MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

# Health Services for People with Haemoglobin Disorders

## North East & Yorkshire Haemoglobinopathy Coordinating Centre

## Sheffield Teaching Hospitals NHS Foundation Trust

Visit date: 17th October 2023

Report date: 1st February 2024

# Contents

# Introduction

This report presents the findings of the review of North East & Yorkshire Haemoglobinopathy Coordinating Centre and the Specialist Haemoglobinopathy Team based at Sheffield Teaching Hospitals NHS Foundation Trust that took place on 17th October 2023. 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 were 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 key issues raised during 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 Sheffield 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:

- Sheffield Teaching Hospitals NHS Foundation Trust
- NHS North East and Yorkshire
- South Yorkshire Integrated Care System

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled using appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for acting 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 Yorkshire and Humber and South Yorkshire Integrated Care System

# 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 Leeds health economy for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks, are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

Return to Index

# Review Visit Findings

## North East and Yorkshire Sickle Cell Haemoglobinopathy Coordinating Centre

**Introduction**

This review looked at the co-ordination of health services provided for children, young people and adults with sickle cell disorders across North-East and Yorkshire. The HCC had close links with the and Rarer Anaemias HCC for the North of England based and led by Manchester University NHS Foundation Trust.

Sheffield Teaching Hospitals NHS Foundation Trust (STH) in partnership with Sheffield Childrens' Hospital (SCH) had been designated a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell disease in 2020 and was working in collaboration with two other Specialist Haemoglobinopathy Teams (SHT): Leeds Teaching Hospitals NHS Trust and Newcastle Upon Tyne Hospitals NHS Foundation Trust. There were two other local Haemoglobinopathy Teams (LHT) with significant patient populations of people with haemoglobin disorders in the region that were engaged with the HCC; James Cook University Hospital in Middlesborough and Bradford Teaching Hospitals NHS Foundation Trust.

The role of the HCC was to provide a high-quality service for people with sickle cell disorders, in line with the service specification laid out by the NHS England and responsible for co-ordinating, supporting and promoting a system-wide networked approach to the delivery of haemoglobinopathy services and reducing unwarranted variation by reducing inequalities. Improving timely access and offering a caring, adaptable and patient centred approach to management and long-term care of patients and to build on and spread best practice throughout the network.

**General Comments and Achievements**

During the visit, reviewers met with members of the North East and Yorkshire Sickle Cell Haemoglobinopathy Coordinating Centre (NE&Y HCC) and commissioners. From discussions during the visits the HCC appeared to be held in high regard by both the patients and staff and it was clear that they were working hard to deliver their agenda but for many aspects of the HCC role they were hampered by the lack of workforce resource.

Since its inception the work of the HCC had been disrupted by the changes in HCC personal. At the time of the visit the HCC had been successful in the appointment of the following key staff:

- Clinical Lead for the HCC (1 PA)
- Paediatric Clinical Lead for children, young people (0.75 PA)
- HCC Network Manager (secondment 0.2wte approx.)
- HCC Administrator and MDT coordinator (0.85wte)
- HCC Transcranial Doppler Lead (0.25 PA)
- NHSBT Transfusion Lead Consultant

At the time of the visit the HCC did not have a Lead nurse / Educational Lead or a Pain Management Lead.

Work had been completed to map all the hospitals in the regions and identify where services were being delivered and the SHT and LHT relationships - see main report in relation to those patients who live in cross boundary areas. As of September 2023, HCC population data for the region identified a total number of those with hemoglobinopathies as 1131 made up of 862 people with sickle cell disease and 269 people with thalassaemia / rare inherited anaemias. The HCC reported that there had been an increase of 151 people with sickle cell disorders in the region compared with the previous year's (2021-22) data. The number of patients with thalassaemia / rare inherited anaemias had also increased by 34 patients. Reviewers were told that this was due to several factors; increase in number of newborn diagnoses via the screening programme, internal and external migration, and proactive recruitment of international students at universities.

The HCC had made progress in mapping the workforce across the North East and Yorkshire. None of the LHTs in the region, excluding Bradford, had any planned time dedicated to hemoglobinopathies and therefore work with this group of patients was combined with broader haematology commitments. Many of the SHTs' work planned time for consultants and clinical nurse specialists was shared with other benign haematology services. The HCC had identified that all hemoglobinopathy services across the HCC region were impacted by the limited cover available, especially in the event of staff absence.

The HCC had developed a person specification for involvement of patients and had been successful in recruiting representatives to join the HCC Board. The HCC had also started to identify other patients across the region who would be interested in working with the HCC in the future. A network wide patient experience survey had been undertaken. The HCC were also working with patients and a digital supplier to develop video testimonials and stories. Each video would include a question-and-answer section covering key information. It was planned that these videos would be available on the HCC website later in 2023.

HCC MDT was working effectively with a clear process and agenda for discussing serious adverse events, current inpatients, planned admissions, clinic reviews, benefits advise and psychological feedback.

HCC has been successful in research studies with several clinical trials running across the network.

At each business meeting the SHTs provided comprehensive service updates.

The HCC had completed an audit of transcranial doppler ultrasound competences for Leeds Teaching Hospital NHS Trust and Sheffield Teaching Hospitals NHS Foundation Trust, with all practitioners exceeding the required number of 40 scans per year. At the time of the visit, the HCC had not received any data from Newcastle upon Tyne Hospitals NHS Foundation Trust as to whether staff met the required transcranial doppler ultrasound competences.

The HCC held monthly regional sickle cell multidisciplinary meetings, during 2022-23 a total of 58 patients had been referred to the MDT for discussion. Due to demand some patients with thalassemia and rarer inherited anaemias, these patients were also discussed at these MDTs (Multi-Disciplinary Team Meeting) with clear pathways to share the outcomes of discussions with the regional thalassaemia and rarer anaemias HCC based in Manchester. More complex patient cases were referred to the National Haemoglobinopathy Panel MDT.

The HCC held three business meetings per year open to the whole HCC; SHTs, LHTs, commissioners and HCC patient representatives. Meetings were held remotely to promote engagement across the region. From the attendance records seen, quoracy had been achieved for the meetings held in the 12 months preceding the visit.

A NE&Y HCC website had been launched and the HCC had also begun to identify training needs for across the HCC and two educational events were planned. The HCC were collaborating with their colleagues in Manchester to develop easy access sickle cell training modules for medical staff in training, clinical nurse specialists and advanced practitioners. The HCC was also part of the national HCC education forum to promote the sharing of resources and ideas. As part of this involvement the HCC had delivered an educational session on acute complications.

