MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

North West England Sickle Cell Haemoglobinopathy Coordinating Centre North of England Thalassaemia and Rare Inherited Anaemia Haemoglobinopathy Coordinating Centre

Manchester NHS Foundation Trust including

The Royal Manchester Children's Hospital

Manchester Royal Infirmary

Visit date: 23rd February 2024

Report date: 11th July 2024

Contents

Introduction

This report presents the findings of the review of Manchester NHS Foundation Trust that took place on 23rd 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:

- Haemoglobinopathy Coordinating Care Centre
- Specialist Haemoglobinopathy Team
- Local Haemoglobinopathy Team (or Linked Provider)

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

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

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Any immediate risks identified will include the Trust and UKFHD/MLSCU response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in Manchester NHS Foundation Trust health economy. Appendix 2 contains the details of compliance with each of the standards and the percentage of standards met.

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

- Manchester NHS Foundation Trust
- NHS England – North West
- NHS Manchester Integrated Care Board

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

About the UKFHD and MLCSU

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

of patients, whilst influencing and advocating on equitable prevention programmes for sickle cell and thalassaemia disorders.

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

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

Acknowledgements

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

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Review Visit Findings

North West England Sickle Cell Haemoglobinopathy Coordinating Centre

North of England Thalassaemia and Rare Inherited Anaemia Haemoglobinopathy Coordinating Centre

General comments and achievements

This review looked at the co-ordination of health services provided for children, young people and adults with sickle cell disorders, and thalassaemia across the North of England.

Manchester University NHS Foundation Trust (MFT) was responsible for two Haemoglobinopathy Coordinating Centres (HCC) networks. Although both HCCs are separate in their commissioned functions much of operational workings were joint across both HCCs, therefore the report below reflects this.

The North West Sickle Cell (SCD) HCC provided support and oversight for specialist and local haemoglobinopathy teams across Cheshire, Cumbria, Greater Manchester, Lancashire, and Merseyside which included four hospitals: Manchester Royal Infirmary, Royal Manchester Children's Hospital, Royal Liverpool and Broadgreen University Hospitals NHS Trust and Alder Hey Children's Hospital.

The North of England Thalassaemia and Rarer Inherited Anaemias HCC covered the Northwest, County Durham, East Yorkshire, Northumberland, North Yorkshire, South Yorkshire, Tyne and Wear and West Yorkshire which included seven NHS Trusts: Manchester University NHS Foundation Trust (MFT), the Royal Liverpool and Broadgreen University Hospitals NHS Trust and Alder Hey; Children's NHS Foundation Trust, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield Children's NHS Foundation Trust, Leeds Teaching Hospitals NHS Trust and The Newcastle upon Tyne Hospitals NHS Foundation Trust.

As of February 2024, the total number of patients across the HCC catchments with haemoglobinopathies was 1491 made up of 913 people with a sickle cell disorder and 578 people with thalassaemia and rare inherited anaemias.

Both HCCs worked in partnership with patient support groups, Manchester Sickle Cell and Thalassaemia Centre/Manchester Local Care Organisation, NHS England and other HCCs across England and both HCCs clearly had a 'whole life' approach to the care of patients with haemoglobin disorders.

The trust was also a designated provider of Specialist Haemoglobinopathy Teams (SHT) for adults, children and young people for their own catchment areas.

Both HCCs had designated clinical leads all of whom had considerable expertise and provided representation at numerous boards and national groups. Each HCC had a lead or deputy who was either a consultant haematologist or paediatric haematologist to ensure that all ages had leadership representation.

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

- Clinical Lead for the North West Sickle Cell HCC (1.5 PA)
- Deputy Lead for the North West Sickle Cell HCC (0.5 PA)
- Clinical Lead for the North of England Thalassaemia and RIA HCC (1.5PA)
- Deputy Lead for the North of England Thalassaemia and RIA HCC (0.5PA)
- HCC Network Manager covering both HCCs (1 WTE)

- HCC Transcranial Doppler Leads (shared between RMCH and Alder Hey Children's Hospital 2.5PA)
- Adult and paediatric Nurse Educators (1 WTE)
- HCC data Manager (1 WTE)
- Administrator (1 WTE)

Both HCC's held regular business meetings during the year open to the whole HCC; SHTs, LHTs, commissioners and HCC patient representatives, as part of these meeting the annual programme of work and audit programmes were agreed. Meetings were held remotely to promote engagement across the region. The specialist services quality dashboard data for HCCs and SHTs was monitored as well as audit and morbidity and mortality levels. Action plans, policy and audits were also monitored as part of the business meeting agenda.

The HCCs had met with commissioners from both the North East and Yorkshire and the North West to discuss their annual work plans and report on progress and any concerns. Commissioners who met with the reviewing team reported having good relationships with both HCCs.

The North West SCD HCC had also completed an audit of transcranial doppler ultrasound competences during the previous 12 months.

The North West SCD HCC scheduled monthly regional sickle cell multidisciplinary meetings (MDTs) and had discussed a total of 16 cases between April 2022 and March 2023. Four meetings during this time period had been cancelled.

The Thalassaemia and RIA HCC also held scheduled monthly multidisciplinary meetings and had discussed a total of 21 cases between April 2022 and March 2023. There was also a regular Email MDT for the more adult and paediatric urgent cases that could not wait until for discussion at the monthly HCC MDT. When applicable, cardiology, transplant and transfusion specialists were also invited to attend.

Both HCCs MDTs had criteria in place for more complex patient cases to then be referred to the National Haemoglobinopathy Panel MDT.

The HCC had established mechanisms in place for providing education and had an active teaching programme. Case studies were included at the monthly HCC MDTs and training on haemoglobin disorder was provided to doctors in training and other speciality teams.

Following feedback from stakeholders a monthly online "Lunch Hour" education series had been implemented. These sessions were recorded and uploaded to HCC websites for anyone to watch. The HCC also held a consultant and nurse education event annually.

Two nurse educators were in post providing education to all hospital and community teams across the region.

Manchester Sickle cell and Thalassaemia Service (MSCTC) also played a vital role in delivery HCC education locally.

The Network Manager was the patient and engagement lead, as part of this role had hosted several patient engagement events and assisted in coordinating the HCC education and training programmes.

Hosted events included:

- Thalassaemia Event at Eid Festival – 8th May 2023
- International Sickle Cell Day - 19th June 2023 (Sickle Cell & Thalassaemia Centre)
- Health & Wellbeing Fair - 20th October 2023 (Manchester University)
- North England Sickle Cell, Thalassaemia & RIA Event - 18th November 2023.

Planned events included a virtual Rare Inherited Anaemia Day, African Men and Women's Engagement event with the Greater Manchester Health Worker Group, a Thalassaemia event with NEBATA and two events in Liverpool.

As a network, 24-hour emergency by NHSBT red cell exchange service for the Northwest region had been implemented.

Good Practice

1. A formalised 24hr network advice service had been implemented to provide support and advice on the management of patients with sickle cell disease and for those with thalassaemia.
2. The range and number of HCC led educational events for professionals and patients was impressive. Five events had been held since 2022 covering a range of themes. Some events were held virtually such as the monthly online "Lunch Hour" education series and then made accessible via website. Other events had been held locally such as the engagement event for those with a sickle cell disorder and MOT Health Check Event in collaboration with the Manchester Sickle Cell & Thalassaemia Centre.
3. The HCC operational manager who was also the lead for patient engagement had a very proactive approach to the patient engagement and had initiated a number of bespoke education events.
4. The North West SCD and North of England Thalassaemia and RIA HCCs had extremely active clinical research programmes with several clinical trials that were network wide.
5. The use of HCC Nurse Educators to provide education about sickle cell disorders across the North West region was novel. Bespoke education sessions were offered to any hospital team who could request a session via an online booking form.
6. The HCC had worked with their finance partners to ensure that HCC funding was clearly earmarked via specific budget codes/lines for the delivery and governance of services for red cell disorders.

Immediate Risks: None were identified during the visit.

