MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Visit date: 17th January 2024

Report date: 11th July 2024

Contents

Introduction

This report presents the findings of the review of The Newcastle upon Tyne Hospitals NHS Foundation Trust that took place on 17th January 2024. The purpose of the visit was to review compliance with the Health Services for People with Haemoglobin Disorders Quality Standards Version 5.1, November 2021 which were developed by the UK Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit was organised by the Nursing and Urgent Care Team (NUCT) at the Midlands and Lancashire Commissioning Support Unit (MLCSU). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

- 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 The Newcastle upon Tyne 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:

- The Newcastle upon Tyne Hospitals NHS Foundation Trust
- NHS North East and Yorkshire
- North East and North Cumbria 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 and North East and North Cumbria Integrated Care Board.

About the UKFHD and MLCSU

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

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

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

Acknowledgements

The UKFHD and MLCSU would like to thank the staff and service users and carers of The Newcastle upon Tyne 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

The Newcastle upon Tyne Hospitals NHS Foundation Trust

Trust-wide

General comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders. During the course of the visit, reviewers attended the Royal Victoria Infirmary and the Freeman 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 Trust provided specialist services for haemoglobin disorders and had been formally recognised as a Specialist Haemoglobinopathy Team (SHT) in April 2019 following the national compliance exercise conducted by NHS England (NHSE).

The Haemoglobinopathy Services for children, young people and adults were specialities within their respective boards (Family Health Clinical Board for Children and Cancer and Haematology Clinical Board for Adults) providing treatment, support, and advice to both adult and paediatric patients and families affected by Sickle Cell Disease (SCD), Thalassaemia (Thal) and Rare Inherited Anaemias (RIA). The SHTs provided direct services for patients residing locally and provided review and advice across a wide geographical area; Northeast and Cumbria, including Tyne and Wear, County Durham, Northumberland and parts of Cumbria and North Yorkshire. The most recent ONS data identified that 4.2% of the population across the region were of an ethnic minority and one in five people were over 65.

The number of patients with haemoglobin disorders cared for by both SHTs had increased from 95 in 2018 to 285 in 2024 (regional patients registered on NHR ~111 children and young people and ~167 adults). James Cook University Hospital NHS Trust acted independently providing a full range of services; acute admissions, outpatient care, hydroxycarbamide monitoring, annual reviews, exchange transfusions and transcranial doppler scans (TCDs were undertaken locally but provided by NUTH). South Tyneside and Sunderland NHS Foundation Trust (Sunderland Royal Hospital) cared for ~50 patients and would care for acute admissions, provide outpatient care, Hydroxycarbamide monitoring and could undertake Ferriscans®. The SHTs cared for a small number of patients at other hospitals across the region and were fully aware of the difficulties that these patients experienced in being able to travel to NUTH on a regular basis.

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

Trust-wide Concerns – Adults, Children and Young People

1. Workload and resources

   Reviewers were concerned at the lack of resources available for the adult, children's and young people services and unless there is work to address these growing health inequalities both at ICB and Trust level the services will continue to feel under increasing pressure.

2. Lack of clear succession planning and network collaboration with The James Cook University Hospital (JCUH)

   Reviewers were concerned about the potential for an abrupt increase in service users for both services at NUTH as the service at JCUH relied on single handed consultant haematologist, and a CNS who covered

both paediatric and adult cases with a caseload of about 80 patients. A consultant paediatrician provided support for children and young people with haemoglobin disorders and a joint paediatric /haematology clinic was in place. Both the JCUH consultant haematologist and CNS were at or approaching retirement age and although the team were functioning as an SHT, they actually only had local haemoglobinopathy team (LHT) status and therefore there would be a lack of funding to expand or maintain existing services in future. Reviewers considered that significant change with input from the wider team at NUTH and improving MDT attendance would be important to ensure the team at JCUH were not working in isolation.

3. Access to FerriScan

   Reviewers were concerned that access to Ferriscans usually meant that patients had to travel to London despite Ferriscans being available at the Sunderland Royal Hospital, a short distance away. Reviewers were told that access was not possible due to regional boundaries and commissioning issues. It was not clear why a service level agreement could not be agreed for FerriScan to be carried out for NUTH haemoglobinopathy patients at Sunderland when required, or to source local availability in Newcastle.

4. Access to analgesia – adults

   An audit of compliance with the NICE Clinical Guideline on the management of acute pain showed that 53% of patients were given pain relief within 30 minutes. Compliance had increased from the previous year of 38% but was still low.

5. Access to analgesia – children and young people

   An audit of compliance with the NICE Clinical Guideline on the management of acute pain showed that an audit of ten patients, none i.e.0% had been given pain relief within 30 mins.