The HCC were in the process of developing a regional bid for the NHS England pilot to provide a 'Hyperacute' service for sickle cell patients.

**Good Practice**

1. Good collaboration across the region and wider by the HCC was evident. The NE &Y HCC with the HCC North for Thalassemia, based in Manchester, held joint monthly education sessions and there was a good process for liaising about patients with thalassemia and rare inherited anaemias. The HCC had good engagement and co-ordination of care across the HCC SHTs and LHTS through the HCC led MDT. The NE &Y HCC had also worked with hepatology services across the region to hold a joint MDT for patients with sickle cell hepatopathy. Reviewers were told that there were plans to extend this type of regional MDT for those sickle cell patients with renal disease and chronic pain.

2. Reviewers were impressed with the work the HCC had undertaken with 'Embrace' the regional retrieval service for critically ill infants and children, to support clinical teams around the care of critically ill children with hemoglobinopathies and when needed, repatriation back to their local team.

3. The HCC were actively working to improve equality of access to automated red cell apheresis for patients in Bradford, Newcastle and Middlesborough. At the time of the visit apheresis was provided by mobile units so could be undertaken at other locations.

4. The HCC were proactively engaged in research. In Sheffield they were actively recruiting to a study of pyruvate kinase agonist and the 'Ascelus' study to develop a patient mobile app to aide compliance and symptom reporting. Leeds and Sheffield were collaborating centres for an NIHR study of Haploidentical transplantation in sickle cell disease and the 'REDRESS' study.

*5.* Reviewers were impressed at the achievement of the team in Leeds who had been awarded a grant to investigate long-term outcomes of haemoglobinopathy patients across Yorkshire. This study involved working with epidemiologists and health economist the study will look at health outcomes and examine mental health, educational and societal factors.

**Immediate Risks:** No immediate risks were identified during the visit.

**Concerns**

1. 24hr Advice across the HCC

Due to the existing shortfall in workforce across the HCC implementation of a formalised 24hr network advice service had not been possible. The lack of 24hr specialist advice had the potential to impact of patient care if patients were delayed in receiving care at the right setting at the right time. In practice there were some informal processes for accessing advice through the goodwill of consultants who would take calls out of hours. Reviewers considered these informal arrangements were not sustainable in the long term and to achieve a formal 24hr advice system across the network will require the HCC to work with their SHTs, trusts and respective commissioners.

2. HCC Infrastructure

Reviewers were concerned about the ongoing feasibility of the HCC due to the lack of infrastructure in the lead team for the HCC to function effectively. The lack of substantive and changes in personnel over the last few years had impacted on the HCC being able to meet the service specification for HCCs and have the capacity to drive the important improvements that the HCC had identified.

   a. The HCC did not have a substantive HCC manager in post. The network manager in post at the time of the visit was on a secondment basis, and due to their substantial directorate operational role, had insufficient time to support the HCC role. The absence of substantive full time manager post had resulted in delays in the HCC agenda to improve coordination, supporting and promoting the HCCs approach to the delivery of haemoglobinopathy services. Reviewers were concerned that the HCC operational management role (with sufficient time) was key in supporting the wider HCC in addressing fragmentation of services and inequality of access for patients with haemoglobin disorders. Reviewers were told at the visit that funding was available and that recruitment to a full time HCC operational management post was planned.

   b. The HCC lead educator role was vacant, and reviewers were told that workload pressures across the region have had an adverse impact of the development of this role. From discussions it was not clear on the timeframes for recruitment to the lead CNS/education role. The lack of a lead for education had resulted in little progress in developing and implementing an education strategy. Reviewers considered that the lead CNS/ educational role was crucial for developing and implementing educational programs for professionals, patients, and the broader community.

Without this role there may be a deficiency in educational initiatives, resulting in reduced awareness, knowledge, and best practices.

c. The HCC pain management lead role was vacant. This was an additional role the HCC had hoped to recruit to but had not been possible due to staff shortages.

3. Risk Management

The HCC did not have a clear governance process for management risks highlighted at HCC level including a process for communicating risk to its constituent SHTs, LHTS and commissioners at regional and at Integrated Care Board level. Reviewers were told of instances where service risks had been highlighted to the HCC and the subsequent difficulties in liaising with multiple organisations to enable the HCC to provide advice and have oversight. Reviewers considered that by creating and maintaining a risk register, the HCC would be able to proactively assess, prioritise the risks across the HCC, support constituents of the network to develop strategies to mitigate risks and monitor actions.

4. HCC Forums

There were no forums in place outside of the business meetings for staff for sharing good practice, audit results and research outcomes. Reviewers considered that implementation of network wide forums were highly beneficial in providing a platform for collaboration, knowledge sharing and support. Forums would also enable a space for interdisciplinary communication, allowing those from various health and care backgrounds to exchange ideas and discuss best practice.

**Further Consideration**

1. There appeared to be a lack of access to community care services across the HCC. Improving the pathways for community support (ultimately admission avoidance) for patients with haemoglobinopathies would enhance patient centred care by providing individuals with comprehensive support services and resources within their communities. Patients would receive timely interventions, education, and ongoing support to help them manage their condition more effectively and prevent complications and unnecessary in-patient stays. Reviewers considered that the HCC could provide leadership in facilitating easier access to these services by engagement with the integrated Care Boards across the HCC.

2. Access to comprehensive data across the HCC was variable, due to the lack of infrastructure which was impacting on some services being able to contribute effectively to the HCC and for the HCC to work on reducing inequalities and unwarranted variation. HCC had not received any data from Newcastle upon Tyne Hospitals NHS Foundation Trust as to whether staff met the required transcranial doppler ultrasound competences, and NHR (National Haemoglobinopathy Registry) data management provision was insufficient for Leeds and Newcastle SHTs and all the LHTs across the region.

3. Reviewers were told about the difficulties in ensuring that patients living in ‘cross-boundary’ areas were not lost to specialist care, for example patients living in the Lake District, and Carlisle were linked to other SHTs and HCCs and the Chesterfield area was split between two HCC areas. The HCC should continue to work with other HCCs to clarify and ensure pathways are agreed and then monitor to ensure that all patients are receiving specialist care.

4. The HCC did not have an agreed schedule for its 2023/24 annual audit and work programme. Reviewers were told that the audit programme and work programme would be agreed at the business meeting being held the week of the visit. Particularly important will be focusing on results of network audits undertaken and agreement of action plans.