Concerns

a. **Complexity of HCC roles**

Reviewers were concerned at the challenges the HCCs were facing due to the complexity of providing a dual HCC role for sickle cell disease and thalassaemia which covered two different geographical boundaries and the balance the HCCs were required to navigate in terms of the managerial and governance perspectives to enable their HCC and SHT to function. Reviewers considered that it will be important for NHSE to have a strategic plan to maximise the benefits for the HCC stakeholders equitably across the disease areas and geography given the small pool of clinicians available to fill diverse roles.

b. **Operational Manager**

The operational manager had the responsibility for two haemoglobinopathy coordinating centres and patient engagement across both networks. Reviewers were concerned at the workload and capacity of the manager and were concerned at the low banding in relation to the expectations of the role.

Reviewers were told that the new data manager post had been split into a band 7 who would undertake the patient engagement leadership role and band 8b who would oversee HCC and link more closing with LHT and SHT.

c. **Lead Nurse Role**

The HCC did not have a lead nurse and whilst the nurse educators undertook education responsibility across the North West and the specialist nurses had informal networks, they did not cover other aspects of the lead nurse role. Development of a lead nurse for the HCCs would help with coordination and engagement across the HCCs.

d. **Education on Thalassaemia and Rare Inherited Anaemia**

The nurse educators appeared to only cover the North West HCC and had not provided any local or network wide teaching on the care of patients with thalassaemia or rare inherited anaemias. Reviewers were told that they did plan to address this later in the 2024.

e. **HCC MDT Meeting attendance**

Engagement from some of the SHT Lead clinicians outside of MFT was low despite the HCC changing the meeting days. Four of the SCD MDT meetings during 2022 -23 had been cancelled with the reason given as the lack of patients for discussion or workforce issues.

The data on the number of patients submitted for MDT discussion was relatively low (16 for the SCD HCC and 21 for the Thalassaemia & RIA HCC) and it was not clear whether all patients who met the criteria for discussion were being presented.

Further communication to all stakeholders on the criteria and function of the MDT meeting may help with engagement especially as some expressed that the HCCs MDTs were not protected work time.

f. **Red Cell Exchange Apheresis Capacity**

Reviewers were concerned about the lack of capacity for elective automated red cell apheresis for the number of sickle cell patients in the network and emergency access to apheresis at the MRI. Reviewers were concerned that the lack of capacity would become more marked with the increase in the number of service users likely to continue year on year that oversight by the HCC will be important to provide ongoing support and working with services to improve access.

Further Considerations

a. The SHT/Trust will need to address the imminent HCC manager vacancy with urgency to prevent a prolonged period with no administrative leadership. Reviewing how to run the two HCC networks and cover patient engagement across the wide geographical area will also be important to consider as well as appropriate banding and clarifying the HCC manager role responsibilities.

b. Feedback from colleagues in the HCC network felt that the MDT meeting should embrace the expertise across the HCC geographical area and should include more case discussions from the HCC itself.

c. Commissioners were well sighted on workforce issues and the HCC annual work programme, but the increase in activity and reasons for this had not yet been shared with them.

d. Reviewers were told of the inequity of access for patients and families attending for their TCD scans who did not have the same access to volunteer support for travel if they lived outside of Greater Manchester. This was a particular issue for those travelling greater distances particularly those residing in East Lancashire.

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Manchester NHS Foundation Trust – Trust-wide

General comments and achievements

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders. During the visit, reviewers met with patients, parents and carers, and with staff providing the services and visited the emergency departments, day units and wards at the Royal Manchester Childrens Hospital and Manchester Royal Infirmary

Manchester NHS Foundation Trust were designated to provided Specialist Haemoglobinopathy Teams (SHT) for children and adults based at the Royal Manchester Children's Hospital (RMCH) and Manchester Royal Infirmary (MRI) respectively.

MRI was the first site in England to establish a Hyper Acute Unit pilot for sickle cell patients which had been in operation since January 2024 and were hoping to be a first site for Wave 1 Gene Therapy if NICE approved (along with RMCH).

Both the adult and children and young people SHTs provided a range of education and teaching for clinical staff and those for clinical staff in training. An urgent care awareness package for administration staff (first point of contact) had also been developed.

Community Good Practice

a. The Manchester Sickle Cell and Thalassaemia Service (MSCTC) were highly thought of by all who met with the review team and the work they undertook to improve the lives of those living with red cell disorders, to increase education and to raise awareness of red cell disorders. Reviewers were also impressed with the implementation of acute clinics at the centre to promoting a holistic approach to reablement as well as providing follow up after discharge from the acute setting.

Trust-wide Good Practice

1. Born from the publication of the 'No-ones listening' report and subsequent recommendations there was a Sickle Cell Partnership Board chaired by the Director of Strategy. With direct board oversight the bi-monthly meeting reported on key service challenges and patient engagement feedback. Reviewers commented that there was opportunity to also extend this to the thalassaemia and rare anaemia service.
2. The review team observed a highly collaborative approach to patient care. The MDT was inclusive not only involving a variety of clinical specialists but also the management team who had a good understanding of the needs of the patients in their care.

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

Trust-wide Concerns

a. **Maintaining services due to staffing and capacity**

The Trust had implemented a number of short-term solutions to mitigate the ever-increasing demands on the SHT but a longer term plan to address workload and service delivery was not evident. Reviewers were made aware of a number of situations whereby the non-recurrent funding was creating a vulnerability to the retention of staff and potential service viability.

b. **Timeliness of Analgesia**

The audits completed have demonstrated that both children, young people, and adults presenting through ED were not receiving timely analgesia. Patients also commented that staff in ED were not knowledgeable about their conditions and the agreed pathways in an emergency. Roll out of the EPIC EPR system had enabled patient flags to be visible and alerted clinicians to the pathway which it was hoped on re-audit may have improved the administration of timely analgesia.

c. **Psychology Support**

Psychology input for children, young people, and adults was insufficient for the needs of the patients and their families. The Trust should consider the ability to invest in psychology support to all patients with haemoglobinopathy instead of this offering to only those who appear to have the greatest clinical need.

d. **Sustainability of the Sickle Cell Unit**

The development of the Sickle Cell Unit, whilst had benefits, also had increased the pressure on the team due to the non-recurrent funding of two years associated with its implementation with the 24hr triage facility and consultant on call commitments, which the latter reviewers considered would not be sustainable in the future, with the likelihood of increasing activity.

Trust-wide Further Considerations

1. The identification of link nurses on general wards may support nurse education in general wards and the use of cascade training. This may also be of benefit to support education in the LHTs.
2. The social worker role is a significant patient advocate and undertakes dialogue to address barriers to accessing care. Growth in demand and limited social work capacity has necessitated a responsive service reliant on one individual. Consideration should be given to increasing the social work support available to meet both the present and future patient need.
3. Reviewers did not see any signage or information for red cell services in any of the adult areas visited including the new SCU. This had the potential to make patients with haemoglobin disorders feel less important than patients with other conditions.

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	N

During the visit the visiting team met 25 service user and carers - a combination of 13 adults, parents, and children with sickle cell disease and 12 adults, parents, and children with thalassaemia representing the adult and children services. The views of the users were wide-ranging and are documented in the children and young people and adult specialist haemoglobinopathy team sections. The review team would like to thank them for their openness and willingness to share their experiences.

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Specialist Haemoglobinopathy Team (Children and Young People Services): Royal Manchester Children's Hospital (RMCH)

General Comments and Achievements

Royal Manchester Children's Hospital (RMCH) was part of the multi-hospital complex that was Manchester University NHS Foundation Trust (MFT). One of the largest paediatric hospitals in Europe the hospital catchment area was almost 1 million children < 16yrs of age. The catchment area covered Leighton (Crewe) on the Southern border and into the Lake District in the North.

The RMCH non-malignant haematology unit formed part of the haematology/oncology day care unit and outpatient department. The unit and staff provided care for approximately 420 registered haemoglobinopathy patients, 550 patients with bleeding disorders, and those with thrombosis. Nationally, this was one of the largest paediatric haemoglobinopathy units. The team at RMCH provided support services to linked hospitals and to those community teams. In addition to the clinics held at RMCH, 3 monthly clinics were held at Blackburn and Burnley, Lancaster (Virtual) and Leighton.

