MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit


# Health Services for People with Haemoglobin Disorders

## Leeds Teaching Hospitals NHS Trust

Visit date: 15th December 2023

Report date: 11th April 2024

# Contents

# Introduction

This report presents the findings of the review of Leeds Teaching Hospitals NHS Trust that took place on 15th December. 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 Leeds 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:

- Leeds Teaching Hospitals NHS Trust
- NHS North East and Yorkshire
- West 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 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 North East and Yorkshire.

## 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.

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# Review Visit Findings

## Trust-wide General Comments

This review looked at the health services provided for children, young people and adults with haemoglobin disorders. During the course of the visit, reviewers attended both Leeds Children's Hospital and St James's University Hospital, and visited the emergency departments, assessment units and wards on both sites; they met with patients and carers, and with staff providing services for the local health economy.

The adult and paediatric Specialist Haemoglobinopathy Team (SHT) provided a service to the regions of North and West Yorkshire, which covered both low and high prevalence areas. The Trust's services included a specialist screening laboratory, an antenatal diagnosis and counselling service, and paediatric and adult haemoglobinopathy services delivered by the following clinical service units: pathology, women's services, Leeds Children's Hospital and oncology (incorporating haematology). The service for adult community nursing care is provided by the acute trust. At the time of the visit the paediatric SHT provided specialist support for children and young people from Bradford Teaching Hospitals NHS Foundation Trust (BTHFT). The Adult SHT provided care for adults from BTHFT with some shared care arrangements for management with Sheffield Teaching Hospitals NHS Foundation Trust.

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

## Trust-wide Good Practice

### Trust-wide Good Practice – adults

1. Reviewers were impressed by the availability of the apheresis service which was operational 24hrs a day and provided a mobile service to areas across Yorkshire and the Humber.
2. The Emergency Department (ED) staff at St James's University Hospital had access to multiple health IT systems which meant they could access patient care plans, hospital, and primary care records.
3. Patients who met with the reviewing team were very positive about the support that they had received from the psychologist. They reported how it had helped improve their ability to cope with their condition as well as their emotional well-being.

### Trust-wide Good Practice – children and young people

1. The Pharmacist role supporting the team provided excellent in reach support. All staff thought the pharmacist gave specialist support to the service users and the team.
2. The Emergency Pathway was well designed to support patient care to minimise the likelihood of a child being admitted to ED. Emergency admissions followed one of two direct access pathways, dependant on the time and type of presentation. Families were advised not to attend ED with symptoms/complications of their sickle cell disorder/thalassaemia.

# Trust-wide Serious Concerns

### Trust-wide Serious Concerns – adults

Reviewers were seriously concerned for a number of reasons relating to the deficiency in adult SHT workforce which was impacting on the workload of the team and the serious level of patient dissatisfaction from those who met with the reviewing team. Issues relating to staffing and workload were identified at the last visit in 2019.

**1 Care of patients with Thalassaemia**

a. During the visit, the reviewers had the opportunity to meet with six patients living with thalassaemia. What they heard from these patients raised serious concerns, which were initially raised as a potential immediate risk to both clinical care and safety at the end of the visit. The patients expressed extreme fear regarding their lack of appropriate monitoring for iron overload and endocrinopathy care. They also shared that when they were unwell, they faced difficulties in contacting members of the specialty team. Additionally, the patients were deeply concerned about the management of potential multisystem complications throughout their lifespan. They felt that their transfusion reactions and other serious complications were not accurately documented in their medical records following transfusions or followed up with specialists.

b. The reviewers were informed of issues related to transfusion management, including delayed and inaccurate cross-matching, recurring problems with cannulation, and inadequate management and reporting of transfusion reactions by staff. The review team found the patient feedback particularly troubling, as patients expressed feeling unheard, undervalued, and were visibly upset throughout the meeting.

c. Following the visit, the trust conducted an audit of treatment plans involving 22 patients with thalassaemia. Whilst this audit provided some information, it did not cover other aspects of multisystem monitoring (such as diabetes, endocrinopathies, gastrointestinal, bone, and cardiac complications). Furthermore, the audit data did not demonstrate adherence to the national guidance laid out in UK Thalassaemia Society's "*Standards for the Clinical Care of Children and Adults living in the UK*."

d. Considering the gravity of the patient feedback, the review team and UKFHD steering group recommend that the Trust and SHT undertake further investigations and develop an action plan in collaboration with their commissioners. It is crucial to ensure that patients are managed in accordance with the UK Thalassaemia Society's "*Standards for the Clinical Care of Children and Adults living in the UK*," 4th edition, published in October 2023. Following the visit, members of the review team and UKFHD peer review steering group contacted NHS England, the North HCC for Thalassaemia and the Chair of the APPG for thalassaemia directly to highlight their concerns.

e. Additionally, the trust and SHT should involve patient experience leads ideally from within the trust and externally, to work closely with this group of patients. This collaboration will help understand the nature and extent of their concerns, as well as identify whether these issues are more widespread. The reviewers suggested exploring other methods of patient engagement, such as organising listening events and implementing patient mentoring programs, which could be beneficial to the service. Offering a second opinion with the HCC for thalassaemia might also help build trust and confidence in the management of the patients' condition.

f. The UK Thalassaemia Society will be keeping in close contact with the patient group whom they met at the visit, to provide ongoing support, education, and to address their concerns about potential victimisation for sharing their personal stories and feedback on the services they received.

**2 Consultant staffing**

Reviewers were seriously concerned that the service had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders to provide cover in the absence of the lead clinician as cover for the lead was from the 'attending' rota. The lead consultant had a total of 3.5PAs for direct clinical care, the SHT network role and no time allocated for specific haemoglobinopathy CPD, which was insufficient for the number of patients cared for by the service. The lead consultant was not able to attend many of the haemoglobinopathy coordinating centre (HCC) business meetings due to clinical commitments.

**3 Clinical Nurse Specialist Workload and Skill mix**

At the time of the visit there was one wte CNS with 0.7 band 5 nursing support in the community for 245 patients with haemoglobin disorders. The reviewers were seriously concerned by the CNS workload and the skill mix for the nursing team for the following reasons:

a. The CNS had a wide-ranging role and no cover for absences. In addition to their clinical workload, the CNS was in the process of developing nurse led hydroxycarbamide clinics and was providing line management and specialist support to the community nurse. The new band 6 post holder once recruited would also require a level of support from the CNS.
b. The increase in the number of adults with haemoglobin disorders in the area was having an impact on the capacity of the SHT including the CNS being able to provide the level of support required. Some patients who met with the visiting team commented that they were not always able to contact the CNS for advice and calls were not returned. This issue was also highlighted in the previous visit report undertaken in 2019.
c. Reviewers were concerned that the band 5 would have limited scope of practice for what the SHT was requiring in the community, particularly the expectation that they would lead on transition for the adult team.
d. Reviewers considered that it was important that the new team have sufficient and dedicated time for training and development of their respective roles.

***See 'Views of Service Users and Carers' in the adult section of the report.***

## Trust-Wide Concern

### Trust-wide Concern - adults

**1. Communication, information, and education**

Reviewers did not see any signage for red cell services, this was also commented at the last visit in 2019. It was notable that no part of any information displayed related to red cell conditions, which again made them feel less important than patients with other conditions.

Emergency care plans were not always followed when patients attended in an emergency and patients reported that when they did have reactions such as pyrexia, in particular transfusion related, these were not recorded and taken seriously.

**2. Access to social worker/ welfare and benefits support.**

Patients with haemoglobinopathies did not have access to welfare and benefits support. Reviewers were told that the CNS and Band 5 nurse were spending time supporting patients with non-clinical issues. The benefits for patients in improving their quality of life by having this level of support should not be underestimated and it is essential that they should have wrap around support for areas such as social prescribing for immigration, housing and applying for Personal Independence Plans (PIP).