5. The HCC had not yet agreed networkwide guidelines. STH had developed a variety of guidelines which were available on the HCC website however reviewers were told that each SHT primarily used their own versions. The issue had been identified and a review of all guidance was part of the forthcoming annual work programme.

6. Patient engagement was in its infancy and the most recent HCC patient survey, although sent to all patients, had generated a limited number of responses. Reviewers considered that it will be important to work with HCC user and carer representatives (once appointed) to develop a strategy for improved patient engagement.

7. Reviewers were told that an HCC wide educational programme was a priority especially implementing standardised competency packages across the network.

# Review visit findings

## Sheffield Teaching Hospitals NHS Foundation Trust

## Trust-wide

**General comments**

This review looked at the health services provided for adults with haemoglobin disorders. During the visit, reviewers met with patients and with staff providing the services and visited the day unit and ward on the Royal Hallamshire Hospital site and the Emergency Department at the Northern General Hospital.

The Trust was a provider of specialist services for haemoglobin disorders and had been formally recognised as a Specialist Haemoglobinopathy Team in April 2019 following the national compliance exercise conducted by NHS England (NHSE).

The team delivered secondary care to over 235 adults with haemoglobin and other inherited red cell disorders and provided significant support to the local haemoglobinopathy (adults) tem (LHT) at Bradford Teaching Hospitals NHS Trust. As the specialist centre for South Yorkshire and due to the small numbers of patients at the LHTS, all adult patients with haemoglobinopathies from Rotherham, Barnsley, Chesterfield and Doncaster were seen by the SHT for all aspects of their specialist care. This included outpatient appointments for routine and annual reviews, and inpatient care for treatment relating to their condition. Arrangements were in place with the LHT at Doncaster to see all their patients annually and hold patients individualised care plans as they had a sizeable population who tended to present to their local emergency department. If ongoing treatment was required, then patients were transferred for further care with the team at Sheffield.

Pathways had been agreed with all the LHTS to undertake blood tests and echocardiograms when required, to reduce travel time and improve patient convenience.

The haemoglobinopathy service at Bradford serves a large population of thalassaemic and a growing number of patients with sickle cell disorders and the trust has not been able to recruit a consultant with a specialist interest in haemoglobin disorders. Since 2021, oversight of this service has been via Sheffield Teaching Hospitals NHS Foundation Trust with one consultant providing an outreach service and undertaking patient annual reviews, attendance at outpatient clinics, providing support to the multidisciplinary meeting and supporting doctors in training and the CNS (Clinical Nurse Specialist) team. The Bradford patients do attend the SHT at Leeds Teaching Hospitals NHS Trust for specialist investigations, routine apheresis and specialist reviews but are no longer reviewed by the Leeds SHT. For this reason, the SHT requested that Bradford patient numbers were included in the table below within their total workload.

Several issues in this report will require executive focus and support from the Trust for the Specialist Haemoglobinopathy Teams (SHT) to continue to function. Further support from the Trust executive team will also be required for the HCC to fulfil its role.

**Trust-wide Good Practice**

1. The Trust had been active in developing the Physician Associate and Advanced Clinical Practitioner roles as part of their strategy for mitigating workforce shortages.

**Trust-Wide Concern**

1. **Emergency Department**

   Medical and nursing staff working in Emergency Department (ED) did not have a framework in place to measure staff competences in the urgent care of people with haemoglobin disorders. From discussions it was generally acknowledged that there was a lack of awareness of any policies / procedures for caring with patients with haemoglobin disorders who attend in an emergency, junior triage nurses had limited knowledge about the symptoms of those patients attending in sickle cell crisis. An educational presentation had been developed by the SHT to be shared with new staff, but the reviewer was told that medical staff in training no longer received the presentation as part of their induction to the ED. Staff also commented that patients who required admission had experienced long waits before transferring to the in specialist haemoglobinopathy services based on the Royal Hallamshire Hospital site.

**Trust-wide Further Consideration**

Reviewers considered it important that the trust management with the financial team liaise with commissioners to gain clarity around maximising funding streams for the SHT and HCC. In addition, work should be undertaken with the contracting team to ensure that SHT and HCC funding is clearly earmarked via specific budget codes/lines for the delivery and governance of services for red cell disorders. This has been agreed with the national NHSE funding team and there should be visibility of funding spend via an annual budget report for the network which is developed in collaboration with the hosting HCC finance team. This should be shared with the NHSE commissioners and reviewed on a regular basis and should also form part of the HCC annual report.

# Specialist Haemoglobinopathy Team (Adult Services): Sheffield Teaching Hospitals NHS Foundation Trust short

**General Comments and Achievements**

This was an experienced service with strong leadership evident throughout. It was clear to the reviewers that the team was highly committed and enthusiastic, although they were working under extreme pressures. Reviewers observed good teamwork on the day unit ward, with good management support. Patients who met with the reviewing team were highly appreciative of the CNSs and ward nursing teams who they considered did everything they could to help, and they reported to reviewers that staff were compassionate and caring. The lead consultants were also praised for 'going above and beyond.'

Well-established links existed, with shared care arrangements between Sheffield Teaching Hospital NHS foundation Trust and other local haemoglobinopathy teams (LHT) across the network. The SHT were also providing a significant outreach service for adults with haemoglobinopathy disorders at Bradford Teaching Hospitals NHS Trust.

Views of patients had been surveyed in the six months before the visit, only 14 responses had been received and analysed and the SHT were exploring ways to improve mechanisms for patient feedback. Some comments such as confidence in the SHT, staff empathy and understanding were consistent with comments made to the visiting team at the time of the visit. The local survey also had 11/14 positive responses about the information provided and being involved with decisions about their condition and treatment options, whereas on the visit some who met with the visiting team were not clear about information relating to their condition or options for treatment. *See* ***'Views of Service Users and Carers' section of the report.***

An audit of inpatient attendances for the 12 months preceding the visit showed that 70 patients with sickle cell disease had been admitted, and no patients with Thalassemia requiring an inpatient admission. The most common length of stay was one day, with the maximum stay for one patient being 55 days. In total 301 days were spent across 70 patients

Access to elective blood transfusions are available Monday – Friday 8am – 8pm and on Saturdays 8am -12pm. In the event that an urgent out of hours blood transfusion was required, this would be delivered as an inpatient when needed.

