses have completed their training and are able to work independently. The review team heard that the Chief Nurse is currently completing a Trust wide CNS review which will hopefully explore alternatives such as skills mix to support delegation of appropriate tasks to release clinical time.

4. Care plans

a) Although the service evidenced the use of flags and the NHS app, and encourages patients to access their letters via this, the patients spoken to were not always aware they had care plans.

b) Patients also discussed with reviewers that the ambulance crew do not generally acknowledge the care plan. The service should consider liaison with the London Ambulance Service (LAS) to support understanding of the care plan and needs of the patients and should work with patients to ensure they understand where to access their care plans.

5. Divisional moves

The service described how they had moved divisions quite a lot which then entailed a new management team having to learn the service to understand the challenges and complexities to support. The service report feeling supported and listened to by the current division; a sustained consistency of management would be helpful to aid and maintain the progress of the team.

Further Considerations

1. Nurse staffing levels and the junior nursing skill mix specifically in ED made dedicated training challenging for the practice education nurses and CNS teams. The introduction of sickle cell link nurses and a sickle cell disease acute admission training tool will support this, alongside a more formalised nursing competency framework.
2. Consideration should be given to the advantages versus disadvantages of the separation of the medical teams working at the two sites. One way to reduce the inequalities between sites maybe to consider more joint working by the medical workforce, particularly the HBO specialists.
3. The required estates provision at QEH should be reviewed to support the haemoglobinopathy patients to attend clinic consultations with all MDT members and access services in line with those at UHL. At the time of the visit, the psychologist could not be physically present in clinics at QEH due to the lack of a clinic room.
4. Upload of care plans onto shared folders will support access across the Trust.
5. An introduction of more formal patient feedback approaches will provide improved assurance that patients' and carers' views are heard. The review team were pleased to hear about representation on the Youth Board however a speciality focused approach would be of benefit. A formalised survey of thalassaemia patients should be competed even if these patients are low in number.
6. The review team were impressed by the joint clinics with obstetrics; the possibility of other joint clinics should be considered such as cardiology, or as a minimum, identification of a link consultant within key specialities.
7. Only a minority of eligible patients were taking hydroxycarbamide. It is recommended that consideration is given as how to best support more eligible patients to start and continue hydroxycarbamide.

8. There is good evidence that hydroxycarbamide should be incrementally increased to the maximum tolerated dose as standard in most patients. It is recommended that the current Trust guidance is updated to reflect this.
9. The review team would like to see progression towards providing an out of hours emergency automated red cell exchange service. This development is understood to be within the current business planning process. The provision of other out of hours services such as phlebotomy, transfusion and clinic appointments at both sites would also benefit the patients.
10. HBO patients should have equal priority to the haematology ward beds alongside the haemato-oncology patients; staff reported that this did not always appear to be the case.
11. The wards visited were not able to provide patient controlled analgesia (PCA). The ability the deliver safe PCA care to sickle cell patients could be considered.

Commissioning

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

The review team identified the below considerations:

1. A long-term strategy for the provision of the service needs to be developed and agreed across the system by commissioners, Trust executives, the speciality team and service users. This should include plans for expansion, alongside clarity around what provision will be available on each acute site, with full consideration of the future population health needs.
2. There is disparity of community care between Lewisham and Bexley and Greenwich boroughs, however commissioners are involved with joint ICB plans to provide investment. The joint ICB/HCC Sickle Cell project will also benefit the Trust greatly with the extension of access to adult community specialist nursing and housing/benefits advisors to the Greenwich/Bromley and Bexley (QEH) patients. This investment is welcomed and essential to improve the equity of access.

Return to Index

Appendix 1 - Membership of Visiting Team

Visiting Team		
Lovina Thomas	Consultant Adult Haematologist	Mid and South Essex NHS Trust
Doreen Richards	Specialist Nurse Practitioner	Nottingham University Hospital
Eva-Marie Clarke	HCC Network Manager	Manchester University NHS Foundation Trust
Jessica Sandham	Consultant Paediatric Haematologist	Alder Hey Children's Hospital
Elizabeth Joshua John	Paediatric Haematology Nurse Specialist	Luton and Dunstable NHS Trust
Clare Clark	Paediatric Haematology Clinical Nurse Specialist (CANP)	Cambridge University Hospitals
Dee Malone (not present on visit day)	Assistant Director of Quality	North Central London ICB
Michele Salter	User Representative	Sickle Cell Society UK
Funmi Dairo	User Representative	Liverpool Sickle Cell and Thalassaemia Support group