The haemoglobinopathy team consisted of four consultants who had a combined 2 WTE for haemoglobinopathy within their job plans. The consultants had dedicated haemoglobinopathy sessions in their job plans to manage both in and outpatient. The separation of malignant and non-malignant haematology in 2021 has allowed the creation of a dedicated non-malignant haematology rota ensuring a consultant paediatric haematologist was available to give advice at RMCH on a 24-hour, 365 day per year basis.

There was a dedicated data manager for the non-malignant haematology service and an administrator who was responsible for NHR data entry and local database maintenance. All clinic administration was managed by other supporting team members.

The team provided teaching and training with commitment from all team members from within the hospital extending to the wider network and community. They were actively involved in teaching medical and nursing students, nurses, doctors in training, clinical fellows, emergency department medical and nursing teams, junior doctors, and consultant colleagues outside and within haematology. Consultants were part of a rotating junior doctor teaching programme that delivered virtual teaching every Tuesday morning and teaching during and after the joint ward round every Thursday morning. There were plans to formalise this to provide dedicated teaching for juniors rotating through the non-malignant service.

The team delivered several sessions encompassing primary to tertiary care and to all levels of nursing and doctor teams. Recent topics have included Sickle Cell Crises on PICU on the PICU GRID regional training programme, a tutorial on Sickle Cell Disease: Anaesthetic Challenges as part of the MSc, PGCert in Paediatric Anaesthesia and Thalassaemia and Challenges in primary care on the GP learning together day. There was an annual dedicated teaching day for trainees in paediatric haematology which always covers haemoglobinopathy, and the haematology trainees also received haemoglobinopathy teaching throughout the year on teaching days ad hoc and HCC Doctors and nursing teachings.

SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE	
Royal Manchester Children's Hospital	Linked Haemoglobinopathy Coordinating Centres (HCC) North West Sickle Cell Haemoglobinopathy HCC North of England Thalassaemia and RIA HCC *(Both hosted by Manchester University Hospitals NHMS Trust)* Linked Local Haemoglobinopathy Teams (LHT) **Hospitals with 10 or more Haemoglobinopathy patients.** • Blackpool Teaching Hospitals NHS Foundation Trust • Bolton NHS Foundation Trust • Royal Blackburn Teaching Hospital • East Lancashire Hospitals NHS Trust • Manchester University NHS Foundation Trust - • Manchester University NHS Foundation Trust - North Manchester General Hospital, Royal Oldham Hospital and Wythenshawe Hospital • Northern care Alliance NHS Foundation Trust- • Lancashire Teaching Hospitals NHS Foundation Trust • Stockport NHS Foundation Trust. • Wrighton, Wigan and Leigh NHS Foundation Trust

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	469	Not provided	239	18	335	164
Thalassaemia	Children & Young People	138	Not provided	40	44	N/A	6

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual WTE (at time of visit)
Consultant haematologist/paediatrician dedicated to work with patients with hemoglobinopathies	607	18 PAs for direct clinical care (DCC)
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with hemoglobinopathies	607	2 x CNS 0.8 WTE totalling 1.6 WTE

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

Clinical Psychologist for paediatric patients dedicated to work with patients with hemoglobinopathies	607	2 Psychologist Posts available for Adult and Paediatric Services – 1 on long term sickness

Emergency Care

The Manchester University NHS Foundation Trust had a dedicated Children's Emergency Department (ED) at the at RMCH. The hospital adjoined the MRI.

Haemoglobinopathy patients attended via the ED. The department was in the process of being refurbished at the time of the visit to improve the patient experience and department flow. Patients requiring admission would be admitted to Ward 86 or an outlying ward.

Sickle cell patients were highlighted on EPIC to alert staff of their sickle cell status and direction towards their emergency care plan for analgesia. Thalassaemia patients were highlighted in a similar way with an EPIC tab to alert the user for their need for regular transfusion requirement and the need for phenotyped matched blood. The Haemoglobinopathy team were notified of the attendance at triage, or the patients would call the CNS before attending.

In-patient Care

The inpatient wards included ward 86 which consisted of a large 32 bed in-patient unit which incorporated the care of both haematology oncology and benign haematology patients. Vital sign observation screens were outside the rooms for greater visibility. The review team heard that the staffing establishment allowed for 24 beds to be open which was increased to 28 in the winter months. The ward, although undergoing refurbishment at the time of the review, was equipped with a teen room, playroom and parent room with the teen room furnishings being funded by the Teenage Cancer Trust. For families requiring accommodation, the option of the Ronald McDonald House was available. QR codes to access patient information leaflets were observed on the walls.

The inpatient team consisted of the attending consultant, rotating haematology registrar(s) and general paediatric junior doctors and clinical nurse specialist. There were six paediatric Haematology trainees rotating in the Northwest Deanery. There was a paediatric registrar (onsite) and haematology registrar (on call) 24 hours a day, 7 days a week. There was a paediatric haematology consultant on call 24 hours a day, 7 days a week.

Surgical admissions (emergency or elective) were admitted to Ward 86 or Ward 76. Elective surgical admissions were referred via EPIC and highlighted at the weekly MDT and surgical plans made and distributed in advance on EPIC. Patients were routinely reviewed on admission and post op/ prior to discharge.

Day and outpatient care

There was a dedicated Haematology Day Case and Outpatients Departments for both benign and oncology patients based on ward 84. The Outpatient Department housed a large reception area, 9 clinic consulting rooms, consultant offices, a well-equipped children's play area and a child friendly waiting room area. Play therapists were available in the outpatient setting. There was a dedicated nursing procedure room available which was shared with other professionals, such as psychology, as space required. The facility had a stadiometer for spinal height measurement.

Those patients on regular transfusions attended ward 84 out-patients for their crossmatch blood tests throughout the week and were then catered for within the integral day-case unit for their transfusion or red cell exchange.

Weekly Wednesday clinic dates took place largely dedicated to patients with sickle cell disease. The clinic was segregated into an annual review or new patient clinic and a follow up clinic for recent inpatients. Every month a teenage/transition clinic took place joined by an adult consultant and specialist nurse.

Due to limited space on the ward 84 Outpatient Departments the Wednesday and Friday Hydroxycarbamide clinics were held in the general outpatient's department. The facility has a dedicated and adapted waiting area with sensory lighting for neurodivergent children and the reviewers observed sickle cell information on the walls.

Iron loading scans and trans-cranial dopplers (TCD) were undertaken in the colourful and calming radiology department where the vascular access service, described as the magic team, were available to support. The team worked closely with colleagues in radiology which enabled the incorporation of transcranial doppler appointments when required, within these clinic slots.

The day care facility was open Monday to Friday 07.30-19.00. The busy unit on the day of the visit had 9 beds and 6 chairs. The play table has only just been restored post pandemic and a play specialist supported the unit Monday to Friday 9am-5pm.

Although not visited during the visit the reviewers heard about a youth facility within the hospital where a dedicated HD youth worker was based and supported the children with non-medical needs.

Community-based Care

Community and genetic counselling services were provided by the Manchester Sickle cell and Thalassaemia Service (MSCTC) which is co-located as part of MFT, which operated within the Division of Medicine and Community services. There were close working links with the RMCH.

The team at the centre team consisted of Specialist Haemoglobinopathy Nurse Counsellors, Midwives, Paediatric Homecare Practitioners and Psychologists. They also had an excellent administration team. Amongst the services they offered were antenatal/prenatal genetic counselling, screening and support, education, health promotion & advocacy.

The team at the centre carried out outreach work in the community, promoting wider awareness of the disorder and played a key role in health education. This included teaching student nurses, midwives, and other health professionals about Haemoglobinopathies so there was good awareness of the disorders, and people with Sickle Cell & Thalassaemia were supported in all parts of the health and care system.

They also worked as a multi-disciplinary team with different professionals from across the hospitals and other services that patients might use. This included Consultant Haematologist in Adults & Paediatrics, Clinical Nurse Specialists in Adults & Paediatrics, Obstetricians, Clinical Scientists in Haematology & Genetics and Social Workers across MFT sites. The team regularly attended MDTs across sites and played a vital role in HCC education and engagement events.

Views of Service Users and Carers

Feedback from the parents representing children with Sickle Cell Disease:

The visiting team met with 5 parents representing 7 children with sickle cell disease, one parent and child was on the day care unit undergoing a planned exchange.

- The parents and children relayed that they felt very much listened to and were generally positive about their experience of the service.
- They reported that they have observed improvements since the implementation of the separate rota.