The ward areas all had link nurses with an interest in haemoglobin disorders. The link nurses were supported by the Clinical Nurse Specialists (CNS) with monthly information sharing meetings in place. The CNS team also attend the clinical areas each day to provide guidance and support when patients are in the unit.

The trust was in the process of implementing Cerner Millenium (a new electronic patient record system) and staff were actively working to ensure the right information would be available via the system once active.

Following an audit of 'To Take Out' (TTO) medications the team had revised the TTO process and improved communication to the patients General Practitioner.

| **SPECIALIST HAEMOGLOBINOPATHY TEAM - CARE OF ADULTS** | |
|---|---|
| Sheffield Teaching Hospitals NHS Foundation Trust | Linked Haemoglobinopathy Coordinating Centres (HCC) |
| | North East and Yorkshire Sickle Cell HCC<br>North of England Thalassemia and Rare Inherited Anaemias HCC |
| | Linked Local Haemoglobinopathy Teams (LHT) |
| | 1. Chesterfield Royal Hallamshire<br>2. Barnsley Hospital<br>3. Rotherham Hospital<br>4. Doncaster Hospital |

| **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 | 119<br>(23 LHT)<br>(+ 44 Bradford) | 119 | 106 + 42 at Bradford | 7 | 95% | 69 |
| Thalassaemia | 40<br>(+<br>30 at Bradford) | 40 | 25<br>+<br>(28 at Bradford) | 20 | N/A | 0 |

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

**Staffing**

| Specialist Haemoglobinopathy Team [2] | Number of patients | Actual PA/ WTE (at time of visit) |
|---|---|---|
| Consultant haematologist dedicated to work with patients with haemoglobinopathies[3] | 159 | 5.00PA |
| Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies | 159 | 1.6wte (recruitment to an additional 1wte was in progress) |
| Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies | 159 | 0.5 wte post vacant and limited access |

**Urgent and Emergency Care**

Patients with haemoglobin disorders who attended the emergency department (ED) at the Northern General Hospital were triaged via the urgent pathway. ED staff will inform haematology medical teams (Green team SpR or consultant during working hours and on call haematology SpR out of hours). Once stable, patients were transferred to a haematology inpatient bed via emergency ambulance (recent audits by the trust had confirmed 100% admission rate to haematology bed). If a patient was critically ill and unwell for safe transfer, they were reviewed by a critical care team and transferred to a Critical Care bed. In this situation the on-call haematology SpR would review the patient at the Northern General Hospital. Staff in the department knew about the sickle cell / thalassaemia alerts on the Lorenzo EPR system and a breakfast club teaching session was in the process of being launched which included patients presenting in sickle cell crisis. Reviewers were told that nursing staff and now medical staff were being invited to attend their in-house RREX (Resus Room Excellence Course) a 2-day course that covered aspects of those patients that may need to be placed in a resuscitation cubicle, which it was planned, would include scenarios on the acutely unwell patient with sickle cell disease.

**In-patient Care**

Patients were encouraged to present directly to the Haematology team rather than via the Emergency Department. During opening hours patients would attend the day unit, overnight they were admitted directly to the ward.

There were three Haematology inpatient wards, all at the Royal Hallamshire Hospital site. New admissions were admitted to ward O1, which was a 17-bed unit, all single rooms to ensure optimal infection control. Ward P3 was a 21 bedded ward with a combination of single-sex bays and single rooms, which includes a 2-bedded 'teenage and young adult' room, to which young people were admitted where possible once moved up from the admissions ward. P4 was a 9-bedded ward with all HEPA-filtered single rooms. Patients requiring more prolonged admission, in whom there are no relevant infection concerns, may be moved from O1 to P3 or P4 during their admission.

---

[2] *Recommended staffing: national NHS England compliance exercise for designations of SHTs 2019. Excludes HCC Network role PA. The Quality Standards for psychology staffing (HA-208) references the recommendation from the British Psychology Society Special Interest Group for Psychologists working in Sickle Cell and Thalassaemia (2017) which suggests 1WTE for every 300 patients.*

[3] *QS 204 notes for calculating consultant requirements a. 0.25 PA CPD per consultant, b. 1.5 PA for every 50 patients for direct clinical duties, c. 0.25 PA for every 50 patients for supporting activities (NHR and data collection, audit, teaching, patient liaison, network participation). d. 1 PA for geographical area clinical lead*

Where it was appropriate for a patient to be admitted under a different specialty (such as when undergoing surgery or during antenatal or perinatal period), haematology review on the appropriate ward was arranged on a regular basis to allow close joint working between teams and ensure optimal management.

Inpatients were reviewed daily by the 'green' haematology team, which looks after patients with haemoglobinopathies and lymphoid conditions on the ward. There was also regular (usually twice-weekly) input with ward rounds from the haemoglobinopathy team, with additional advice or review arranged as required.

The haemoglobinopathy Clinical Nurse Specialist team attend the daily ward handovers and the inpatient patient unit had daily input from the Palliative and Supportive care team who provide specialist input to all patients with sickle pain.

**Day care**

Daycare services were delivered on the 02-haematology day care unit at the Royal Hallamshire Hospital.

The 02 Day ward had 18 chairs in total however four to six of these are specifically used for blood products depending on current activity levels. The unit also had three chairs allocated for the teenage unit, six chairs for ambulatory care and eight chairs (two within side rooms) for the Haematology assessment unit.

The CNS attended the unit each morning for handover with the medical staff and would also attend the unit if patients are attending for treatment or clinic. The Haematology assessment unit was covered by either ACP or Physician Associate on a rota basis but haemoglobinopathy patients can also be booked into see the Green team SpR who runs a day unit clinic for early discharges and acute problems on Tuesdays.

**Community-based Care**

There was no commissioned specialist haemoglobinopathy disorder community service. Patients could access general community services. See further consideration section of the report.

**Views of Service Users and Carers**

| Support Group available for patients and carers | Y/N |
|---|---|
| Sickle Cell Disease – Adults | N |
| Thalassemia – Adults | N |

The visiting team met with three service users with sickle cell disease and one service user with thalassaemia during the visit and therefore the caveat is that some feedback may not be wholly representative of the services provided.

The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences. Overall, the patients and carers were highly complementary about the care they received at the hospital, and they were particularly appreciative about the support from the haemoglobinopathy team. In addition:

- They felt 'listened to', as if they had a 'voice', and that their opinions were respected.
- Patients unanimously agreed that the care they received on the haematology ward was very good. They commented about the confidence they had in the day unit and ward staff. They thought that the nursing staff understood their conditions and that they were compassionate and helpful.
- They liked the 'drive through' phlebotomy service which had been implemented during the Covid-19 pandemic and had continued.