Clinical Leads		
Clare Samuelson	Consultant Adult Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Sabiha Kausar	Consultant Paediatric Haematologist	Manchester University NHS Foundation Trust

MLCSU Team		
Kelly Bishop	Assistant Director of Nursing and Urgent Care	Nursing and Urgent Care Team - MLCSU
Rachael Berks	Clinical Lead	Nursing and Urgent Care Team - MLCSU

Return to Index

Appendix 2 - Compliance with the Quality Standards

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

Percentage of Quality Standards met

Service	Number of Applicable QS	Number of QS Met	% Met
Specialist Haemoglobinopathy Team (SHT) Children and Young People	48	30	63%
Specialist Haemoglobinopathy Team (SHT) Adults	45	27	61%

Specialist Haemoglobinopathy Team for Children and Young People with Haemoglobin Disorders

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

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents [SCD and Th] c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health (if appropriate) d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HC-106	**Information about Transcranial Doppler Ultrasound** Written information should be offered to children, young people and their families covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	Y	
HC-107	**School or College Care Plan** A School or College Care Plan should be agreed for each child or young person covering at least: a. School or college attended b. Medication, including arrangements for giving / supervising medication by school or college staff c. What to do in an emergency whilst in school or college d. Arrangements for liaison with the school or college e. Specific health or education need (if any)	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	N	The phlebotomy area for CYP was collocated within adult outpatients. There was no sound and visual separation from adult patients.
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	N	Despite having a robust system in place at UHL (identified as good practice), concerns were highlighted by individuals at the patient focus group in relation to the transition to adult services at QEH. Feedback from one 17-year-old patient was that they hadn't heard from anyone. The reviewers were concerned that gaps in adult workforce were letting the transition pathway down as there was a vacant adult haematologist post impacting the transition to adult services.
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	N	Only 27 responses had been received therefore did not meet the 10% patient population Quality Standard. The survey is also not differentiated between sites or SCD and Thalassaemia. Feedback from patients at the patient focus group was that they had never received a patient survey questionnaire.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	N	At the UHL site, there was no mechanism in place for patient/relative feedback or decisions about the organisation of the service however the Clinical lead informed the review team that they plan to develop this. Pre covid, they had a local support group, but this had not been resurrected since covid. At Greenwich, there is a youth board.
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	Based on the UK Forum recommendations, the consultant staffing is significantly under-resourced. Despite having an exceptionally passionate consultant team of General Paediatricians, the dedicated amount of time for Haemoglobinopathies was insufficient to meet the needs of the number of patients. There was no Paediatric haematologist at either site however three of the KCH paediatric haematologists conduct clinics at the 2 sites.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The CNS workforce was insufficient with only 1.0 WTE CNS covering both sites within the Trust. There was no cover for sickness or absence. At the time of visit the CNS was completing specialist academic study which took her out of practice 2 days per week leaving CNS cover 3 days per week for two sites. This was highlighted by the review team as a serious concern. Pre-covid, a business case to increase capacity was written however this has not progressed. The service plan to re-submit an updated business case to increase CNS capacity. The business manager stated that the 'quality improvement' business case would be considered in relation to other Trust priorities. If approved, the business case would allow the service to recruit to an ANP post to facilitate automated exchanges at QE site as well as to provide a more robust teaching programme for nurses, ward and ED junior doctors. The additional funding would allow recruitment of an ANP as cross site nurse lead, additional CNSs, family support workers for each site and additional data management.

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	Training was provided for doctors by the lead clinician however the reviewers considered that medical competencies were insufficient, and the lead was contacted outside of working hours to check the plans for patients.
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.	N	No evidence seen
HC-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	No competency document for nursing was seen. This was highlighted by the service as an aspiration. A sickle cell module was available but not mandatory. Inadequate numbers of nursing staff were trained in phlebotomy and at the focus group patients and relatives reported being traumatised by some experience of phlebotomy. Consideration of moving to finger prick blood tests.