6. Lack of formal escalation to Commissioners

   The reviewers were concerned about the lack of escalation of issues faced by the SHTs by the Trust. From discussions with Trust and commissioners representatives at the time of the visit, it did not appear that commissioners were made aware/ were aware of the issues related to the service, such as the poor compliance with the with NICE Clinical Guideline on the management of acute pain , other SSQD monitoring and the inadequate staffing levels for the patient population covered.

Trust-wide Further Consideration

1. Reviewers considered that a forward plan was required which considered the rise in demand for both the adult and children's services and any impact on current and future immigration. Data showed that there had been an increase in patients cared for by the services since 2022 from 89 to 111 children and young people and 107 to 167 adults.
2. 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.
3. The Trust policy for transition of young people occurred at the age of 16 with no one aged 16 years or older permitted on inpatient paediatric wards, however reviewers were told that there was flexibility for paediatric haemato-oncology cases but not those with haemoglobin disorders. This would mean that parents of 16-17 year olds would not easily be able to stay overnight to support unwell adolescents unless they were admitted to Ward 35 at the Freeman Hospital and a side room was available. Access to The Teenage Cancer Trust facilities were in the main prioritised for patients with malignant conditions, but other inpatients could have access if there was capacity. Patient controlled analgesia devices (PCA) were not allowed on The Teenage Cancer Trust unit but were available on Ward 4.

4. The CNSs in both teams had commenced in post within the last three years and were providing an excellent service. Reviewers considered that it would be important that they are able to have sufficient and dedicated time for training and development of their CNS roles.

5. Reviewers were told that virtual clinics were not possible as the 'AttendAnywhere' system had not been felt useful for the clinical teams in supporting patient video consultations. Some telephone patient reviews were undertaken. Further options were being explored and the service and reviewers considered that with the wide geographical area it would be helpful to improve communication and minimise travel for patients to have this option as well as face to face appointments.

Views of Service Users and Carers

Support Group available for patients and carers	Y/N
Sickle Cell Disease – Children and Young People	Y - Commenced January 2024
Thalassaemia – Children and Young People	N
Sickle Cell Disease – Adults	Y - Commenced January 2024
Thalassaemia – Adults	N

During the visit the visiting team met with four service users and carers, one patient with sickle cell disease, one carer of a child with sickle cell disease and one patient with a rare inherited anaemia and their carer representing the adult and children services. The views of the users are documented in the children's and adult specialist haemoglobinopathy team sections. The review team would like to thank the service users for their openness and willingness to share their experiences.

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Specialist Haemoglobinopathy Team (Children and Young People Services):

The Newcastle upon Tyne Hospitals NHS Foundation Trust

General Comments and Achievements

The Specialist Haemoglobinopathy Paediatric team was a small team exhibiting a high level of dedication and enthusiasm, despite operating under considerable pressure due to substantial staffing challenges. Over the past two years, the service had undergone significant staffing changes concurrent with a notable surge in patient numbers (four-fold increase in patient numbers).

The team consisted of the lead Consultant Paediatric Haematologist (2PAs), a Paediatric Consultant (1PA) and a Clinical Nurse Specialist (0.8 WTE) covering haemoglobin disease and non-malignant haematology. The whole team had changed within the last two years and were gaining experience in the care of children with haemoglobin disorders.

During the visit, it became evident to the assessment team that there had been advancements towards meeting the Quality Standards, with an evident awareness of areas requiring improvement. For instance, they had submitted a business case for the improvement of the apheresis service to provide 24/7 red cell exchanges which had been approved and Hydroxycarbamide Monitoring Clinics had been implemented. The CNS was also providing some outreach support to the LHT in Sunderland.

The team consistently displayed a robust commitment to deliver a quality service for their patients. Furthermore, they showcased positive working relationships with specialty teams.

SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE	
Newcastle Upon Tyne Hospitals NHS Foundation Trust (NuTH): Great North Children's Hospital, Royal Victoria Infirmary	Linked Haemoglobinopathy Coordinating Centres (HCC)
	North East and Yorkshire Sickle Cell HCC Thalassemia and Rare Inherited Anaemias: North of England
	Linked Local Haemoglobinopathy Teams (LHT)
	The James Cook University Hospital (JCUH), Middlesbrough South Tyneside and Sunderland NHS Foundation Trust County Durham and Darlington NHS Foundation Trust Northumbria Healthcare NHS Foundation Trust North Cumbria Integrated Care NHS Foundation Trust

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[1]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Children & Young People	90 as SHT; 55 for NUTH direct care	78	84/95 (Apr 22 – Mar 23)	2 (automated exchange)	57/64	32 (Apr 22 – Mar 23)
Thalassaemia and rare inherited anaemias	Children & Young People	21 as SHT; 14 for NUTH direct care	18	18/21 in total (Apr 22 – Mar 23)	3		1 (Apr 22 – Mar 23)

Staffing

Specialist Haemoglobinopathy Team	Number of patients	**Actual PA/WTE (at time of visit)**
Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies	111	3 PAs /2 WTE
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with haemoglobinopathies	111	0.8, who also covered other non-malignant haematology
Clinical Psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies	111	0

Urgent and Emergency Care

Children with a haemoglobinopathy have access out of hours to telephone triage and admission via the Paediatric Accident & Emergency department at the Great North Children's Hospital (GNCH). Within normal working hours, parents were asked to triage through the haematology/oncology service. In line with Trust policy all acute admissions were reviewed within 14 hours.