### Trust-wide concern – children and young people

1. **Consultant Staffing**

   The review team highlighted shortage of Lead Consultant time to support core services and the geographical spaced LHT's. Succession planning for the Lead consultant should also be considered. The on-call consultant rota was 1:3 and reviewers considered this was not sustainable due to the frequency of on call commitments and the clinicians' level of other planned activities.

2. **Psychology Services**

   Patients with haemoglobinopathies did not get access to psychology or neuro cognitive assessments for those who had an abnormal TCD. Some generic psychological support was available for service users, though it was bespoke and difficult to access. Individual cases for neurocognitive assessment had been accepted recently following review recommendations by the National Haemoglobinopathy Panel. Reviewers were concerned that the lack of specialist psychology for children and young people may result in them having difficulties in coping with challenges associated with their condition. Reviewers were told that there was no immediate recruitment plan to address this concern.

3. **Community Nursing Support**

   The review team felt that the Community Nursing support was under resourced with no immediate recruitment plan to support.

4. **Social Care**

   The lack of a social worker and associated social care was highlighted by the review team, the advantages of such a role to the service users were clear to the team. For instance, social care referrals and signposting along with highlighting what benefits were available to this group of service users and how to access them.

## Trust-wide Further Consideration

1 Reviewers considered it important that the trust SHT management and financial teams liaise to gain clarity around maximising funding streams for both the adults, and children and young people SHTs. In addition, work should be undertaken with the contracting team to ensure that funding is clearly earmarked for the delivery of appropriate core and support services.

### Trust-wide Further Consideration - adults

1 Psychology support was 0.6wte for 245 patients and did not quite meet British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia recommendation of one wte for 300 patients. This is unlikely to be sufficient as rise in demand for the service continues. At the time of the visit access to psychology was limited due post holder leave and cover was only available for one day a week.

2 With the reorganisation of responsibilities for transition it would be sensible to review whether the transition policy is being fully implemented and those who have transitioned are being fully supported. Reviewers were told of one patient who was given a letter and told to report to the ward but had not met the adult team before and a parent, whose child was preparing to transition, said it was proving difficult to arrange a joint meeting with the adult team.

3 Medical 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. Training was only provided during the induction programme for new staff.

### Trust-wide Further Considerations – children and young people

1 Following the meeting with the Operational, Finance and Nursing Lead, the review team felt that engagement and oversight from the immediate senior management team could be improved, to understand the key service gaps and risks.

2 The reviewers were told about a general lack of administration support which the CNS team especially felt impacted on their time spent delivering patient care. Increased administration support may benefit the patient experience and release further time back to the team delivering the service whilst making sure that issues such as high DNA rates and appropriate checks and follow ups are monitored and actioned.

3 The reviewers noted and were told about in-patient wall branding leaning heavily towards the oncology service users. Increasing branding to be more inclusive of Haemoglobinopathy patients would improve perceptions of how service users think about the service and make them feel that they are equally as important as other service user groups.

**Views of Service Users and Carers**

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

During the visit the visiting team met with twelve service users and carers, five with sickle cell disease and seven thalassaemia users and carers representing the adult and children services. The views of the users were extensive and wide-ranging and are documented in the children's and adult specialist haemoglobinopathy team sections. The review team would like to thank them for their openness and willingness to share their experiences.

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# Specialist Haemoglobinopathy Team (Children and Young People Services)

## General Comments and Achievements

This was a responsive service, which was well-led by the lead clinician, lead clinical nurse specialist (CNS). Patients and carers were highly appreciative of the care that they received. The linked haemoglobinopathy teams which covered a wide geographical area were highly complementary of the service and support they received from the lead team at Leeds. Staff were optimistic and enthusiastic about planned developments of the service and were acutely aware of service gaps and how they would like the service to evolve.

At the time of the visit the number of paediatric patients with sickle cell disease had increased by 39% since 2021 (2021/22 12%, 2022/23 16%, 2023/24 11%). The number of paediatric patients with thalassaemia had remained unchanged since the last visit.

The Leeds SHT for Children and Young People were proud of several innovations which they shared with the review team:

- Provision of a nurse and pharmacy led hydroxycarbamide/iron chelation drug dosing clinic.
- Nurse and NHSBT led exchange transfusions. This had resulted in a 95 - 100% success rate for each patient. In Jan 2021 - Jan 2022, the percentage of success rate in exchange transfusion completion ranged from 20% to 77%. Aside from the obvious improvement in treatment and patient experience, this service development had saved the Trust an estimated £50,000 per year.
- The service had developed a streamlined blood product pathway, in response to serious delays in transportation from blood bank to clinical area.
- The Clinical Nurse Specialist team had been adopted by the Roald Dahl Marvellous Children's Charity, meaning children, young people, and families were now able to access the family support and advice service.
- The service had introduced Consultant-led virtual clinics, a joint operation with local paediatrician, to provide more rounded and integrated care.
- A radiology email alert system for concerning scan results had been implemented, with the introduction of new pathways for referral of babies into clinical care.
- The service had developed close ties with Millie Wright Children's charity, particularly provision of a family support worker.
- The service had also introduced the 'patient hub', a bespoke area for patients to use.

| SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE | |
|---|---|
| SHT Leeds Children's Hospital, Leeds Teaching Hospitals NHS Trust | Linked Haemoglobinopathy Coordinating Centres (HCC) |
| | North East and Yorkshire Sickle Cell HCC<br>North of England Thalassaemia and Rare Inherited Anaemias HCC |
| | Linked Local Haemoglobinopathy Teams (LHT) |
| | Bradford, Calderdale and Huddersfield, Airedale, Mid Yorkshire, Scarborough and York, Harrogate, Hull |

| ATIENTS 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 | 203 | 130 | 84 | 7 | 81 | 64 |
| Thalassaemia | Children & Young People | 52 | 34 | 8 | 31 | 0 | 7 |

**Staffing**

| Specialist Haemoglobinopathy Team | Number of patients | Actual WTE (at time of visit) |
|---|---|---|
| Consultant haematologist/paediatrician dedicated to work with patients with hemoglobinopathies | 196 | 2.75 PA (+ 1 PA of supported professional activities, no specific PA allocation to haemoglobinopathies CPD) |
| Clinical Nurse Specialist for paediatric patients dedicated to work with patients with hemoglobinopathies | 196 | 1.5 wte for HD shared between 3 wte CNSs |
| Clinical Psychologist for paediatric patients dedicated to work with patients with hemoglobinopathies | 196 | 0 WTE. No access to neuro-cognitive assessments. In exceptional circumstances, referral for psychology support may be accepted. |

## Urgent and Emergency Care

Children and Young People presenting in an emergency followed one of two pathways. In hours Monday to Friday 8am – 6pm the patients presented directly to the Children's Haematology and Oncology Day Unit (CHODU) where clinical assessments and initial treatment were undertaken in the day hospital environment. Admission to inpatient wards followed, if deemed necessary. Out of hours 6pm and 8am, and Saturday-Sunday, Children and Young People presented direct to the inpatient wards (L31 and L33). Families were advised not to attend ED with symptoms / complications of their sickle cell disorder / thalassaemia.

The emergency pathways were accessible in the sickle cell disorder and thalassaemia guidelines published on the Trust intranet and specialist advice and guidance was available 24 hours a day. Out of hours advice was provided by the Consultant Paediatric Haematologist or Consultant Paediatric Oncologist on call. The Consultant Paediatric Oncologist can escalate to a Consultant Paediatric Haematologist who provides a telephone out of hours service on a parallel rota.