- They talked around the need to improve the awareness and knowledge of sickle cell disease across the hospital beyond ward 86, they described that they were missing a sense of regular education and training of SCD on the general wards.
- They were unsure if care plans were individualised and used by staff. A specific example provided related to the patient needing a specific approach to cannulation and that this did not feel to be referenced in a care plan due to experiences of cannulation at an LHT.
- There was a wish that there were more consultants.
- They were aware of who to contact in an emergency and within the HD team but sometimes were unaware of wider events about their condition that were on offer.
- They experienced good communications at clinics and the team had good communications with the schools.
- The service users were extremely positive about their school's knowledge of SCD and the benefits of their access to the youth worker.

Feedback from the parents and children with Thalassaemia

The visiting team met with 6 parents and 5 children with thalassaemia during the visit. Two of the children were undergoing transfusions on the day unit at the time of the visit.

- There was uncertainty on the emergency pathway, where to go and who to contact. The patients had closer hospitals to home than RMCH and they felt unsure that the LHT would have knowledge of thalassaemia.
- They described having to convince ambulances to bring them to RMCH as the North West Ambulance Service (NWAS) were unaware of the most appropriate hospitals for their care.
- The biggest challenge for out of hours access was for crossmatch and transfusion. One child described that they had to take time off school and felt pressure to then catch up. Parents described the challenge of taking the time off work.
- Parents described that they often felt that they had to chase test results. One described a non-response of the Trust in reference to completing a DNA sample for a sibling bone marrow match and another was unsure about the outcome of MRIs and other referrals within the system.
- Limited Halal options on the wards often meaning they had a diet of bread and parents had concerns around nutritional intake.
- Parents stated that they would like more local patient engagement and support groups. Charity support groups and branches were often based in London.
- One service user who travelled regularly for transfusions from Preston by car described how Novartis UKTS had helped greatly and provided good information.
- The review team heard that the LHTs ED wait time, both weekday and weekends, had been really long. Teams at the LHT were easy to contact if in-hours but they were unsure of who to contact out of hours. Parents were unsure about the communication and availability of information and the transition pathway if RMCH was not their nearest hospital.
- There were examples provided of patients not feeling listened to with regards to their pain and presenting symptoms via the emergency pathway. Sometimes symptoms were put down to the side effects of the Exjade medication rather than requiring further investigation.

Good Practice

a. Reviewers were impressed with the level and amount of patient engagement work. Education for families and staff were available through the HCC events alongside the Manchester Sickle Cell and Thalassaemia Centre (MSCTC) which provided a unique service for all patients with sickle cell and thalassaemia patients (all ages), education providers and primary care providers across the Greater Manchester region.

b. There was an excellent video available that involved a child talking through his day at RMCH receiving a blood transfusion. The personalised and accessible approach to providing information on this experience was commendable and the pride of the trust team for the boy in the video was palpable.

c. The team at RMCH had close working relationships with other clinical specialities such as neuro and endocrinology. Dedicated monthly Thalassaemia Clinics and 3 monthly Joint Endocrine Clinics had been established.

d. There was a structured transition pathway which commenced as the child started secondary school. A Sickle Cell Adolescent clinic that was held monthly involved joint working between a Paediatric Consultant, Paediatric CNS, youth worker, and Consultant Haematologist to improve the process of transition.

e. The review team heard positive comments about the vascular access service 'magic team'. Situated in the radiology department the magic team were responsive and supported the child or young person to receive timely vascular access with limited distress.

f. A youth worker (dedicated 0.6 WTE) was employed to support children with a haemoglobinopathy from 11 years up to the age of 35 years. A charity funded post the youth worker had succeeded in building relationships with the patients who they could contact in person or via text about any non-medical concern or query. RMCH had a Youth Facility available where children could access support away from the clinical areas.

g. The review team observed a highly collaborative approach to patient care. The MDT was inclusive not only involving a variety of clinical specialists but also the management team who had a good understanding of the needs of the patients in their care.

h. Born from the publication of the 'No-ones listening' report and subsequent recommendations there was a Sickle Cell Partnership Board chaired by the Director of Strategy. With direct board oversight the bi-monthly meeting reported on key service challenges and patient engagement feedback.

i. The HBO Team had close working relationships with the Manchester Local Care Organisation (MLCO). Part of this was the provision of the MSCTC whose was very highly thought of by teams across the MFT site. The review team heard how the MSCTC improved the lives of those living with red cell disorders and provided dedicated education and awareness raising of red cell disorders. This year celebrated 40 years of the sickle cell centre.

j. The social worker, although limited in capacity, provided essential support to the children, young people, and their families. Identifying those with vulnerable risk factors such as poor housing, dedicated support with medical letters, and contacting the ombudsman, council etc was provided. The social worker phoned the TCD patients every morning to ensure the child could attend in terms of any transport issues or social barriers to access of care.

k. The team had allocated non-recurrent funding to support the recruitment of a Band 5 nurse to join the team. The reviewers heard how this role had a positive impact in the release of the CNS to better support the MDT and review children in outpatients and in crisis. The CNS described increase satisfaction in their roles.

l. The Specialist Nurse team from acute and community worked well together to deliver a good service for patients local to Manchester. Reviewers were impressed with the patient information, which was of a high standard, and it was evident that a lot of heard work had gone into its collaborative production.

Immediate Risks: None were identified during the visit.

Concerns

a. **Psychology staffing**

Psychology input was only available 2 days a week therefore attendance at the MDT was minimal and they had to respond to referrals for high-risk patients such as those requiring cognitive assessment and undergoing transplant. There was no capacity to provide proactive care such as attending clinics and visiting the wards. The team reported that the greatest barrier to this was finance and that with financial resource this role could easily be recruited to.

The Trust should consider the ability to invest in psychology support to all patients with haemoglobinopathy, and instead offering to only those who appear to have the greatest clinical need.

b. **Consistent engagement and support to LHTs**

Although the review team heard about good collaborative working and clinical presence at East Lancashire NHS Trust, they felt that this level of support and engagement was not consistent across all the LHTs. The geographical patch of the SHT was large and consideration should be given to how to provide equity of care for patients across the full footprint, specifically those LHTs with a small number of patients, who may not have sufficient staff with specialist haemoglobinopathy expertise.

The review team were pleased to hear about a bid that had been submitted to invest in CNS support in LHTs placing 1 WTE CNS in centres with over 30 patients and 0.5 WTE in smaller centres. However, reviewers were told that centres with less than 10 patients will not receive any of this investment therefore potentially increasing the disparity of care for these more remote patients.

c. **Medical staffing rota**

At the time of the visit the Consultant 1:4 dedicated non-malignant haematology rota was not possible due to one haematologist being absent. This had resulted in the remaining consultants providing a 1:3 rota which became 1:2 if one of the consultants was on leave. Reviewers were concerned that this was not sustainable as the on-call consultant would have to undertake the ward rounds as well as the provision of the out of hours telephone support for the network. The review team heard that options were being explored to sustain this rota potentially using gene therapy funds to support an additional substantive post or going back to a combined rota.

d. **Provision of Analgesia**

The audits completed have demonstrated that children and young people presenting through ED were only receiving timely analgesia 30% of the time. Roll out of the EPIC EPR system had enabled patient flags to be visible and alerted clinician to the pathway which it was hoped on re-audit may have improved the administration of timely analgesia.

The management had gone at risk to increase the pain nursing hours into the service to support patients in sickle cell crisis however with increased demand, and the education required both within RMCH and the LHTs this input is inadequate and unable to support patients presenting in crisis at the weekend. The lack of capacity to support education at LHTs has meant that children and young people presenting to the LHT were less likely to have patient-controlled analgesia (PCA)

The Trust should consider substantive investment of specialist pain nurses to support the timely administration of analgesia in ED alongside the need to support the education of colleagues working in LHTs across the SHT wide geography.