- They felt their care was well planned, they liked the flexibility they had in attending clinics and they thought that the transfusion service worked well for them.
- If they needed to attend for ophthalmology issues, then the 'eye' service was 'great', and they liked that the audiology service would let them be monitored as often as they felt was required.
- They all commented that their annual reviews were undertaken on time
- During discussions there was some confusion as to whether they had care plans, potentially due to the use of the term, as they did say that medical staff had provided information during their annual reviews. Some when asked were not sure about treatment side effects and commented that information could be improved.
- Occasionally delays in venepuncture being undertaken meant delays in receiving adequate pain relief. Reviewers were told that they could not have analgesia until their bloods had been taken.
- Medical staff with more experience in their conditions were empathetic but they felt that some doctors in training were not so interested and less empathetic.
- Patients commented that community services were not available and so sometimes it felt that things 'were not joined up.' They missed not having access to community care especially after their discharge from hospital.
- The booking system was commented on being overly complex. Reviewers were told that patients were not keen on the texts and emails and valued the previous system when they would be telephoned. Those who spoke to the reviewers also commented that the booking service could be more nurse led by the day unit staff so that their next appointments could be arranged when they were attending.

Return to Index

**Good Practice**

1. Reviewers were impressed that the facilities for teenagers on the haematology day unit and ward which were available to all teenagers regardless of their underlying condition.
2. The SHT had collaborated with the local universities to implement a screening programme at the start of each academic year. Students were invited to complete a questionnaire and depending on results were triaged for further investigations. This process had identified both young people with haemoglobin disorders and some who had not previously been under any haemoglobin service
3. The provision of the welfare and benefits advisor service had received widespread praise from patients and staff. The evaluation had shown the benefits of signposting patients to services and supporting patients to navigate the complexities of the welfare system much more easily and promoting their wellbeing.
4. The drive through phlebotomy service was highly valued by patients.
5. Reviewers were impressed with the information boards displayed outside the wards. The information presented was clear, with visual impact and covered specific areas about their condition, for example signs and symptoms of acute chest syndrome.
6. Reviewers were impressed by the transition team who supported those with complex needs to transition to adult services.

**Immediate Risk:** No immediate risks were identified during the visit.

**Serious Concern**

1. **Consultant staffing**

   At the time of the visit, the two consultants had only 5 programmed activity (PA) sessions rather 7 PAs for work with the service which included work with the SHT network as well as providing a clinical service (3 PAs) for the Bradford Teaching Hospitals NHS Foundation Trust. Out of hours cover was supplied by other consultant haematologists who may not have competences in haemoglobin disorders resulting in the informal arrangement of contacting one of the two red cell consultants for advice.

   In addition, one of the consultants had retired but as the trust had twice been unable to recruit to the consultant vacancy and had returned to provide interim short-term cover of 2PA for direct clinical care which was not sustainable. Reviewers were told that this was due to the lack of senior trainees with an interest in hemoglobinopathies. The Trust was aware of the situation; however, reviewers considered that should recruitment of an additional haematologist with allocated PAs for the haemoglobin disorder service not be successful then the service viability would be at risk.

**Concern**

1. **Access to Psychology**

   Access to psychology was limited due to the post being vacant. In practice, urgent referrals could be made to the general psychology service. However, the general psychology service would not have the relevant experience in caring for patients and families with haemoglobin disorders. Reviewers were concerned as without a dedicated psychological practitioner 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. Reviewers were told that interviews for recruitment to the vacant post were being held the week of the visit.

2. **Access to analgesia**

   The most recent service audit of compliance with the NICE clinical guideline on the management of acute pain showed that only 55% of patients had received analgesia within 30 minutes of arrival to either the Emergency department or 01 ward. Results were better for those attending the ward, the preferred pathway, than the emergency department.

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

   Reviewers were concerned that the charitable funding for welfare and benefits support post was due to cease in January 2024 although a business case was in the process of being developed. The benefits for patients in improving their quality of life by having this level of support should not be underestimated.

**Further Consideration**

1. At the time of the visit, CNS support was provided by 1.6 wte at band 6 level, with the 1 wte post holder in a developmental post. It was raised about the appropriateness of the banding of the CNS post and the support being provided by the 0.6 wte.
2. Reviewers only met with a small number of patient representatives, however from discussions they were not particularly aware as to whether they had care plans or understood treatment side effects. This is inconsistent with the SHT feedback survey results, which also had a low response rate. It may be helpful for the team to investigate further and identify if this is a wider issue that needs addressing and then how best to meet their patient's needs and the language used. A care plan template used by the clinical team was provided as evidence.
3. There was no community service to provide support for patients and their carers. Reviewers were told that the post had not been continued following the retirement of the previous postholder. Patients also commented on the lack of, and difficulty in, accessing community nursing, physiotherapy, occupational therapy, and dietetic support in the community. The lack of community access has the potential for

unnecessary inpatient admissions and work should be undertaken with local commissioners to discuss the issue and consider community pathways for patients with haemoglobin disorders.

Return to Index

## Commissioning

The review team had discussions with a local commissioner from Yorkshire Integrated Care System and the regional NHSE North East Specialist Commissioner. Several of the issues in this report will require the active involvement of the Trust and commissioners to ensure that timely progress is made.

**Further Consideration**

1. Reviewers considered it important that the commissioners and Trust management liaise to gain clarity around maximising funding streams for the SHT and HCC and to ensure that funding for the HCC and SHT should be ring fenced going forward.