In some cases, Children and Young People with Sickle Cell or Thalassaemia would present to the paediatric emergency department sited in Jubilee wing on the Leeds General Infirmary site. Circumstances being if they constituted a life-threatening emergency presentation; if they were a new patient to the area or if they presented in error rather than to the day unit or inpatient units. The guideline for care of patients with either sickle cell disorders or thalassaemia disorders were available on Leeds health pathways which is a facility hosted by the trust intranet. The emergency department were directed to contact ward 31 for advice and possible patient transfer.

Families were informed of the emergency admission pathway at their first outpatient clinic appointment with information also provided in writing using sickle cell disorder and thalassaemia patient information leaflets. The

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

information provided also included the circumstances under which parents/carers should seek medical attention. i.e., fever, symptoms suggestive of anaemia, pain etc, which is reiterated at annual review and nurse-led clinic appointments.

All families were given the mobile telephone numbers of the clinical nurse specialist team, who were often the first port of call for advice.

## In-patient Care

The inpatient unit consisted of the key areas. L31 was the Children's Haematology and Oncology inpatient ward which accommodated patients aged 0 – 12 years. The ward comprised of 16 inpatient beds, 5 of which were single occupancy cubicles. L32 was a 4 bedded Children's Haematology and Oncology bone marrow transplant unit accommodating patients aged 0 – 18 years. L33 was a Teenage Haematology and Oncology inpatient ward accommodating young people aged 13 – 18 years which comprised of a 4 bedded bay and 4 single occupancy cubicles. There was a recreation room for the sole use of the young people. An activities coordinator was based on the ward.

All the inpatient wards were dual speciality; Haematology (including all non-malignant diagnoses) and Oncology. Children and young people with sickle cell disorder and thalassaemia had open access to the inpatient wards.

The team reported increasing numbers of haemoglobinopathy patients undergoing stem cell transplantation. In 2022 three patients with beta thalassaemia were transplanted. In 2023 so far, 7 patients with sickle cell disorder and 2 with beta thalassaemia had received a stem cell transplant.

## Day care and Outpatients

The outpatient department and day unit were a combined facility within the Children's Haematology and Oncology Day Unit (CHODU). There was a sizable waiting room in the reception area, six consultation rooms, phlebotomy, procedure rooms, three four bedded bays and an isolation cubicle. The unit was dual speciality Haematology (including all non-malignant diagnoses) and Oncology.

Clinics were often over booked with more patients than available clinic slots and attendance was poor, in annual review clinics, which limited the access the team had to the families to support them in their long-term condition management, education, and transition to adult pathways. The waiting list had been incorrectly populated, leading to errors in appointments offered.

## Community-based Care

In 2019, the Paediatric Haematology service was commissioned to lead the community care of children and young people with haemoglobinopathies. Due to disruptions caused by COVID-19 and subsequent staffing issues, this aspect of the service has yet to be fully reviewed. A service evaluation was planned, and it is thought likely by the management team that it will reveal insufficient staffing within the current resource to safely take this forward. The community service specification was available to the review team.

The team had key aspirational themes for this service that they felt were not currently achievable within the current resource:

- Organisation and facilitation of patient/family support groups and fun events.
- Formalised long term condition management plan, evolving into transition plan for all children, young people, and families with sickle cell disorder/thalassaemia.
- Signposting to statutory and voluntary services. Resources currently do not allow a comprehensive needs assessment or time to refer to/assist self-referral to external agencies.
- Support to new-borns; previously, the lead CNS would accompany the screening midwives on home visits, to deliver the haemoglobinopathy diagnosis and introduce the paediatric service. This provided a seamless transition from ante-natal to paediatric care. Pressures upon the paediatric service have rendered this

impossible in recent months. It is not anticipated that this will be achievable again with the current staffing levels.

***Health education and promotion in a variety of settings***

The CNS team were responsive to requests for education however staffing levels did not permit the pro-active offering of education or health promotion. The team are aware this may mean they are missing contact with families/agencies that need assistance. School care plans are offered following every annual review appointment.

## Views of Service Users and Carers

The SHT had received 26 responses from a survey of parents whose children had with children sickle cell disease and 0 from those with Thalassaemia and rare inherited anaemias. The SHT had analysed the responses received as follows: -

- In questions relating to satisfaction about routine care, 60% were positive about the care received.
- In questions relating to satisfaction about emergency care, 87% were positive about the care received.
- In questions relating to hospital ward admissions, 69.5% were positive about their experiences.
- In questions relating to knowledge about their child's condition, treatment options and current medications, 83% responded positively.
- In questions relating to having enough information to cope with pain, 63% felt equipped.
- In questions relating to the availability of peer support, support groups and access to psychology, 20% of respondents felt they had adequate support.

## Service user Feedback

The review team met with one parent of a child with sickle cell disease and one parent with a child with thalassaemia during the visit.

**Thalassaemia**

The review team spoke with a parent of a child living with transfusion dependent thalassaemia. Please see comments below.

The team were approachable and easy to talk to and they were grateful for their ongoing support and care However, the parent didn't feel comfortable telling the team about some of their medical or social worries for a fear that the team would involve social services. The parent mentioned discussing concerns with their GP instead of the haemoglobinopathy team.

The parent felt able to confidentially communicate with the team whenever necessary by using the 'Interpreter on Wheels'. This was a trusted measure.

The parent explained that whilst they knew who to contact or where they needed to take their child in an emergency, they were not entirely sure about what signs to look out for with regards to infection, side effects of iron chelation medication and monitoring if febrile.

Transition discussion had not commenced with the patient yet because it was believed these would negatively affect the young person, as they attached to the current team and is familiar with their processes. The team and parent had agreed not to raise the transition period at this time with a plan to delay and then to do it very slowly over a long period of time.

The parent received regular reminders about upcoming transfusions, clinic dates and diagnostic tests.

When asked about the experience of the child, the parent felt their child was very comfortable using the service and was confident in the nurses providing care.

**Sickle Cell Disease**

The review team spoke with a parent whose children were living with sickle cell disease. Please see comments below.

The parent was very appreciative of the team who they believed went above and beyond to take care of their children.

They felt confident in the team's knowledge of the condition and commented that there was a true family feel to the unit.

It was described that because they follow the information the team give them and they attend all their reviews and their appointments, the children have not been admitted to the ward for at least 5 years and are monitored closely. However, they were well aware of triggers and symptoms to look out for in the event of an emergency and knew who to contact and where to attend if there was a need.

The children were aware of what to do for priapism, signs of acute chest syndrome and when pain thresholds become unmanageable.

Brief discussions about transitioning had been had, but they have not been able to have meetings with the adult team despite the paediatric team trying to engage them in the transitioning process.

It was reported that they have a medication ladder that they follow.

There was a support group operating with charity money until last year when funding stopped, and this helped the community to feel supported with some input from healthcare professionals.

They felt that the cancer patients were prioritised in terms of being allowed access to rooms in the waiting area or in terms of not seeing literature that relates to sickle cell or thalassaemia in the waiting rooms in the day unit. They understood this to mean that cancer patients received more funding than sickle or thalassaemia patients.

It was acknowledged that they were quite anxious about the transitioning period for their child because they have heard unpleasant stories about the adult service, but they have full confidence in their current team despite 'the pressures that the team have'.

## Good Practice

1. Reviewers were impressed with the Pharmacist role in supporting the team, including attending the morning briefing. This was a relatively unique role and provided excellent in-reach and team support for medication, dosing, and pharmacology. Staff commented of the positive benefits in the specialist support that the pharmacist was able to provide to service users and the team.
2. The Emergency Pathway was well designed to support patient care to minimise the likelihood of a child being admitted to ED. Emergency admissions followed one of two direct access pathways, dependant on the time and type of presentation with the aim that Families would not attend the ED with symptoms/complications of their sickle cell disorder/thalassaemia. The emergency admission pathway was available in the sickle cell disorder and thalassaemia guidelines, which were easily accessible on the Trust intranet.
3. The Play therapist was held in high regard by all those who met with the visiting team. Reviewers were also informed that the play specialist had won a national award.
4. The reviewers were impressed with the high-quality environment and facilities for patients throughout the walk of the patient pathways.