Further Considerations

1. The appointment of the band 5 nurse had released the CNS from performing tasks such as bloods and cannulas both on the wards and in clinics. As a result of this post the CNS team were able to be present in clinics to offer specialist holistic support to the children and young people, including the provision of some nurse led clinics. Moving forward the Trust should consider how they may retain the band 5 nurse as a permanent post.
2. The Haematology team employed six specialist nurses with one specialist nurse for thalassaemia and one for sickle cell disease. It should be considered if, with the growing patient population, this would be enough to provide a future sustainable service and greater oversight of general nurses outside of the HBO environment.
3. The identification of link nurses on general wards may support nurse education in general wards and the use of cascade training. This may also be of benefit to support education in the LHTs.
4. The service users the review team spoke to on the visit were unsure if care plans were individualised and used by staff. A specific example was provided related to the patient needing a specific approach to cannulation and that this did not feel to be referenced in a care plan due to experiences of cannulation at an LHT. Consideration should be given to the involvement and awareness of patients in their care plans. The potential use of patient passports may now be possible due to the EPIC system.
5. The social worker role was an essential patient advocate and undertakes dialogue to address barriers to accessing care. Growth in demand and limited social work capacity had necessitated a responsive service reliant on one individual. Consideration should be given to increasing the social work support available to proactively meet both present and future patient need.
6. The review team heard about the increasing numbers of patients on sickle modifying interventions, the need for infrastructure to monitor and maintain this plus increasing complexity. Dedicated time in consultant job plans should be continually reviewed to ensure the changing case mix is accounted for.
7. The service users the review team spoke to highlighted the need for an out of hours transfusion service. The day unit and the feasibility of this should be considered to reduce disruption to time at school for the young people.

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Specialist Haemoglobinopathy Team (Adult Services): Manchester Royal Infirmary (MRI)

General Comments and Achievements

This was a well organised team who were flexible to the needs of their patients and families and had good relationships across the multidisciplinary team and with senior management of the trust.

The adult haemoglobinopathy service at MRI managed the care of 685 adults with haemoglobinopathy diagnoses who were registered on the National Haemoglobinopathy Register. Not all patients were registered on the NHR due to the lack of data management support, with data held locally on the HIVE system. The lack of data management support was included on the trust risk register. Shortly before the visit the team had recruited a haemoglobinopathy data manager post who would take responsibility for ensuring all patients were registered on the NHR.

The team consisted of four consultants, who all had dedicated haemoglobinopathy sessions in their job plans to manage the care of patients both in and outpatient. There were three dedicated haemoglobinopathy specialist nurses led by the Band 7 CNS. The SHT also included 0.6 WTE specialist haemoglobinopathy midwife a dedicated psychologist and access to a youth worker and social worker.

The Manchester Royal Infirmary had been the first site in England to establish a Hyper Acute Unit for patients with sickle cell disorders which had been in operation since (live from January 2024). The unit was known locally as the Sickle Cell Crisis Unit (SCU). As a result, there had been significant changes in the way that the MRI Red Cell Service operated and work was ongoing to review how the unit would operate in the longer term in terms of consultant job plans, operational procedures, and clinics.

The MRI were hoping to be the first site for Wave 1 Gene Therapy if, NICE approved, in partnership with RMCH.

The SHT had recently partnered with the Sickle Cell Society to promote and support their peer mentoring programme for patients across the Northwest of England.

When asked during the visit, the team had a number of areas they would like to develop to improve their service:

- Increase in psychology and social worker support to support a more holistic approach to care.
- The haematology social worker was only commissioned to provide 2 days support which was insufficient for the number of patients. Increasing the social care support would enable joint patient meetings with health care professionals and reduce the time clinical staff were spending on non-clinical activities and ensure that patients were informed of available social care support and access to appropriate welfare benefits.
- Development of a welfare rights advisor role would help support patients to access the right level of support as the community team were spending a significant amount of time negotiating with the number of different boroughs across the community to access support, particularly help with housing.
- There was no access to routine red cell exchange across the region.
- Permanent funding and increase in time available from Youth Worker to continue the support for young people to transition to the adult service.
- Increasing nursing staffing and seniority of nursing staff.

SPECIALIST HAEMOGLOBINOPATHY TEAM - ADULTS	
Manchester Royal Infirmary	Linked Haemoglobinopathy Coordinating Centres (HCC)
	North West Sickle Cell Haemoglobinopathy HCC North of England Thalassaemia and RIA HCC *(Both hosted by Manchester University Hospitals NHS Trust)*
	Linked Local Haemoglobinopathy Teams (LHT)
	Hospitals with 10 or more Haemoglobinopathy patients. • Blackpool Teaching Hospitals NHS Foundation Trust • Bolton NHS Foundation Trust • Royal Blackburn Teaching Hospital • East Lancashire Hospitals NHS Trust • Manchester University NHS Foundation Trust - • Manchester University NHS Foundation Trust - North Manchester General Hospital, Royal Oldham Hospital and Wythenshawe Hospital • Northern care Alliance NHS Foundation Trust- • Lancashire Teaching Hospitals NHS Foundation Trust • Stockport NHS Foundation Trust. • Wrighton, Wigan and Leigh NHS Foundation Trust

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	520	Data not provided	290	56	Data not provided	208
Thalassaemia and RIA	Adults	165	Data not provided	96	69	N/A	24

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/ WTE (at time of visit)
Consultant haematologist dedicated to work with patients with hemoglobinopathies	685	4 WTE consultant posts
Clinical Nurse Specialist (CNS) for adult patients dedicated to work with patients with hemoglobinopathies	685	1 WTE band 7 and 2 band 6

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

Clinical Psychologist for adult patients dedicated to work with patients with hemoglobinopathies	685	0.4 WTE Psychologist

Emergency Care

The Manchester University NHS Foundation Trust had four Accident and Emergency Departments based at Royal Manchester Children's Hospital, Manchester Royal Infirmary, Wythenshawe Hospital, and North Manchester General Hospital. Arrangements were in place with the ambulance service to deliver patients with a hemoglobinopathy disorder who required an emergency assessment to either the Royal Manchester Children's Hospital or Manchester Royal Infirmary.

Adult patients with a sickle cell crises were advised to call the Sickle Cell Unit (SCU) triage phone, held by CNS team in hours and ward nurses out of hours. Once triaged, the patient was either advised to either attend the SCU, their local emergency department or be provided with advice on how to manage their pain. For those who were advised to attend the SCU, the patients were asked to attend the emergency department entrance reception and ask for the SCU to be notified. A member of the SCU would then meet them and take them to the SCU. Any friends or family members would have to stay in the waiting area due to limited space in the SCU treatment area. Following analgesia, the patient would be monitored and stay on the unit and either admitted or discharged home.

Patients with acute complications of their sickle cell disorder or those with thalassaemia were advised to attend the A&E department for assessment. During working hours, the Haemoglobinopathy Clinical Nurse Specialist (CNS) or one of the specialist nurses would be contacted to attend along with the red cell registrar (if available). Patients could be admitted directly under the haematology team or the on-take medical team according to clinical problems. Out of hours patients were admitted by the medical team and transferred to the haematology team the next working day. Patients had individualised care plans agreed with them in advance and a copy of their plan was available in the ED and in the patient records.

Inpatient Care

Patients could be admitted to the haematology ward (ward 10, ward 44) or medical wards depending on bed availability. Patients admitted through the ED were often admitted into the Acute Medical Unit (AMU) or SCU depending on their condition and bed availability. Where long term treatment and monitoring was required, patients were then transferred to either ward 10, 44 or 2. Patients with sickle cell disease who required patient controlled analgesia (PCA) were admitted to a ward with staff trained in PCA management.

Since January 2024, sickle cell patients had access to a 24-hour nurse triage line for advice on acute sickle crisis management, patients had direct access to two SCU ring-fenced beds on ward 10 for management of acute sickle cell crisis. The SCU was overseen by a dedicated haemoglobinopathy on call service and 7 day attending consultant presence. The CNS's had led on providing training for staff on the SCU on Ward 10. Ward 10 (where the SCU is located)) had 21 beds including the two dedicated SCU side rooms and 1 treatment area.

Ward 44 had 34 dedicated haematology beds which were all single rooms, all of which were fitted with HEPA filtration and are pressurised rooms. Patients admitted to the haematology ward tended to be teenage and young adults or adult patients under the care of the clinical haematology team that included the specialist haemoglobinopathy team.