Return to Index

# Membership of Visiting Team

| Clinical lead | | |
|---|---|---|
| Emma Drašar | Clinical Lead & Consultant Haematologist | Whittington Health NHS Trust |

| Visiting Team | | |
|---|---|---|
| Stephen Boyd | Consultant Haematologist | North Middlesex University Hospital NHS Trust & University College Hospital NHSFT |
| Carol Edwards | Clinical Nurse Specialist Sickle Cell & Thalassaemia – Antenatal and Newborn Screening Lead | Croydon Health Services NHS Trust |
| Doreen Richards | Specialist Nurse Practitioner | Nottingham University Hospital NHS Trust |
| Ruth Anderson | Counselling Psychologist | University College Hospital NHSFT |
| Ralph Brown | HCC Network Manager – West London | Imperial College Healthcare NHS Trust |
| Roanna Maharaj | Executive Director | UK Thalassemia Society |
| Vanessa Wills | Service User | |

| MLCSU Team | | |
|---|---|---|
| Sarah Broomhead | Professional Lead | Nursing and Urgent Care Team - MLCSU |
| Andy Regan | Clinical Lead | Nursing and Urgent Care Team - MLCSU |

Return to Index

# Compliance with the Quality Standards

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

## Percentage of Quality Standards met

| Service | Number of Applicable QS | Number of QS Met | % Met |
|---|---|---|---|
| North East & Yorkshire Sickle Cell Haemoglobinopathy Coordinating Centre (HCC) – all ages | 13 | 6 | 50 |
| Specialist Haemoglobinopathy Team (SHT) Adults | 45 | 31 | 70 |

# Haemoglobinopathy Coordinating Care Centre - People with Haemoglobin Disorders of All Ages

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-198S | **Network-wide Involvement of Children, Young People and Families (SCD)**<br>The Sickle Cell Disorder HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702). | N | The HCC committee did not yet have representatives at HCC business meetings who would cover children, young people, and their families. Mechanisms for engaging with those representing adult services was in place. Wider engagement of patients and carers in the HCC network was in the process of being developed. See main report. |
| H-201 | **Lead Consultant**<br>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available. | N | The HCC lead had sufficient PA for leadership of the HCC (1 PA) |
| H-202 | **Lead Nurse**<br>A lead nurse should be available with:<br>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders<br>b. Responsibility for liaison with other services within the network<br>c. Competences in caring for people with haemoglobin disorders<br>The lead nurse should have appropriate time for their leadership role and cover for absences should be available. | N | There was no identified lead nurse for the HCC. |

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-202A | **Lead Manager**<br>A lead manager should be available with:<br>a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs<br>b. Responsibility for liaison with other services within the network<br>The lead manager should have appropriate time for their role. | *N/A* | *New Quality Standard agreed at UKFHD Steering Group on the 10/1/24 and not assessed at time of the visit* |
| H-203 | **Lead for Transcranial Doppler Ultrasound**<br>The HCC should have a nominated lead for Transcranial Doppler Ultrasound screening. | Y | |
| H-602S | **HCC Service Organisation (SCD)**<br>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:<br>a. Telephone or email advice for outpatient and inpatient care<br>b. Advice on emergencies outside of normal working hours | N | Due to workforce shortages across the HCC advice on emergencies outside normal working hours had not been implemented. In practice informal arrangements were in place to provide advice and transfer of patients.<br>MDT referral criteria was in place to enable clinicians to dial in to discuss their patients at MDT meetings. |
| H-605S | **HCC Multidisciplinary Discussion (SCD)**<br>MDT meetings for the discussion of more complex patients with sickle cell disorder should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use. | Y | |
| H-609 | **NHS Blood and Transplant Liaison**<br>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. | Y | |

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-702S | **HCC Business Meetings (SCD)**<br>The Sickle Cell Disorder HCC should organise at least two meetings each year with its referring SHTs and LHTs to:<br>a Agree network-wide information for patients and carers of all ages<br>b Agree network-wide policies, procedures and guidelines, including revisions as required<br>c Agree the annual network education and training programme<br>d Agree the annual network audit plan, review results of network audits undertaken and agree action plans<br>e Review and agree learning from any positive feedback or complaints involving liaison between teams<br>f Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams<br>g Review progress with patient experience and clinical outcomes (QS H-797) across the network and agree any network-wide actions to improve performance<br>h Consider the TCD annual monitoring report and agree any actions required (QS H-704) | Y | The annual report stated that there had been one reported significant complication for 22/23 (table 2) page 4. Adverse event reports were discussed in the HCC MDT, but structured recording of adverse events across the HCC region could be more robust.<br>There had been little progress on NEY HCC education strategy implementation. The HCC lead educator role has been vacant and workload pressures across the region was having an adverse impact on progress. See main report.<br>Complaints were not reviewed on an inter-service basis.<br>A website had been developed which did have some patient information and the review of network guidelines had been included in the 2023/24 HCC work programme.<br>The HCC held Morbidity and Mortality meetings for the discussion of adverse events<br>The outcomes from the surveys undertaken at the SHTs had been discussed in the business meetings. |
| H-703 | **HCC Annual Programme of Work**<br>The HCC should meet with their commissioners at least annually in order to:<br>a. Review progress on the previous year's annual programme of work<br>b. Review progress with improving patient experience and clinical outcomes across the network (QS H-797)<br>c. Agree the annual programme of work for the forthcoming year | N | Due to changes in HCC and commissioning personnel, a work programme had not been agreed for 2023/24 or a review held with commissioners to review progress with the previous year's annual programme of work.<br>A programme of work for 2023/24 was due to be discussed at the next HCC business meeting.<br>Patient experience had been collected via PREM survey and clinical outcomes work was being driven as part of research projects that were in the set-up stage. |

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-704 | **Transcranial Doppler (TCD) Monitoring Report**<br>The HCC TCD lead should monitor and review at least annually:<br>a. The list of staff undertaking TCD ultrasound and whether they have undertaken 40 procedures in the last year (QS HC-209)<br>b. Results of internal quality assurance systems (QS HC-504)<br>c. Results of National Quality Assurance Scheme (NQAS) for TCD ultrasound (when established) or local peer review arrangements (until NQAS established)<br>d. Number of TCD ultrasounds performed and the number of abnormal TCDs across the network<br>e. Whether any changes to the TCD Standard Operating Procedure (QS HC-504) are required | N | The annual report did not include any data from Newcastle upon Tyne Hospitals NHS Foundation Trust. All those listed in the HCC annual report from Leeds and Sheffield had completed more than 40 scans annually and Leeds Teaching Hospital quality assurance audit was seen. |
| H-707 | **Research**<br>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**<br>All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | This QS was met from the evidence submitted but historic versions of some guidelines had been accidently deleted from the Trust system |