5. The phlebotomy service was easy to access for service users and minimised disruption to their activities of daily living. The expediting of results enabled treatment planning and treatment could be delivered promptly.
6. Representatives from local haemoglobinopathy teams linked to the SHT, who met with the visiting team, were overwhelmingly positive about the support and specialist care the SHT provided.

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

## Concern

1. **Lead Clinician and Consultant Workload**

   a Lead consultant did not have sufficient time, in additional to other clinical commitments, to provide adequate leadership of the SHT and oversight for the development of guidelines, protocols, training and audit relating to haemoglobin disorders.

   b There was limited time available due to clinical commitments to develop and support the local haemoglobinopathy teams (LHTs), who had limited staff with experience in caring for patients with haemoglobinopathies some of which had significant patient numbers.

   c The capacity of the SHT would also become a more significant issue as there was no definitive plan around succession planning for the Lead consultant.

   d The on-call consultant rota was 1:3 and reviewers considered this was not sustainable due to the frequency of on call commitments and the clinicians' level of other planned activities.

2. **Access to Psychology**

   Patients with haemoglobinopathies did not get access to psychology or neuro cognitive assessments for those who had an abnormal TCD. Some generic psychological support available for service users, though it was bespoke and difficult to access. Individual cases for neurocognitive assessment had been accepted recently following review recommendations by the National Haemoglobinopathy Panel. Reviewers were concerned that the lack of specialist psychology for children and young people may result in them having difficulties in coping with challenges associated with their condition. Reviewers were told that there was no immediate recruitment plan to address this concern.

3. **Community Nursing Support**

   There was no community nursing in place to provide support for patient and carers. Reviewers were told that there was no plan to develop any specialist support and that funding had been made available but diverted to the acute service. The SHT acknowledged that this was an urgent area for development.

4. **Access to Social Care**

   Patients with haemoglobinopathies did not have easy access to welfare and benefits support and the team were spending significant time supporting patients with non-clinical issues. The benefits for patients in improving their quality of life by having this level of support should not be underestimated. Essential wrap around support such as social prescribing for immigration, housing and DLAs would enable the team to focus on their increasing clinical workload while ensuring families gain access to dedicated financial and well-being advice. As the CNS has been adopted by the Roald Dahl Marvellous Children's Charity, there was some access to the charity support service, but this would not negate the need for more local social care support.

5. **Annual Review Clinic – patients who 'were not brought' rate**

   Reviewers were concerned about patients being 'lost from the system', who potentially would have inadequate care or no follow up, increasing the risks of complications or poor patient outcomes. The clinical team did not have well defined process for check and support triggers to follow up those patients were not brought for appointments and reviews. This issue was also compounded by the limited amount of administrative support available to the SHT.

## Further Consideration

1. Following the meeting with the Operational, Finance and Nursing Lead, the review team felt that engagement and oversight from the immediate senior management team could be improved, to understand the key service gaps and risks.
2. Reviewers considered it important that the trust management and financial team liaise with commissioners to gain clarity around maximising funding streams for the SHT. In addition, work should be undertaken with the contracting team to ensure that SHT funding is clearly earmarked for the delivery of services including recruitment to key posts.
3. Whilst there was overwhelming positivity from the representatives from the LHT's, when reviewers asked about formal MDT meetings with LHT's it did not appear that there were formal arrangements to meet and share learning and feedback.
4. The reviewers were told about a general lack of administration support which the CNS team especially felt impacted on their time spent delivering patient care. Increased administration support may benefit the patient experience and release further time back to the team delivering the service whilst making sure that issues such as high 'not brought' rates and appropriate checks and follow ups are monitored and actioned.
5. The reviewers were told about a lack of patient education and education events. Patient education programmes could be delivered to people with long term conditions as an aid for effective self-management to maintain or enhance their health and well-being as well as their clinical, emotional, and social outcomes.
6. The reviewers noted and were told about in-patient wall branding leaning heavily towards the oncology service users. In particular the only "quiet spaces" available in CHODU were very heavily branded with cancer charity slogans and representation. Increasing branding to be more inclusive of haemoglobinopathy patients would improve perceptions of how service users think about the service and make them feel that they are equally as important as other service user groups.

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# Specialist Haemoglobinopathy Team (Adult Services)

## General Comments and Achievements

This was an experienced team with strong leadership from the lead clinician and clinical nurse specialist (CNS). Since the last visit the team had psychology support (0.6 wte) and some Band 5 nursing support (0.7 wte) in the community, who was the lead for transition of young people to the adult service. The CNS was a nurse prescriber and the SHT were in the process of implementing nurse led hydroxycarbamide clinics. The SHT were in the process of recruiting an additional band 6 nursing post.

The team reported that since 2019 the service had seen an increase in patient activity of around 66% and although there had been an increase in nursing and psychology support, there had been no change in the dedicated consultant time and as noted in the previous visit report from 2019, the SHT was reliant on the key lead individuals.

Following the changes in the provision of the haemoglobin disorder service at Bradford Teaching Hospitals NHS Foundation Trust in early 2019, Sheffield Teaching Hospitals NHS Foundation Trust undertook most annual reviews and provided weekly outreach support clinics to patients for patients living in Bradford. Patients would attend the Leeds Teaching Hospitals NHS Trust for monitoring and diagnostic investigations, and to access some specialist support. A few patients attended for their annual reviews from the team at Leeds.

Reviewers met with one representative from the Local Haemoglobinopathy Team from Hull University Teaching Hospitals NHS Trust (HUT). New patients were initially assessed at HUT and then referred to the SHT at Leeds. Shared care arrangements were in place with all patients having their annual reviews at Leeds, who also registered patients on the national haemoglobin registry (NHR). Good arrangements were in place for advice from the SHT and the LHT used the guidelines from Sheffield Teaching Hospitals NHS Foundation Trust which were available on the North East and Yorkshire HCC website. The LHT reported difficulties in accessing psychology and social worker support.

Views of patients had been surveyed in the three months before the visit. Twenty-eight responses from those with sickle cell disease and 14 from those with thalassaemia and rare inherited anaemias (although some of those who met with the reviewing team had only received the survey a week before the visit), had been received and analysed. Comments described about having information about their condition, coping with pain, support groups and treatment options, as well as knowing when to seek emergency care were consistent with comments made to the visiting team at the time of the visit. 100% of respondents said the healthcare staff were sympathetic and understanding, whereas on the visit some who met with the visiting team were not positive about their experiences, their condition, or options for treatment.