Day Care and Outpatients

The Haematology Day Unit (HDU) was where patients could attend for treatments such as transfusion of blood products, infusion of drugs (antibiotics, other), apheresis (red cell exchange) and general phlebotomy.

The clinics were staffed by consultants, middle grade doctors, specialist nurses, counsellors, phlebotomists, and health care assistants. Patients requiring an urgent appointment could be seen within 2 weeks. Patients were also sent an appointment reminder via text message reminder to their mobile phone.

Red Cell Clinics were held on a weekly basis, a young person's clinic twice a month and a transition clinic monthly. A nurse led hydroxycarbamide monitoring clinic was held weekly.

A range of joint specialist clinics were held with obstetrics, endocrine/ bone, orthopaedics, and stroke teams on a regular basis.

The psychologist was also available to see patients and those attending the young person's sickle cell clinic. All patients were also seen at least annually by the Manchester Sickle cell and Thalassaemia Service (MSCTC), community team.

The SHT also provided a 3-month outreach clinic at the Royal Blackburn Hospital, part of the East Lancashire Hospitals NHS Trust (ELHT).

Laboratory diagnostics, including a northwest of England regional referral service were provided Red Cell laboratory and Molecular Diagnostics Centre based at the trust.

Community services

Community and genetic counselling services were provided by MSCTC, which operated within the Division of Medicine and Community Services. The team at the centre team consisted of Specialist Haemoglobinopathy Nurse Counsellors, Midwives, Paediatric Homecare Practitioners and Psychologists and administrative support. Amongst the services they offered were antenatal/prenatal genetic counselling, screening and support, education, health promotion & advocacy.

The team at the centre carried out outreach work in the community, promoting wider awareness of haemoglobin disorders and played a key role in health education. This included teaching student nurses, midwives, and other health professionals about Haemoglobinopathies.

They also worked as a multi-disciplinary team with different professionals from across the hospitals and other services. This included Consultant Haematologists in Adults & Paediatrics, Clinical Nurse Specialists in Adults & Paediatrics, Obstetricians, Clinical Scientists in Haematology & Genetics, and Social Workers across MFT sites.

Views of Service Users and Carers

Views of service users had been undertaken during 2023 for patients with hemoglobinopathies with 17 responses from patients with sickle cell disease and 11 responses from patients with thalassaemia and RIA. The team had collated and identified themes and reported that the majority of feedback was favourable about the care they received and knowledge core staff had of their condition. For patients with living with sickle cell disease, improving pain management, faster transfusions and access to psychology were areas where they considered improvements could be made as well as access to more advice, information, and opportunities to meet with other patients. For patients living with thalassaemia, themes ranged from access to endocrinology, and eye and ear specialists, poor care when they attended the emergency department, and improving start times for their blood transfusions were identified areas for improvement.

The visiting team met with two adults with sickle cell disease and one patient with thalassaemia during the visit. See their feedback below about the services provided by the Trust:

Patients living with a Sickle Cell Disease feedback

- Patients who spoke to the reviewing team were aware of protocols and pathways out of hours. Being able to text the CNS was helpful.
- A number of comments were received about poor care when they attended the ED. The protocols especially the priority access during the COVD 19 pandemic had not been implemented when they attended. They commented that the audit of first time to analgesia would have been inflated as marked met when offered pain relief rather than administered which was often much later than the expected 30 mins timeframe. If they had taken paracetamol at home, they were told they could not have any further analgesia for four hours regardless of what had been agreed on their emergency care plan. They would like the 'drug seeker' culture they experienced when attending the ED to be addressed with the comment being made that it was important not to not to 'decouple the physical vs wellbeing side'.
- They were often left in side rooms for hours. Comments were also received about the ceasing of opioids because staff felt they 'looked ok' and felt that staff did not take the potential of sepsis seriously with comments heard about them being that they 'just wanted morphine'. When a general complaint had been made to the Trust (not via PALS) no apology or acknowledgment had been received.
- They would like more information about the Trust protocol for intravenous paracetamol to understand why they were not given pain relief and also commented that staff did not always follow their care plans.
- One patient recounted an experience of attending the Trust unwell and was walked to the ED by the CNS. The CNS explained to reception they were a priority patient but they had then waited more than four hours to be seen. During this time, they had tried to contact the CNS several times but were told that nothing more could be done and they needed to 'go through the emergency pathway'. The last time they contacted the CNS mobile they were told that the CNS had gone home.
- 'myMFD' allowed them to see letters to GPs and also blood test results which was useful.
- Some were not sure of the support available to enable them to be empowered to advocate for themselves.
- Patients who were aware of the HCC considered there were now opportunities for the HCC to lead on the improvement of services. Areas they felt the HCC could support were; ambulances did not always take them to the designated hospital and they would like the HCC to work with ambulance services to address this; communication between acute discharge and the community service could be improved; and developing more education for parents, existing patients, and new patients to the area.

Patients living with Thalassaemia feedback

- The patients knew who their consultants were but were unsure who to approach in an emergency.
- One patient was not diagnosed until late 30s but considered that they had received sufficient information about starting on a regular transfusion programme and chelation medication and monitoring but did not believe they had received information about the side effects of chelation and would like more information leaflets about their condition.
- When a consultant had not been available they had to chase to be able to see someone else and therefore did not think that contingency plans for the consultant absence had been communicated to patients.

Good Practice

1. A hyperacute sickle cell unit (SCU) had been commissioned and commenced operation in January 2024 to enable patients to be seen quickly and avoid attending the ED or other emergency admission areas. Patients who met with the reviewing team liked the concept and revised pathway.
2. Weekly 'hot clinics' had been implemented to review patients who had recently been discharged from an inpatient setting. The clinics were held at the Manchester Sickle Cell and Thalassaemia Service (MSCTC) building which had a wealth of information and access to other members of the community team so that additional support could be provided.
3. Reviewers were impressed with the integration of the community and acute services service. Patients were seen by the community service annually and had access to a wealth of support and education at the centre. The development of follow up clinics held by the SHT at the community centre (MSCTC) meant that there was a greater focus on reablement.
4. The Trust had implemented a system whereby the consultants on call did not have any other clinical commitments which meant they were not having to manage competing clinical priorities during this time.
5. The transfusion care plan for thalassaemia and rare anaemia patients was very clear and comprehensive.
6. The SHT had implemented a number of sub speciality clinics for patients. Clinics ranged from joint/bone, endocrine, diabetes, orthopaedic, obstetrics and a specialist thalassaemia and endocrine clinic. A joint sickle cell and stroke had been recently established.
7. The competence framework was very comprehensive and was adapted from the new RCN framework. Sections had been separated to cover the different staff competences needed for the different conditions and areas of work.
8. A youth worker provided support for all young people between the ages of 11 to -25 with a long-term condition. The post was initially charitably funded and had been extended on short term basis for three years, with 60% of their time allocated to the care of patients with haemoglobin disorders. The youth worker worked across the adult and children's haemoglobinopathy teams to help and prepare young people to transition to adult care. The youth worker would meet with patients on a regular basis and could offer residential and peer support. Feedback from patients and staff was that the support from the youth worker had been invaluable especially the support for young people prior to attending their haemoglobinopathy appointments and the provision of away days for young people to meet and share experiences.

Immediate Risks None were identified during the visit.

Concerns

a. **Maintaining services due to staffing and capacity**

The trust had implemented a number of short term solutions to mitigate the ever increasing demands on the SHT but a longer term plan to address workload and service delivery was not evident. Reviewers were made aware of a number of situations whereby the non-recurrent funding was creating a vulnerability to the retention of staff and potential service viability.

a) The development of the SCU whilst having benefits, also had increased the pressure on the team due to the non-recurrent funding of two years associated with its implementation with the 24hr triage facility and

consultant on call commitments. Reviewers considered this would not be sustainable in the future with the likelihood of increasing activity.

b) Due to the number of consultants caring for those with haemoglobin disorders they had not been able to designate a lead clinician for the SHT as well as the two HCCs and the leads for the HCCs were then spending HCC allocated leadership time addressing SHT leadership issues with no specific allocated time for this work.

c) At the time of the visit only two of the four consultants were available to provide the wide range of clinical services and on call commitments. The SHT were also providing an outreach service to the Royal Blackburn Hospital and Burnley General teaching Hospital which had significant numbers of patients with haemoglobin disorders.