Return to Index

## Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

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

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-102 | **Information about Haemoglobin Disorders**<br>Patients and their carers should be offered written information, or written guidance on where to access information, covering at least:<br>a. A description of their condition (SCD or Th), how it might affect them and treatment available<br>b. Inheritance of the condition and implications for fertility<br>c. Problems, symptoms and signs for which emergency advice should be sought<br>d. How to manage pain at home (SCD only)<br>e. Transfusion and iron chelation<br>f. Possible complications<br>g. Health promotion, including:<br>i. Travel advice<br>ii. Vaccination advice<br>h. National Haemoglobinopathy Registry, its purpose and benefits<br>i. Self-administration of medications and infusions | N | Information was available for those with sickle cell disease, but reviewers did not see the following information for those with thalassemia.<br>'b' Inheritance of the condition and implications for fertility<br>'c' Problems, symptoms and signs for which emergency advice should be sought<br>'e' information about iron chelation<br>'f' possible complications<br>'I' Self-administration of medications and infusions |
| HA-103 | **Care Plan**<br>All patients should be offered:<br>a. An individual care plan or written summary of their annual review including:<br>i. Information about their condition<br>ii. Planned acute and long-term management of their condition, including medication<br>iii. Named contact for queries and advice<br>b. A permanent record of consultations at which changes to their care are discussed<br>c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable). | Y | The SHT had a care plan template however two of the three patients who met with the visiting team, were not clear if they had a care plan. See further consideration section of the report. |
| HA-104 | **What to Do in an Emergency?**<br>All patients should be offered information about what to do in an emergency covering at least:<br>a. Where to go in an emergency<br>b. Pain relief and usual baseline oxygen level, if abnormal (SCD only) | Y | |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-105 | **Information for Primary Health Care Team**<br>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:<br>a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD)<br>b. Side effects of medication, including chelator agents (SCD and Th)<br>c. Guidance for GPs on:<br>i. Immunisations<br>ii. Contraception and sexual health<br>d. What to do in an emergency<br>e. Indications and arrangements for seeking advice from the specialist service | Y | |
| HA-194 | **Environment and Facilities**<br>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**<br>Young people approaching the time when their care will transfer to adult services should be offered:<br>a. Information and support on taking responsibility for their own care<br>b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services<br>c. A named coordinator for the transfer of care<br>d. A preparation period prior to transfer<br>e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care<br>f. Advice for young people leaving home or studying away from home including:<br>i. Registering with a GP<br>ii. How to access emergency and routine care<br>iii. How to access support from their specialist service<br>iv. Communication with their new GP | Y | Ready Steady Go Transition programme was in place. The Sheffield Children's Hospital to Sheffield Teaching Hospital cross trust transition pathway document provided clear information for clinical staff about what should happen at each stage of the young person's transition journey.<br>See main report re good practice for those with complex transition needs. |
| HA-197 | **Gathering Patients' and Carers' Views**<br>The service should gather patients' and carers' views at least every three years using:<br>a. 'Patient Survey for Adults with a Sickle Cell Disorder'<br>b. UKTS Survey for Adults living with Thalassaemia | Y | |
| HA-199 | **Involving Patients and Carers**<br>The service's involvement of patients and carers should include:<br>**a.** Mechanisms for receiving feedback<br>b. Mechanisms for involving patients and their carers in:<br>i. Decisions about the organisation of the service<br>ii. Discussion of patient experience and clinical outcomes (QS HA-797)<br>c. Examples of changes made as a result of feedback and involvement | Y | |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-201 | **Lead Consultant**<br>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available. | N | The SHT Lead had insufficient PA allocated for lead role (0.5 PA) |
| HA-202 | **Lead Nurse**<br>A lead nurse should be available with:<br>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders<br>b. Responsibility for liaison with other services<br>c. Competences in caring for people with haemoglobin disorders<br>The lead nurse should have appropriate time for their leadership role and cover for absences should be available. | N | The SHT did have a named lead nurse (1wte) for the acute trust service. At the time of the visit the named lead nurse was in a band 6 development role. |
| HA-204 | **Medical Staffing and Competences: Clinics and Regular Reviews**<br>The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | N | The SHT cared for 161 patients at STH and a further 84 at Bradford. The HCC lead had 2PAs for direct clinical care.<br>The SHT lead had 0.5 PA for network activities and 2.5 PAs for direct clinical care at STH and a further 3 PAs to provide specialist care at Bradford. The SHT lead did not have any PAs allocated specifically for Haemoglobinopathy CPD. |
| HA-205 | **Medical Staffing and Competences: Unscheduled Care**<br>24/7 consultant and junior staffing for unscheduled care should be available.<br>**SHTs and HCCs only:**<br>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. | N | Cover out of hours was from the 'Green Team' who may not always have experience in haemoglobin disorders. The QS was met during normal working hours.<br>HCC 24 hr advice across the network was not in place due to the lack of workforce with an interest in the care of patients with haemoglobin disorders to cover an out of hours rota. |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-206 | **Doctors in Training**<br>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**<br>The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>a. Clinical nurse specialist/s with responsibility for the acute service<br>b. Clinical nurse specialist/s with responsibility for the community service<br>c. Ward-based nursing staff<br>d. Day unit (or equivalent) nursing staff<br>e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion.<br>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 | 1 .6 wte CNS covered the inpatient service.<br>Two competence documents were in use: A competence framework for the management of acutely unwell patients with Sickle Cell disease which had been updated to include the 'No One's Listening report. and the RCN competence framework (revised 2021). |
| HA-208 | **Psychology Staffing and Competences**<br>The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>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<br>b. Time for input to the service's multidisciplinary discussions and governance activities<br>c. Provision of, or arrangements for liaison with and referral to, neuropsychology<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | N | At the time of the visit the 0.5wte funded post was vacant. See concerns section of the main report |
| HA-299 | **Administrative, Clerical and Data Collection Support**<br>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service. | Y | The SHT /HCC had 0.85wte time for MDT and data collection support |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-301 | **Support Services**<br>Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required:<br>a. Social worker / benefits adviser<br>b. Leg ulcer service<br>c. Dietetics<br>d. Physiotherapy (inpatient and community-based)<br>e. Occupational therapy<br>f. Mental health services | N | The dietetics, physiotherapy and occupational therapy services were for inpatients only. Reviewers were told that patients had limited access to these services in the community.<br>Charitable funding had been secured till January 2024 for a Social worker/benefits adviser with plans to submit a business case for a substantive post. |
| HA-302 | **Specialist Support**<br>Access to the following specialist staff and services should be easily available:<br>a. DNA studies<br>b. Genetic counselling<br>c. Sleep studies<br>d. Diagnostic radiology<br>e. Manual exchange transfusion (24/7)<br>f. Automated red cell exchange transfusion (24/7)<br>g. Pain team including specialist monitoring of patients with complex analgesia needs<br>h. Level 2 and 3 critical care | Y | Manual exchange transfusion (24/7) was not commonly required as automated exchange was available 24/7 and polices for manual exchange were in place if I f required |
| HA-303 | **Laboratory Services**<br>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**<br>Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders. | N | The Lead for the SHT had provided an induction presentation though reviewers were told that junior doctors no longer received the education presentation when being inducted to the dept and that the junior triage nurses were not always aware of the symptoms of those patients attending in sickle cell crisis. A framework for measuring urgent care staff competence was not in place. |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-501 | **Transition Guidelines**<br>Guidelines on transition to adult care should be in use covering at least:<br>a. Age guidelines for timing of the transfer<br>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<br>c. Allocation of a named coordinator for the transfer of care<br>d. A preparation period and education programme relating to transfer to adult care<br>e. Communication of clinical information from paediatric to adult services<br>f. Arrangements for monitoring during the time immediately after transfer to adult care<br>g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable)<br>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**<br>Guidelines or templates should be in use covering:<br>a. First outpatient appointment<br>b. Annual review<br>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**<br>Transfusion guidelines should be in use covering:<br>a. Indications for:<br>i. Emergency and regular transfusion<br>ii. Use of simple or exchange transfusion<br>iii. Offering access to automated exchange transfusion to patients on long-term transfusions<br>b. Protocol for:<br>i. Manual exchange transfusion<br>ii. Automated exchange transfusion on site or organised by another provider<br>c. Investigations and vaccinations prior to first transfusion<br>d. Recommended number of cannulation attempts<br>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<br>f. Patient pathway for Central Venous Access Device insertion, management and removal | N | Guidelines for Transfusion in Patients with Haemoglobinopathies and Rare Inherited Anaemias were in draft. |
| HA-506 | **Chelation Therapy**<br>Guidelines on chelation therapy should be in use covering:<br>a. Indications for chelation therapy<br>b. Choice of chelation drug/s, dosage and dosage adjustment<br>c. Monitoring of haemoglobin levels prior to transfusion<br>d. Management and monitoring of iron overload, including management of chelator side effects<br>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2<br>f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible | Y | |