***See 'Views of Service Users and Carers' and serious concern section of the report.***

| CARE OF ADULTS | | | |
|---|---|---|---|
| St James's University Hospital, Leeds Teaching Hospitals NHS Trust | Linked Haemoglobinopathy Coordinating Centres (HCC) | | |
| | North East and Yorkshire Sickle Cell HCC<br>North of England Thalassaemia and Rare Inherited Anaemias HCC | | |
| | Linked Local Haemoglobinopathy Teams (LHT) | Patient Distribution | |
| | | SCD | Thal. |
| | Airedale NHS Foundation Trust | 1 | 1 |
| | Bradford Teaching Hospitals NHS Foundation Trust | 43 | 38 |
| | Calderdale and Huddersfield NHS Foundation Trust | 20 | 6 |
| | Harrogate and District NHS Foundation Trust | 2 | 1 |
| | Hull University Teaching Hospitals NHS Trust & Grimsby | 10 | 4 |
| | The Mid Yorkshire Hospitals NHS Trust | 13 | 3 |
| | York Teaching Hospital NHS Foundation Trust (York and Scarborough Hospitals) | 3 | 4 |

| 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 | 224 | 158 | 138 | 19 | 85 | 196 Apr22-Mar 23 |
| Thalassaemia | Adults | 92 | 81 | 74 | 57 | N/A | 19 Apr22-Mar 23 |

***Some annual reviews are undertaken by Bradford Teaching Hospital NHS Trust and not counted in the trust numbers in the table above*

**Staffing**

| Specialist Haemoglobinopathy Team | Number of patients | Actual PA/WTE (at time of visit) |
|---|---|---|
| Consultant haematologist dedicated to work with patients with haemoglobinopathies | 245 | 3.5PA[3] |
| Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies | 245 | 1 wte (band 7) |
| Nurse for adult patients dedicated to work with patients with haemoglobinopathies in the community | 245 | 0.7 (Band 5) |
| Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies | 245 | 0.6 wte |

## Emergency Care

Patients who were known to the service were encouraged to use the JONA admission pathway where nurse practitioners on the haematology/oncology assessment area were available 24 hrs a day, seven days a week, to

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

[3] Clinics 6 hours, Ward rounds 1.5 hours, Day unit, ad hoc 1 hour , Local MDT 1 hour, Teaching 0.5 hour, Clinical admin 2 hours, SHT time 2 hours

provide advice, and if necessary, arrange admission to ward J95. During normal working hours the CNS or community staff nurse could also be contacted for advice.

If patients attended the ED, they were initially assessed via the emergency department (ED) at St James's University Hospital (SJUH). Ambulance arrivals were brought SJUH, where the clinical haematology services were based. If patients attended the ED at Leeds General Infirmary (LGI) then they would be transferred to SJUH or assessed via the JONA pathway.

## Inpatient Care

Overall, the reviewers found the ward areas light and spacious. The main haematology wards were J88/J89. The wards had 40 specific beds for the care of haematology patients. The admission wards J96/95 were for the use of haematology and oncology patients, who were then moved to the base ward for their specific team when a bed became available. Young adults were able to access a young adult ward (J94) and could be transferred to J94 either by direct admission or via wards J95 or J96. Staff on J89 and J94 were trained on the use patient-controlled analgesia systems (PCAS).

Inpatients were seen daily by the myeloid/red cell team, which included a specialist registrar, a junior doctor, and a consultant (on a 1 in 5 'attending' rota). Inpatients were reviewed by the clinical nurse specialist. The lead consultant, when not 'attending', contributed to the care of haemoglobinopathy patients. At the weekends, inpatients were reviewed by the on-call haematology registrar or consultant.

## Day Unit

A large haematology day unit (J87) provided facilities for transfusion and acute pain management. The unit had extended its opening hours since the last visit in 2019 and was open Monday to Friday (excluding bank holidays) 8am to 6.30 pm and at weekends 8am to 4.30pm, the ambulatory care unit (part of J87) provided facilities for weekend top up transfusions.

The therapeutic apheresis suite (TAS) was adjacent to the day unit and was run by the National Blood and Transplant service. This suite had facilities to perform automated red cell exchange and the apheresis unit provided a 24-hour service across the Yorkshire and Humber regions.

## Outpatient and Community-Based Care

Red cell clinics were held in the oncology outpatient suite on L1, Bexley Wing SJUH on the 2nd and 4th Friday morning with an additional clinic being held monthly on a Tuesday. The SHT provided a range of face to face, telephone, and video appointments. A joint red cell and obstetric clinic was held on the 1st Thursday of each month in the Clarendon Wing of LGI where maternity services were based. If an urgent medical review was required, then patients could be seen by appointment on ward J87. Some care in the community was provided by the Band 5 Nurse.

## Views of Service Users and Carers

The visiting team met with eight adults and one carer with sickle cell disease and thalassaemia during the visit.

**Feedback from the patients living with Sickle Cell disease meeting:**

Not all patients met with were familiar with the direct admission to the ward option and commented that they only received paracetamol and oxygen if they were an ambulance transfer. Some said they experienced delays in receiving analgesia in the Emergency Department (ED) with the longest wait being reported as seven hrs. The users reported that sometimes the ED staff are not aware of their analgesia plan.

Those that accessed the JONA pathway found it preferable to attending the ED. Occasionally there are delays before they are asked to attend for assessment.

Overall, the patients were happy with their inpatient care though there were two reports of an admission when they considered that doctors did not listen to them or follow their analgesia plan.

Those who met with the reviewers commented that outpatient attendance is virtual (started during 2020 in the Covid pandemic) and hasn't returned to face to face appointments. This has resulted in them being able to phone to get medications, and bloods can be taken locally without attending the hospital. Patients reported being able to get their results by phone with an updated plan of action.

If they were prescribed hydroxycarbamide, then they attended the OPD every four months with virtual appointments in between. All those who met with the reviewing team said that letters were copied to them and their GP.

There were mixed views about services available. None present in the meeting were aware of the psychology service. Some were engaged with the SHT and had supported service developments whereas others were not aware of any support locally either in the hospital or community. Users on Personal Independence Payments (PIP) had found out about whether they were eligible themselves but had been able to access letters of support from the community or the hospital team. They commented about feeling isolated when applying for welfare support.

All were very keen to have a support group reinstated and for peer education and support.

**Feedback from the patients living with Thalassaemia meeting:**

Four patients spoke about issues relating to the inaccuracies of blood bottle labelling and having to come back to the unit on subsequent days to be resampled. This was not a rare occurrence, and the delay affected their work (and home responsibilities) and at times also caused them to have to rebook their transfusions on other days. They said they had to ask if Ferritin could be added to the blood tests requests.

Five out of the six attendees commented that it was difficult to contact the CNS if they needed advice from one of the team. They didn't know who else they could speak to or how else they could get into contact.

The majority spoke of difficulties when being cannulated due to the lack of experience and knowledge of their condition by some staff and because of this they were made to feel guilty if the staff were unsuccessful. One patient commented that on one occasion they had 17 cannulation attempts.

The majority expressed concerns about the nursing team who administered their blood transfusions who they did not consider had sufficient knowledge of their condition. There was view that staff did not take transfusion reactions seriously and they were sent home after reactions and told to come back to ED if there was a problem. Some patients spoke about having serious transfusion reactions and that the reactions were not always documented appropriately in their records and therefore they were not followed up by the senior members of the haematology team. Accessing transfusions in the afternoon was not always possible as staff would not be able to transfuse more than one unit if they came after 1pm. They would like to have access to the 7-day service for transfusions that patients living with other conditions were offered but have been told that this is not possible.

A patient was not aware of the young person's unit where they could attend for blood transfusions in a more relaxed and appropriate atmosphere and that they did not know of any other young patients to talk to.

Most patients experienced significant issues with regards to accessing their iron chelating medication. They spoke about having to go without medication for weeks as they were not able to get hold of anyone. Types of needles for subcutaneous infusions and deferral pumps were also identified as an issue. Patients said that the needles currently being used were blunt and took several attempts to administer and the pumps were heavy, bulky and difficult to transport affecting adherence and their overall quality of life.

Patients described experiences of side effects of iron chelation but again were not able to talk to anyone about this. A couple of patients mentioned they stopped taking their iron chelation medication for several months to over a year due to not being heard or being able to contact the team.

Most patients commented that they had not had any recent cardiac or liver MRI scans in the past few years. Some were also unclear about the tests they had undergone. Some when asked, said they had not been referred to audiology, ophthalmology, or dental services despite experiencing issues with their eyes, hearing or teeth. No one mentioned about the bone scans when asked about tests. Others had not seen an endocrinologist for some time.

Patients recounted that they were not being referred to see an endocrinologist for years for hormone management and were not being tested for diabetes or other endocrine complications by the haematology team.

This group were not aware about the direct access pathway - JONA and tended to attend the Emergency Department. They commented that they often waited 8-9 hrs to be seen.