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

e) The Lead CNS role included a significant clinical workload and in practice did not have sufficient time for leadership of the SHT in terms of oversight of guidelines, training, and audit or for liaison with other services. The CNS had informal connections with some nurses across the network but no formal networking across the whole region the SHT served.

f) The CNS team were also relatively junior in terms of experience and coupled with the low banding of the apheresis nurse posts, reviewers considered this carried a high risk of non-retention.

g) The Youth Worker post was commissioned on a recurrent charitable short term funding with long term funding uncertain. This had the potential to affect how the service could develop to meet the needs of the patients.

h) The SHT had only 0.5 WTE social worker which had resulted in CNSs spending time on non- clinical activity for example providing information for Personal Independence Payment (PIP) and preparing information to support those needing welfare and housing support.

i) Patients feedback was that when they were admitted, staff did not have sufficient time for care for them and they felt vulnerable when acutely unwell.

b. **Increase in day unit and apheresis activity**

With the expanding patient haemoglobinopathy population, reviewers were concerned that both the day unit and apheresis service were both already at capacity and space and equipment access would remain challenged with the increasing number of new patients likely to require day care and apheresis in the future. Reviewers were told that there had been a 60% increase of patients within the Manchester and 40% across the region and the increase in number of service users likely to continue year on year.

At the time of the visit forty out of 520 patients were on the red cell exchange programme, which reviewers considered was a relatively low proportion of patients. NHSBT had a case load of 12 patients with two elective slots per week and the SHT had eight elective slots for the remaining patients on the programme. The lack of capacity from NHSBT had resulted in the in-house service extending patient red cell exchange intervals to accommodate patients who required a red cell exchange procedure in an emergency . The nursing staff were also undertaking femoral line insertion without any additional staffing to reflect the increase in their workload.

c. **Access to analgesia**

Access to analgesia and staff attitudes to those in pain were a concern to the reviewers for a number of reasons:-

a) Patients did not consider that they had a good experience when attending the ED. Patients believed that care was less than optimal, and they waited long times for analgesia. Patients who met with the reviewing team commented that they were offered analgesia within the 30 min timeframe but often waited a long time for the analgesia to actually be administered which they considered did not meet the NICE Clinical Guideline on the management of acute pain.

b) They would like the 'drug seeker' culture they experienced when attending the ED and other areas to be addressed with the comment being made that it was important not to not to 'decouple the physical versus the wellbeing side'.

c) There was no clear pathway with the pain team for joint management of acute and chronic pain. The use of 'weaning' plans for reduction of opioids were not in use. Reviewers were told by the patients that their GPs were not always informed about their analgesia plan management following discharge.

d) The acute pain audit was not a rolling audit and only covered a snapshot of three months and although it reported and documented that 75% of patients were offered analgesia (rather than received) within the timescale of 30 mins, in view of patient feedback may not be an accurate position of compliance.

d. **Access to psychology**

The service had 0.4 WTE psychologist which was insufficient for the 685 patients registered with the service and did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE psychologist for every 300 patients. The postholder had been absent for 24 months and it was not clear what cover arrangements had been put in place to ensure patients could access psychology support in their absence. There did not seem to be a neuropsychology pathway for adults. Reviewers were concerned as without sufficient dedicated psychologist support individuals affected by these disorders will have limited specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition.

e. **Community Haemoglobinopathy Provision**

The community team covered the care of all adults, children and young people with haemoglobin disorders and had seen a significant increase in the number of patients in the area. In one week, it was reported that they had 35 new patients referred following their screening outcome and reviewers were concerned about the sustainability of the community service without a strategic approach to addressing this ever increasing activity. The community team were also providing some support out of area but were not appropriately commissioned for this additional work.

Further Considerations

1. Reviewers did not see any signage or information for red cell services in any of the adult areas visited including the new SCU. This had the potential to make patients with haemoglobin disorders feel less important than patients with other conditions. Ownership of information in these areas would also help promote staff knowledge and understanding of these conditions.
2. An audit of acute admissions to inappropriate settings including patient and clinical feedback on these admissions had not been completed which, if undertaken would help with identifying pathway issues and identifying educational needs in these areas, planning patient management and support to areas, as well as

identifying if there were any specific training needs for staff. An audit would also enable a review of the patients length of stay in these areas and targeting of any actions to ensure timely assessment, treatment, and discharge of patients.

3. Nurse educators provided training for staff on the ward and in the ED on the care of patients with sickle cell disease but did not provide training on those with thalassaemia. From discussions it was not clear how staff knowledge and competencies were monitored and enforced and whether the content of their education reviewed monitored in collaboration with the SHT. The CNS had developed link nurses in several areas and regionally but there was no information about how they were supported, and the CNS did not have the capacity to support ongoing training that was initially provided by the nurse educators.
4. The lack data support had meant that there was a delay in registering patients on the National Haemoglobinopathy Register (NHR). Additional data was collected locally and the SHT had recently appointed a data manager to provide additional data support.
5. There was no satellite provision of elective apheresis for the LHTs. The NHSBT service level agreement only covered emergency red cell exchange provision, which resulted in patients having to travel long distances for their red cell exchanges creating additional pressures on capacity for the already stretched HDU.

Commissioning

The review team had discussions with a commissioners from NHS England North East and Yorkshire and NHS England North West. Several of the issues in this report relating to the North West Sickle Cell and North of England HCCs and the adults and children and young people SHTs will require the active involvement of the Trust and commissioners in order to ensure that timely progress is made.

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Appendix 1 - Membership of Visiting Team

Visiting Team		
Christine Wright	Consultant Adult Haematologist	Sandwell & West Birmingham NHS Trust
Annette Blackmore	Non-Malignant Haematology CNS	Cardiff and Vale UHB
Hannah Jerman	Clinical Nurse Specialist	Guy's and St Thomas NHS Trust
Stuart McGunnigle	Network Manager	University College London Hospital
Samah Babiker	Consultant Paediatric Haematologist	Guy's and St Thomas NHS Foundation Trust
Lesley McCarthy	Haemoglobinopathy Nurse Specialist	Oxford University Hospital
Janice Llewellyn	Haemoglobinopathy Nurse Specialist	Shrewsbury and Telford NHS Trust
Heather Rawle	Consultant Clinical and Health Psychologist	Guy's and St Thomas NHS Foundation Trust
Lulu Awori	Devolution, Contracts and Performance Manager	NHS England
Romaine Maharaj	User representative	UK Thalassaemia Society

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

MLCSU Team		
Sarah Broomhead	Professional Lead	MLCSU
Kelly Bishop	Assistant Director	MLCSU

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Appendix 2 - Compliance with the Quality Standards

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

Percentage of Quality Standards met TBA

Service	Number of Applicable QS	Number of QS Met	% Met
North West Sickle Cell Haemoglobinopathy Coordinating Centre (HCC)– All Ages	13	11	79%
North of England Thalassaemia and RIA Haemoglobinopathy Coordinating Centre (HCC)– All Ages	11	8	73%
Specialist Haemoglobinopathy Team (SHT) Children and Young People	49	43	88%
Specialist Haemoglobinopathy Team (SHT) Adults	45	37	82%

North West Sickle Cell Haemoglobinopathy Coordinating Care Centre - All Ages

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-198S	**Network-wide Involvement of Children, Young People and Families (SCD)** The Sickle Cell Disorder HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702).	Y	
H-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	Y	
H-202	**Lead Nurse** A lead nurse should be available with: a) Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b) Responsibility for liaison with other services within the network c) Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	There was no lead nurse with responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders and with responsibility for liaison with other services within the network.
H-202A	**Lead Manager** A lead manager should be available with: a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs b. Responsibility for liaison with other services within the network The lead manager should have appropriate time for their role.	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-203	**Lead for Transcranial Doppler Ultrasound** The HCC should have a nominated lead for Transcranial Doppler Ultrasound screening.	Y	
H-602S	**HCC Service Organisation (SCD)** A Sickle Cell Disorder HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including: a. Telephone or email advice for outpatient and inpatient care b. Advice on emergencies outside of normal working hours	N	There was a service organisation document (SOP) but it did not include the telephone / email advice contacts or advice on emergencies outside of normal working hours.
H-605S	**HCC Multidisciplinary Discussion (SCD)** MDT meetings for the discussion of more complex patients with sickle cell disorder should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use.	Y	The referral process was clear, and as per the service specification the complex HCC MDT discussions were scheduled monthly.
H-609	**NHS Blood and Transplant Liaison** The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies.	N	A link person from NHSBT met with the reviewers but there was no evidence of a formal meeting as stipulated by the QS.