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

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-510 | **Clinical Guidelines: Chronic Complications**<br>Guidelines on the management of the chronic complications listed below should be in use covering at least:<br>i. Local management<br>ii. Indications for discussion at the HCC MDT<br>iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred<br>iv. Arrangements for specialist multidisciplinary review<br>a. Renal disease, including sickle nephropathy<br>b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease<br>c. Eye problems, including sickle retinopathy and chelation-related eye disease<br>d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease<br>e. Pulmonary hypertension<br>f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea<br>g. Endocrine problems, including endocrinopathies and osteoporosis<br>h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology<br>i. Chronic pain<br>j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease<br>k. Urological complications, including priapism and erectile dysfunction<br>l. Dental problems | Y | |
| HA-511 | **Anaesthesia and Surgery**<br>Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery. | N | Peri-operative Management of Patients with Thalassaemia were n draft at the time of the review as A Haematology management plan for surgical intervention in sickle cell disease patients was in place. |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-512 | **Fertility and Pregnancy**<br>Guidelines should be in use covering:<br>a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis<br>b. Care during pregnancy and delivery<br>c. Post-partum care of the mother and baby<br>**Guidelines should cover:**<br>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<br>ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery<br>iii. Arrangements for access to special care or neonatal intensive care, if required<br>iv. Indications for discussion at the HCC MDT (QS HA-605)<br>v. Arrangements for care of pregnant young women aged under 18 | N | Guidelines for the Management of Pregnancy and Delivery in Women with Sickle Cell Disease and Management of Women with Thalassaemia During Pregnancy were in draft at the time of the review. |
| HA-599 | **Clinical Guideline Availability**<br>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**<br>A service organisation policy should be in use covering arrangements for:<br>a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission<br>b. Patient discussion at local multidisciplinary team meetings (QS HA-604)<br>c. Follow up of patients who 'did not attend'<br>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<br>e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together<br>f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations | Y | |
| HA-603 | **Shared Care Agreement with LHTs**<br>A written agreement should be in place with each LHT covering:<br>a. Whether or not annual reviews are delegated to the LHT<br>b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated)<br>c. LHT management and referral guidelines (QS HA-503)<br>d. National Haemoglobinopathy Registry data collection (QS HA-701)<br>e. Two-way communication of patient information between HCC / SHT and LHT<br>f. Attendance at HCC business meetings (HA-607) (if applicable)<br>g. Participation in HCC-agreed audits (HA-706) | Y | Agreements (SOPs) for joint working with Doncaster, Rotherham and Chesterfield were in place |
| HA-604 | **Local Multidisciplinary Meetings**<br>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 | |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-606 | **Service Level Agreement with Community Services**<br>A service level agreement for support from community services should be in place covering, at least:<br>a. Role of community service in the care of patients with haemoglobin disorders<br>b. Two-way exchange of information between hospital and community services | N | Arrangements with community services had not been formalised. See main report. |
| HA-607S | **HCC Business Meeting Attendance (SCD)**<br>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)**<br>At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HA-702). | Y | |
| HA-701 | **National Haemoglobinopathy Registry**<br>Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed. | Y | |
| HA-705 | **Other Audits**<br>Clinical audits covering the following areas should have been undertaken within the last two years:<br>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)<br>b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions | N | Audits covering patient pathway for patients needing regular transfusions and acute admissions to inappropriate settings had been undertaken in the two years before the review |
| HA-706 | **HCC Audits**<br>The service should participate in agreed HCC-specified audits (QS H-702d). | N/A | An HCC programme of audit had not been agreed but was due to be discussed at the October 2023 business meeting.<br>Audits on the NICE Guidance on the treatment of emergency care had been undertaken within the SHTs. |
| HA-707 | **Research**<br>The service should actively participate in HCC-agreed research trials. | Y | |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-797 | **Review of Patient Experience and Clinical Outcomes**<br>The service's multidisciplinary team, with patient and carer representatives, should review at least annually:<br>a. Achievement of Quality Dashboard metrics compared with other services<br>b. Achievement of Patient Survey results (QS HA-197) compared with other services<br>c. Results of audits (QS HA-705):<br>i. Timescales and pathway for regular transfusions<br>ii. Patients admitted to inappropriate settings<br>Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored. | Y | |
| HA-798 | **Review and Learning**<br>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**<br>All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | This QS was met from the evidence submitted but historic versions of some guidelines had been accidently deleted from the Trust system |

Return to Index