They all would like to have education sessions and more information about their condition and side effects of medication.

The patients who were able to access the psychology services, spoke highly of their interaction and support.

Overall, patients did not feel they were important to their haemoglobinopathy team and felt others living with other conditions were treated differently. Patients expressed feeling unheard, undervalued, and were visibly upset throughout the meeting and concerned about any adverse consequences for speaking out.

## Good Practice

1 The JONA pathway since implemented had improved access and time to analgesia. Those who had used the pathway were very appreciative, as it provided them with quick access to advice 24hrs as day and staff were able make arrangements if they needed admission.

2 The SHT provided some monitoring appointments virtually, when this was the case patients were able to have their medications sent to them, which meant they did not have to attend the hospital to collect their prescriptions.

3 Patients who met with the reviewing team were very positive about the support that they had received from the psychologist. They reported how it had helped improve their ability to cope with their condition as well as their emotional well-being.

4 The Emergency Department staff had access to multiple health IT systems which meant they could access patient care plans, hospital, and primary care records.

## Immediate Risk: see serious concerns section of the report

## Serious Concerns

Reviewers were seriously concerned for a number of reasons relating to the deficiency in SHT workforce, which was impacting on the workload of the team, and resulting in a serious level of patient dissatisfaction articulated by those user representatives who met with the reviewing team. Issues relating to staffing and workload were identified at the last visit in 2019 and since this time patient activity had increased by approximately 66%.

**1 Care of patients with Thalassaemia**

a. During the visit, the reviewers had the opportunity to meet with six patients living with thalassaemia. What they heard from these patients raised serious concerns, which were initially raised as a potential immediate risk to both clinical care and safety at the end of the visit. The patients expressed extreme fear regarding their lack of appropriate monitoring for iron overload and endocrinopathy care. They also shared that when they were unwell, they faced difficulties in contacting members of the specialty team. Additionally, the patients were deeply concerned about the management of potential

multisystem complications throughout their lifespan. They felt that their transfusion reactions and other serious complications were not accurately documented in their medical records following transfusions or followed up with specialists.

b. The reviewers were informed of issues related to transfusion management, including delayed and inaccurate cross-matching, recurring problems with cannulation, and inadequate management and reporting of transfusion reactions by staff. The review team found the patient feedback particularly troubling, as patients expressed feeling unheard, undervalued, and were visibly upset throughout the meeting.

c. Following the visit, the trust conducted an audit of treatment plans involving 22 patients with thalassaemia. Whilst this audit provided some information, it did not cover other aspects of multisystem monitoring (such as diabetes, endocrinopathies, gastrointestinal, bone, and cardiac complications). Furthermore, the audit data did not demonstrate adherence to the national guidance laid out in UK Thalassaemia Society's "*Standards for the Clinical Care of Children and Adults living in the UK*."

d. Considering the gravity of the patient feedback, the review team and UKFHD steering group recommend that the Trust and SHT undertake further investigations and develop an action plan in collaboration with their commissioners. It is crucial to ensure that patients are managed in accordance with the UK Thalassaemia Society's "*Standards for the Clinical Care of Children and Adults living in the UK*," 4th edition, published in October 2023. Following the visit, members of the review team and UKFHD peer review steering group contacted NHS England, the North HCC for Thalassaemia, and the Chair of the APPG for Thalassaemia directly to highlight their concerns.

e. Additionally, the trust and SHT should engage patient experience leads ideally from within the trust and externally, to work closely with this group of patients. This collaboration will help understand the nature and extent of their concerns, as well as identify whether these issues are more widespread. The reviewers suggested exploring other methods of patient engagement, such as organising listening events and implementing patient mentoring programs, which could be beneficial to the service. Offering a second opinion with the North of England HCC for Thalassaemia and Rarer Anaemias might also help build trust and confidence in the management of the patients' condition.

f. The UK Thalassaemia Society will be keeping in close contact with the patient group whom they met at the visit, to provide ongoing support, education, and to address their concerns about potential victimisation for sharing their personal stories and feedback on the services they received.

**2 Consultant staffing**

Reviewers were seriously concerned that the service had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders to provide cover in the absence of the lead clinician as cover for the lead was from the 'attending' rota. The lead consultant had a total of 3.5PAs for direct clinical care, the SHT network role and no time allocated for specific haemoglobinopathy CPD which was insufficient for the number of patients cared for by the service. The lead consultant was not able to attend many of the haemoglobinopathy coordinating centre (HCC) business meetings due to clinical commitments.

**3 Clinical Nurse Specialist Workload and Skill mix**

At the time of the visit there was one wte CNS with 0.7 band 5 nursing support in the community for 245 patients with haemoglobin disorders. The reviewers were seriously concerned by the CNS workload and the skill mix for the nursing team for the following reasons:

a. The CNS had a wide-ranging role and no cover for absences. In addition to their clinical workload the CNS was in the process of developing nurse led hydroxycarbamide clinics and was providing line management and specialist support to the community nurse. The new band 6 post holder once recruited would also require a level of support from the CNS.

b. The increase in the number of adults with haemoglobin disorders in the area was having an impact on the capacity of the SHT including the CNS being able to provide the level of support required. Some patients who met with the visiting team commented that they were not always able to contact the CNS for advice and call were not returned. This issue was also highlighted in the previous visit report undertaken in 2019.
c. Reviewers were concerned that the band 5 would have limited scope of practice for what the SHT was requiring in the community, particularly the expectation that they would lead on transition for the adult team.
d. Reviewers considered that it was important that the new team have sufficient and dedicated time for training and development of their respective roles.

## Concern

1 **Communication, information, and education**

A number of issues identified during the visit related to communication, information and education of patients and staff.

a The trust team who met with the reviewers reported that no complaints about the service had been received in the last year. This was a complete variance from the feedback reviewers received from patients with thalassaemia. Further work on systems for gathering meaningful feedback should be considered especially as the patient group did not feel they could escalate their concerns as they did not think any action would be taken or in turn they would be 'victimised'.

b The team were aware that there was little patient information available and planned to develop and publish on the website. Reviewers considered that there were opportunities to involve patients and patient groups at this stage so that information can be developed to meet their needs. Reviewers were told that the Support group for SCD had recommenced but those service users who met the reviewing team were not aware the group had restarted. The lack of information and patient education provision was highlighted, and a programme of education would empower patients ensure accurate messaging.

c Reviewers did not see any signage for red cell services, this was also commented at the last visit in 2019. It was notable that no part of any information displayed related to red cell conditions, which again made them feel less important than patients with other conditions.

d Emergency care plans were not always followed when patients attended in an emergency and patients reported that when they did have reactions such as pyrexia, in particular transfusion related, these were not recorded and taken seriously.

e Not all the patients who met with the visiting team were aware of the direct access pathway JONA. Patients who were aware of the service found it to be excellent. Likewise, not all were aware they could access the young people's ward for transfusions, and this would help those who are transitioning to adult services.

f Patients with thalassaemia who were transfusion dependant had mixed messages about access to transfusions in the afternoon. Patients were told that if they wanted to attend after 1.30pm then there was only time to deliver one unit of blood as transfusions needed to be completed by 5pm even though the unit was open till 6.30pm. Even if the unit closed at 5pm reviewers were not clear why patients attending in the afternoon were told this or staff thought they could not have more than one unit of blood.

2 **Access to social worker/ welfare and benefits support.**

Patients with haemoglobinopathies did not have access to welfare and benefits support. Reviewers were told that the CNS and Band 5 nurse were spending time supporting patients with non-clinical issues. The benefits for patients in improving their quality of life by having this level of support should not be

underestimated and essential that they should have wrap around support for areas such as social prescribing for immigration, housing and applying for Personal Independence Plans (PIP).