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

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-704	**Transcranial Doppler (TCD) Monitoring Report** The HCC TCD lead should monitor and review at least annually: a The list of staff undertaking TCD ultrasound and whether they have undertaken 40 procedures in the last year (QS HC-209) b Results of internal quality assurance systems (QS HC-504) c Results of National Quality Assurance Scheme (NQAS) for TCD ultrasound (when established) or local peer review arrangements (until NQAS established) d Number of TCD ultrasounds performed and the number of abnormal TCDs across the network e Whether any changes to the TCD Standard Operating Procedure (QS HC-504) are required	Y	
H-707	**Research** The HCC should have agreed a list of research trials available to all patients within the network and SHTs should actively participate in these trials.	Y	
H-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

North of England Thalassaemia & RIA Haemoglobinopathy Coordinating Care Centre - All Ages

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-198T	**Network-wide Involvement of Children, Young People and Families (Th)** The Thalassaemia HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702).	Y	
H-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	Y	
H-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders d. The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	There was no lead nurse with responsibility for guidelines, protocols, training, and audit relating to haemoglobin disorders and with responsibility for liaison with other services within the network
H-202A	**Lead Manager** A lead manager should be available with: a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs b. Responsibility for liaison with other services within the network The lead manager should have appropriate time for their role.	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-602T	**HCC Service Organisation (Th)** A Thalassaemia HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including: a. Telephone or email advice for outpatient and inpatient care b. Advice on emergencies outside of normal working hours	N	There was a service organisation document (SOP) but it did not include the telephone / email advice contacts or advice on emergencies outside of normal working hours.
H-605T	**HCC Multidisciplinary Discussion (Th)** MDT meetings for the discussion of more complex patients with thalassaemia should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use.	Y	The referral process was clear, and as per the service specification the complex HCC MDT discussions were scheduled monthly.
H-609	**NHS Blood and Transplant Liaison** The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies.	N	A link person from NHSBT met with the reviewers but there was no evidence of a formal meeting as stipulated by the QS.
H-702T	**HCC Business Meetings (Th)** The Thalassaemia HCC should organise at least two meetings each year with its referring SHTs and LHTs to: a Agree network-wide information for patients and carers of all ages b Agree network-wide policies, procedures and guidelines, including revisions as required c Agree the annual network education and training programme d Agree the annual network audit plan, review results of network audits undertaken and agree action plans e Review and agree learning from any positive feedback or complaints involving liaison between teams f Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
	g Review progress with patient experience and clinical outcomes (QS H-797) across the network and agree any network-wide actions to improve performance h Consider the TCD annual monitoring report and agree any actions required (QS H-704).		
H-703	**HCC Annual Programme of Work** The HCC should meet with their commissioners at least annually in order to: a Review progress on the previous year's annual programme of work b Review progress with improving patient experience and clinical outcomes across the network (QS H-797) c Agree the annual programme of work for the forthcoming year	Y	The annual programme of work covered both Sickle Cell Disease and Thalassaemia.
H-707	**Research** The HCC should have agreed a list of research trials available to all patients within the network and SHTs should actively participate in these trials.	Y	
H-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

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	
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	Y	
HC-197	**Gathering Views of Children, Young People and their Families** The service should gather the views of children, young people and their families at least every three years using: a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder' b. UKTS Survey for Parents of Children with Thalassaemia	Y	
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	Y	
HC-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	
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.	Y	
HC-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of children and young people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	
HC-206	**Doctors in Training** If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	Y	
HC-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	0.4 WTE Psychologist for the children and young people service covering 607 patients which did not meet the recommended 1:300 standard.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	Y	
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	
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	Y	
HC-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	y	
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders.	N	Good links to department and education however no formal competency frameworks in place at the time of the visit.

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	
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	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible	Y	
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	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: Local management Indications for seeking advice from the HCC / SHT 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 hrs of acute admission c. Patient discussion at local multidisciplinary team meetings (QS HC-604) d. Referral of children for TCD screening if not provided locally e. 'Fail-safe' arrangements for ensuring all children and young people have TCD ultrasound when indicated f. Arrangements for liaison with community paediatricians and with schools or colleges g. Follow up of patients who 'were not brought' h. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care i. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together j. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	N	No service specific organisation policy was in place.
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)		No shared care agreements with LHTs were in place

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	The SLA was in draft at the time of the visit.
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	
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	Y	
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS HC-702d).	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	
HC-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HC-197) compared with other services c. Results of audits (QS HC-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	Y	
HC-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	Y	
HC-799	**Document Control** All information for children, young people and their families, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

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

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**	Information covering the QS was seen for Sickle Cell Disease and for Thalassaemia
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
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**	
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	Specific information for the primary health care team was in place. The leaflet for children with thalassaemia was very good.
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	**Y**	
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	**Y**	Specific days and events had been held with patients and carers with sickle cell disease and thalassaemia in a variety of locations.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback b. Mechanisms for involving patients and their carers in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HA-797) c. Examples of changes made as a result of feedback and involvement	**Y**	
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**	A lead for the SHT had not been designated.
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training, and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	**N**	There was a named lead nurse but the lead did not have sufficient time for oversight of the SHT (guidelines, training, and audit) or for liaison with other services

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.	Y	The SHT had three WTE consultants for 685 patients. At the time of the visit, two consultants were absent so cover was provided by a locum consultant and an SpR
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	The competence framework was very comprehensive and was adapted from the new RCN framework. Sections had been separated to cover the different staff competences needed for the different conditions and areas of work. The training booklet which was due for review had very little information about SCD

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**	The SHT had only 0.4 WTE psychologist for the adult service covering 485 patients, which did not meet the recommended standard of 1 WTE :300 patients. The postholder had been absent for 24 months and it was not clear what cover arrangements had been put in place to ensure patients could access psychology support in their absence. There did not seem to be a neuropsychology pathway for adults
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**	A data manager had just been appointed
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**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
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	**Y**	
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	**Y**	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	**N**	Training for ED staff on the emergency care of patients with thalassaemia was not provided by the nurse educators. Sixteen patients with thalassaemia had been admitted via ED in the last year. Staff training on the emergency care of patients with sickle cell disease was delivered for ED and CSU staff but no formal competency framework was in place. On the day of the visit not all staff who met with the revieing team had received training in haemoglobin disorders.

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	**Y**	The standard operating procedure was very clear. Transfusion advice was also included in the 'Management of the unwell thalassaemia patient' guidance.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	**Y**	
HA-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring of complications e. Indications for discontinuation	**Y**	
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 i. 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 ii. For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-510	**Clinical Guidelines: Chronic Complications** Guidelines on the management of the chronic complications listed below should be in use covering at least: i. Local management ii. Indications for discussion at the HCC MDT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred iv. Arrangements for specialist multidisciplinary review a. Renal disease, including sickle nephropathy b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease c. Eye problems, including sickle retinopathy and chelation-related eye disease d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease e. Pulmonary hypertension f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea g. Endocrine problems, including endocrinopathies and osteoporosis h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology i. Chronic pain j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease k. Urological complications, including priapism and erectile dysfunction l. Dental problems	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
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**	
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	**Y**	
HA-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	**N**	Governance arrangements for providing consultations, assessments, and therapeutic interventions virtually, in the home or in informal locations was not included in the operational policy. All other aspects of the QS were met.
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**	Some shared care agreements were in place with high prevalence areas e.g. Blackburn and Bolton. Reviewers were told that the HCCs were working to agree with other LHTSs

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	**Y**	
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.	**N**	Not all patients known to the SHT had been registered on NHR
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	**Y**	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	**Y**	
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**	It was not clear from the evidence and discussions that the SHT MDT had met with patient representatives to discuss the achievement of Quality Dashboard metrics compared with other services (a) and achievement of Patient Survey results compared with other services
HA-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	**Y**	
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	**Y**	