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	
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.	N	Administrative and data collection support was deemed Inadequate and additional funding will be requested for this in the business case. Consultants and nurses reported submitting NHR data.
HC-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required: a. Social worker / benefits adviser b. Play specialist / youth worker c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Child and adolescent mental health services	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	Manual exchange transfusions and automated red cell exchange was available at KCH however not 24 hours per day. There was no Paediatric pain service and PCAs were not available in the Trust. Patients requiring a PCA were transferred to KCH.
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	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders.	N	The 2022 Pain Audit was available which highlighted the requirement for re-audit based on issues with monitoring blood pressure in patients presenting with SCD painful crisis, reassessment of pain relief every 30 minutes until adequate pain control and ensuring laxatives were prescribed with opioids. No competency framework was in place for nurses however some areas of good practice were seen in ED at Lewisham site where there was visible information available for staff in relation to haemoglobinopathies. There was a large notice board in the main corridor dedicated to red cell disorders and the team reported that ED staff had created this themselves to improve awareness and knowledge in this area.

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

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Arrangements for accessing staff with cannulation competences f. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion g. Patient pathway for Central Venous Access Device insertion, management and removal	Y	
HC-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: Indications for chelation therapy a. Choice of chelation drug/s, dosage and dosage adjustment b. Monitoring of haemoglobin levels prior to transfusion c. Management and monitoring of iron overload, including management of chelator side effects d. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 e. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible	N	No guideline seen

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring complications e. Indications for discontinuation	Y	
HC-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	
HC-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred For children and young people with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration For children and young people with thalassaemia: l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	

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

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HC-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HC-503) d. National Haemoglobinopathy Registry data collection (QS HC-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HC-607) (if applicable) g. Participation in HCC-agreed audits (HC-706)	NA	
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	No SLA available however good working relationships with community services across both sites. Reviewers were informed that the SLA was out of date and would be reviewed. Community nurses very passionate and fulfil many roles at both sites however better communication (MDT attendance) would improve communication.
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).	Y	

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HC-197) compared with other services c. Results of audits (QS HC-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	No evidence seen and patients at the focus group were unaware of any arrangements covering the requirements of the QS.
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	

Return to Index

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 HA-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).	**N**	a. not met. The Thalassaemia patients spoken to during the visit were unaware of having a care plan or what the care plan should contain. Patients with SCD had care plans in place on the electronic database however patients reported that they had not received copies of these.
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	N	Insufficient capacity on dedicated haematology wards to support the inpatient requirements of the Sickle Cell and Thalassaemia population.
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	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	N	No standardised or formal feedback from Thalassaemia patients, although numbers were small the review team felt this was important.
HA-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback b. Mechanisms for involving patients and their carers in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HA-797) c. Examples of changes made as a result of feedback and involvement	N	No information for Thalassaemia or other areas of the Quality Standards 'b' and 'c'. There was some patient representation on General Youth Board. The psychology support group via MS Teams had not been well attended.
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The designated lead clinician only had 0.5 PA for SHT leadership role. This allocation had been reduced from 1 PA which is the expected time for leadership of the SHT.
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	Insufficient PAs available for the 456 patients and limited dedicated time for supporting activities such as audit and participation in network meetings. The appropriate PAs for this size of patient population would be 17.5 PAs
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	
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	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	1.1 WTE for 456 patients – Insufficient to meet the enough to meet 1:300 patient ratio as defined by the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017).
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	
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	Requirements not met: 'b' - no access to genetic counselling evidenced. 'f' - Only available during normal working hours for elective program at UHL site. Not available at QEH and not available out of hours at UHL. 'g' No access to regular review by the pain team.

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	N	Trust guidelines and elements in SCD and Thalassaemia guidelines, but 'd', 'e and 'f' not met.
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring of complications e. Indications for discontinuation	N	'b' not met: guideline recommends using the lowest effective dose rather than achieving maximum tolerated dose as per best practice
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred. For patients with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision iv. 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	N	'g' yes for Thalassaemia but not for SCD 'h' not included 'k' yes for priapism but not for erectile dysfunction 'l' not included
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	N	SCD – good practice identified. Evidence not presented on the care available to pregnant women with Thalassaemia or those under the age of 18.
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	
HA-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HA-503) d. National Haemoglobinopathy Registry data collection (QS HA-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HA-607) (if applicable) g. Participation in HCC-agreed audits (HA-706)	N/A	

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	No arrangements in place to support adult patients attending QEH
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).	Y	
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	N	Quality Standard not evidenced.
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	No patient involvement in MDT, no Thalassaemia patient survey or evidence of review of required audits or Quality Dashboard metrics
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'.	N	It was unclear about what action had been taken from feedback and complaints HCC MDT reporting met
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Some guidance was out of date although this was going through the governance process at the time of the visit.

Return to Index