3. **Access to analgesia**

   The most recent service audit of compliance with the NICE clinical guidelines on the management of acute pain showed that only 53% of patients had received analgesia within 30 minutes of arrival as an emergency. Compliance had increased from the previous year of 38% but was still suboptimal.

## Further Consideration

1 Psychology support was 0.6 wte for 245 patients and did not quite meet British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia recommendation of one wte for 300 patients. This is unlikely to be sufficient as rise in demand for the service continues. At the time of the visit access to psychology was limited due post holder leave and cover was only available for one day a week.

2 With the reorganisation of responsibilities for transition it would be sensible to review whether the transition policy is being fully implemented and those who have transitioned are being fully supported. Reviewers were told of one patient who was given a letter and told to report to the ward but had not met the adult team before and a parent, whose child was preparing to transition, said it was proving difficult to arrange a joint meeting with the adult team.

3 Medical 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. Training was only provided during the induction programme for new staff.

# Commissioning

The review team had discussions with the regional NHS specialist commissioner and the local commissioner from NHS North East and Yorkshire. The serious concerns and several other issues in this report will require the active involvement of the Trust and commissioners to ensure that action plans are monitored, and timely progress is made.

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# Membership of Visiting Team

| Visiting Team | | |
|---|---|---|
| Rachel Kesse-Adu | Consultant Adult Haematologist | Guy's and St Thomas' NHS Foundation Trust |
| Annette Blackmore | Non-Malignant Haematology CNS | Cardiff and Vale University Health Board |
| Samah Babiker | Consultant Paediatric Haematologist | Guys and St Thomas NHS Foundation Trust |
| Louise Smith | Sickle Cell, Thalassaemia & RIA CNS | Alder Hey Children's Hospital |
| Dede-Kossi Osakonor | Clinical Psychologist | East London NHS Foundation Trust |
| Marie Cummins | Director of Nursing and Quality, Specialised Commissioning | NHS England |
| June Okochi | Service user | |
| Roanna Maharaj | Service user | UK Thalassaemia Society |

| Clinical Leads | | |
|---|---|---|
| Magbor Akanni | Consultant Haematologist | Milton Keynes University Hospital NHS Foundation Trust |
| Mark Velangi | Consultant Paediatric Haematologist | Birmingham Women's and Children's NHS Foundation Trust |

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

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# Compliance with the Quality Standards

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

## Percentage of Quality Standards met

| Service | Number of Applicable QS | Number of QS Met | % Met |
|---|---|---|---|
| Specialist Haemoglobinopathy Team (SHT) Children and Young People | 49 | 32 | 67% |
| Specialist Haemoglobinopathy Team (SHT) Adults | 45 | 30 | 70% |

## 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**<br>Written information should be offered to children, young people and their families, 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 HC-199) | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-102 | **Information about Haemoglobin Disorders**<br>Children, young people and their families 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. Parental or self-administration of medications and infusions | Y | |
| HC-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>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?**<br>All children and young people 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 | A well-developed Emergency Care pathway was in place. The analgesia flow chart was very clear. |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-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 (if appropriate)<br>d. What to do in an emergency<br>e. Indications and arrangements for seeking advice from the specialist service | Y | The letters sent to the service users and the primary care health team included a link to the Leeds Children's Hospital website where the health pathways and information sheets about sickle cell and thalassaemia could be accessed |
| HC-106 | **Information about Transcranial Doppler Ultrasound**<br>Written information should be offered to children, young people and their families covering:<br>a. Reason for the scan and information about the procedure<br>b. Details of where and when the scan will take place and how to change an appointment<br>c. Any side effects<br>d. Informing staff if the child is unwell or has been unwell in the last week<br>e. How, when and by whom results will be communicated | Y | |
| HC-107 | **School or College Care Plan**<br>A School or College Care Plan should be agreed for each child or young person covering at least:<br>a. School or college attended<br>b. Medication, including arrangements for giving / supervising medication by school or college staff<br>c. What to do in an emergency whilst in school or college<br>d. Arrangements for liaison with the school or college<br>e. Specific health or education need (if any) | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-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. 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 | The environment and facilities for children and families were of a high quality. |
| HC-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 | N | The transition process was not fully implemented as young people were not always able to have a joint meeting with paediatric and adult services. |
| HC-197 | **Gathering Views of Children, Young People and their Families**<br>The service should gather the views of children, young people and their families at least every three years using:<br>a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder'<br>b. UKTS Survey for Parents of Children with Thalassaemia | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-199 | **Involving Children, Young People and Families**<br>The service's involvement of children, young people and their families should include:<br>a. Mechanisms for receiving feedback<br>b. Mechanisms for involving children, young people and their families in:<br>i. Decisions about the organisation of the service<br>ii. Discussion of patient experience and clinical outcomes (QS HC-797)<br>c. Examples of changes made as a result of feedback and involvement | N | It was not clear from the evidence and discussions that their mechanisms for involving children and young people for 'b' and 'c' |
| HC-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 lead consultant did not have sufficient time for leadership of the SHT as per the quality standard |
| HC-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 children and young people with haemoglobin disorders<br>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**<br>The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | N | The service had insufficient medical staff for the 255 patients cared for by the service |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-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 children and young people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available. | N | 24/7 cover was reliant on the consultants working a 1:3 on call rota which reviewers considered not sustainable due to the frequency and their other clinical commitments |
| HC-206 | **Doctors in Training**<br>If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders. | Y | |
| HC-207 | **Nurse Staffing and Competences**<br>The service should have sufficient nursing staff with appropriate competences in the care of children and young 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. | N | Competency framework had been developed and was in the process of being implemented. The ward also had a high vacancy rate. |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-208 | **Psychology Staffing and Competences**<br>The service should have sufficient psychology staff with appropriate competences in the care of children and young 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 | No specific psychologist for the service or access to neuro-cognitive assessments. In exceptional circumstances, referral for psychology support may be accepted. |
| HC-209 | **Transcranial Doppler Ultrasound Competences**<br>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**<br>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service. | N | The team only had 0.25 wte data and quality management support. Administrative support was also limited. |
| HC-301 | **Support Services**<br>Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required:<br>a. Social worker / benefits adviser<br>b. Play specialist / youth worker<br>c. Dietetics<br>d. Physiotherapy (inpatient and community-based)<br>e. Occupational therapy<br>f. Child and adolescent mental health services | N | There was no access to a social worker. All other aspects of the quality standard were met. |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-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 | |
| HC-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 | |
| HC-304 | **Urgent Care – Staff Competences**<br>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 | A framework for measuring urgent care staff competence was not in place. Some training was delivered to medical staff. |
| HC-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 HC-195) | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-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 children, young people and their families. | Y | |
| HC-504 | **Transcranial Doppler Ultrasound Standard Operating Procedure**<br>A Standard Operating Procedure for Transcranial Doppler ultrasound should be in use covering at least:<br>a. Transcranial Doppler modality used<br>b. Identification of ultrasound equipment and maintenance arrangements<br>c. Identification of staff performing Transcranial Doppler ultrasound (QS HC-209)<br>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<br>e. Arrangements for recording and storing images and ensuring availability of images for subsequent review<br>f. Reporting format<br>g. Arrangements for documentation and communication of results<br>h. Internal systems to assure quality, accuracy and verification of results | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-505 | **Transfusion Guidelines**<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. Arrangements for accessing staff with cannulation competences<br>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<br>g. Patient pathway for Central Venous Access Device insertion, management and removal | Y | |
| HC-506 | **Chelation Therapy**<br>Guidelines on chelation therapy should be in use covering:<br>Indications for chelation therapy<br>a. Choice of chelation drug/s, dosage and dosage adjustment<br>b. Monitoring of haemoglobin levels prior to transfusion<br>c. Management and monitoring of iron overload, including management of chelator side effects<br>d. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2<br>e. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-507 | **Hydroxycarbamide and Other Disease Modifying Therapies**<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 complications<br>e. Indications for discontinuation | Y | |
| HC-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 | |
| HC-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>**For children and young people 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>k. Acute splenic sequestration<br>**For children and young people with thalassaemia:**<br>l. Fever, infection and overwhelming sepsis<br>m. Cardiac, hepatic or endocrine decompensation | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-510 | **Clinical Guidelines: Chronic Complication**<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. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea<br>f. Endocrine and growth problems, including endocrinopathies and osteoporosis<br>g. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology<br>h. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease<br>i. Growth delay / delayed puberty<br>j. Enuresis<br>k. Urological complications, including priapism<br>l. Dental problems | Y | |
| HC-511 | **Anaesthesia and Surgery**<br>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**<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 (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-601 | **Service Organisation**<br>A service organisation policy should be in use covering arrangements for:<br>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<br>b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hrs of acute admission<br>c. Patient discussion at local multidisciplinary team meetings (QS HC-604)<br>d. Referral of children for TCD screening if not provided locally<br>e. 'Fail-safe' arrangements for ensuring all children and young people have TCD ultrasound when indicated<br>f. Arrangements for liaison with community paediatricians and with schools or colleges<br>g. Follow up of patients who 'were not brought'<br>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<br>i. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together<br>j. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-603 | **Shared Care Agreement with LHTs**<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 HC-502) (if annual reviews are delegated)<br>c. LHT management and referral guidelines (QS HC-503)<br>d. National Haemoglobinopathy Registry data collection (QS HC-701)<br>e. Two-way communication of patient information between HCC / SHT and LHT<br>f. Attendance at HCC business meetings (HC-607) (if applicable)<br>g. Participation in HCC-agreed audits (HC-706) | N | Shared care agreements with the LHTs were not yet in place. In practice informal arrangements were in place for seeking advice and transfer. |
| HC-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 required, representatives of support services (QS HC-301). | N | The formal arrangements local MDT meeting was not clear and appeared inconsistent |
| HC-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 children and young people with haemoglobin disorders<br>b. Two-way exchange of information between hospital and community services | N | Service level agreement for support from the community services as per the Quality Standard was not in place. |
| HC-607S | **HCC Business Meeting Attendance (SCD)**<br>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)**<br>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**<br>The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results, identify issues of mutual concern and agree action. | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-701 | **National Haemoglobinopathy Registry**<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 | |
| HC-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 HC-505)<br>b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions | N | Audit covering the patient pathway for those requiring regular transfusion was in the process of being undertaken. |
| HC-706 | **HCC Audits**<br>The service should participate in agreed HCC-specified audits (QS HC-702d). | N/A | The HCC had not agreed an audit programme |
| HC-707 | **Research**<br>The service should actively participate in HCC-agreed research trials. | Y | |
| HC-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 HC-197) compared with other services<br>c. Results of audits (QS HC-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. | N | The review of patient experience and clinical outcomes between the MDT and with patient and carer representatives had not yet been formalised |
| HC-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'. | N | The arrangements for review and learning had not been formalised |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-799 | **Document Control**<br>All information for children, young people and their families, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | |

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## 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 | Patients who spoke to the reviewing team were not aware of any information or written guidance covering the aspects of the Quality Standard.<br>The SHT said that new patients would receive written information about the service and other health information.<br>The SHT were in the process of developing information that would be made available via a website. |
| 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 | Patients were sent copies of clinic letters which were also saved on the trust management system. However, not all the patients who met with the visiting team had seen their care plans or been involved in their development. Some commented that where they had a care plan it was not always followed. |
| 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 | The team used an emergency care plan template and staff in the emergency department were able to access electronic version of any care plans. Some of the patients who met with the reviewing team were not aware of the emergency pathway via JONA. |

| 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 | |
| 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 | N | The transition process was not fully implemented as patients were not always able to have a joint meeting with paediatric and adult services.<br>All other aspects of the Quality Standard were met. The SHT used the 'ready steady go' transition documentation with additional information on the trust website. The newly appointed band 5 nurse who worked in the community was the as the lead for transition for the SHT. |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| 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 | Surveys had been undertaken in 2023. 28 responses had been received from those with sickle cell disorders and 14 from those with thalassaemia and rare inherited anaemias. Key themes from the surveys had been collated. |
| 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 | N | Mechanisms for receiving feedback were in place but not mechanisms for involving patients and carers in decision about the organisation of the service, patient experience and outcomes. |
| 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 lead consultant had a total of 3.5PAs for direct clinical care, the SHT network role and no time allocated for specific haemoglobinopathy CPD (.25PA) |
| 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. | Y | 1 wte CNS was in post |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| 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 lead consultant had a total of 3.5PAs for direct clinical care, the SHT network role and no time allocated for specific haemoglobinopathy CPD (.25PA). Cover for the lead was from the on-call rota. |
| 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. | Y | |
| 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. | N | (b) was not met as the 0.7 wte Band 5 with responsibilities for the community service was also the lead for transition – see main report about role expectations.<br>The service had 1wte CNS for inpatient care (a)<br>Patients were cared for on wards; J88, J89, J94,and JONA . Day unit care was provided on J87<br>The RCN competence framework had been adapted for use locally for use with registered and unregistered staff. Two competence documents were in use covering those caring for patients with sickle cell disease and thalassaemia. |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| 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 | The SHT had 0.6wte psychology time for 245 patients which did not meet the recommended level of 1:300 pts<br>At the time of the visit the postholder was on leave and cover was only available one day a week. |
| 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 had 15hrs data and administrative support |
| 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 | Y | |
| 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 | |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| 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 | Reviewers were told that medical staff had training on induction only. A competence framework was not yet in place, although the SHT were planning to implement. Training was provided to nursing staff working the Emergency Departments and a register kept of those who attended.<br>An audit of compliance with NICE Clinical Guideline on the management of acute pain showed that only 53% of patients were given pain relief within 30 mins. Compliance had increased from the previous year of 38% but was still suboptimal |
| 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 | The guidance was included in the guideline compendium. The service operational policy included the transition arrangements in place and a more detailed pathway was included in the paediatric transition guidance. |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| 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 | |
| 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 | Y | |
| 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 |
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| 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>iv. 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>v. For patients with thalassaemia:<br>k. Fever, infection and overwhelming sepsis<br>l. Cardiac, hepatic or endocrine | Y | |

| 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 | N | Guidelines were in place but in view of the patient feedback and audit results were not fully implemented |
| 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. | Y | |

| 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 | Y | |
| 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 |
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| 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 hrs 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) | N | There were no written agreements covering shared care arrangements with the LHTs. In practice informal arrangements were in place for seeking advice and transfer. |
| 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/A | The MDT included a Community Sickle Cell and Thalassaemia Nurse (band 5) who provided the majority of care in the community |
| 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 | HCC data from April 22 – March 23. Attendance tended to be by the CNS (4) Counsellor (2) Biomedical rep (4). The SHT did not send any representation for two meeting (December and January).<br>The lead consultant had only been able to attend one of the meetings in the timespan due to clinical commitments. |
| 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). | N | The SHT had not manged to send representation to each thalassaemia HCC Business Meeting |
| 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 | An audit covering 'a' had not been undertaken.<br>An audit covering clinical feedback on admissions to inappropriate setting had not been undertaken (b) however patient feedback on admissions had been received. |
| HA-706 | **HCC Audits**<br>The service should participate in agreed HCC-specified audits (QS H-702d). | N/A | The HCC did not have an agreed list of HCC audits. |

| Ref. | Quality Standards (Adults) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HA-707 | **Research**<br>The service should actively participate in HCC-agreed research trials. | Y | |
| 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. | N | Review of Patient Experience and Clinical Outcomes as described by the Quality Standard had not taken place. |
| 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 | |

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