The Emergency Department operated a scoring system whereby patients with Haemoglobinopathies were flagged and prioritised for triage on arrival in the Department. During the visit, the review team walked the pathway and spoke to a Consultant within the Emergency Department who demonstrated a very clear knowledge of the guidelines for the management of patients with haemoglobinopathies. There was a protocol available for staff to access which provided clear guidance on the management of patients experiencing a sickle cell crisis. In addition to this, staff could access the patient's Care Plan on the Electronic Patient Record (EPR) system.

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

The views of service users that were met with by the visiting team were all positive in relation to their experience of the Emergency Department. However, the number of views was limited (a parent and child with a rare inherited anaemia (RIA) and one parent of a child with sickle cell disorder (SCD), therefore, the reviewing team commented that they would have liked to have heard from a wider range of patient and child experiences.

Outpatient, In-patient, and Day Care

Paediatric Haemoglobinopathy outpatients were seen in a Children and Young People (CYP) clinic based within the CYP haematology/oncology day unit.

Inpatients were cared for on a 24 bedded inpatient unit dedicated to CYP with haematological and oncological diagnoses (Ward 4, GNCH). Paediatric Haemoglobinopathy admissions averaged around 4-5 admissions per month therefore too few for a dedicated ward for red cell disorders. The environment and facilities on the ward were child friendly hosting a range of activities such as music and art therapy. Play specialists were also employed on the wards. There was a Teenage Cancer Trust funded unit on the ward that haemoglobinopathy patients under 16 years old could access. Service users reported a positive experience on the ward, parents commenting on their ability to stay with their child on the ward.

Day Care was provided on the CYP haematology/oncology day unit. There were 24 spaces available (6 beds, 18 chairs) for urgent and routine care.

Community-Based Care

There was no dedicated community-based care for patients with haemoglobin disorders. However, the patients within the service had access to the Children's Community Nursing Teams for bloods and specific medication administration (i.e. iron chelation pumps). There was no Service Level Agreement in place with the community services, but the team reported that they had good working arrangements with the community nursing services.

Views of Service Users and Carers

The visiting team met with one parent and their child with a Rare Inherited Anaemia and a parent of a child with SCD during the visit. The feedback from services users was all positive about the service. Their feedback included:

- Those who met with the reviewers commented on the good experience they had when attending the Emergency Department
- The facilities were excellent, and they appreciated the ability for a parent to stay with their child when they were admitted.
- There was good access for parent and child to access psychology support when preparing for transplant.
- Even when pressed to make recommendations the parents struggled to identify any improvements.

Good Practice

1. The team were evidently working hard and are committed to providing high-quality services and making progress towards achieving the national quality standards. Individuals within the team went above and beyond the remit of their role to support patients and ensure safe and effective care.
2. A Specialist Haemoglobinopathy Midwife was employed 0.5 WTE to lead the neonatal screening pathway. The Specialist Midwife was experienced, passionate and very knowledgeable about the programme. The midwife would also undertake newborn visits.
3. The environment and facilities throughout the whole pathway were excellent. Inpatient facilities were particularly highlighted as child friendly, hosting play specialists and a range of activities for children and

young people including music and art therapy. There was also a Teenage Cancer Trust funded unit on the ward that haemoglobinopathy patients under 16 years of age could access.

4. There were systems in place to score and prioritise patients being seen in ED, enabling haemoglobinopathy patients to be flagged on arrival.
5. All patients were issued with a standardised care plan which is easily accessible on the Electronic Patient Record (EPR) system.
6. Reviewers were impressed with the good relationships that the SHT had with other speciality teams for seeking advice and referral for patients with acute and chronic complications of their disorder. In particular, work had been undertaken with the respiratory and dental teams to improve the patient pathway for children with haemoglobin disorders.

Immediate Risks - No immediate risks were identified during the visit.

Serious Concern

1 **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 staffing for regular reviews, emergency care and clinics.

a At the time of the visit the Lead consultant had 2PA's for 111 patients, providing leadership and advice across the network and leadership of the SHT. Some support was in place from a Consultant Paediatrician (1PA). The on call rota was 1:9 rota and included seven oncologists and two haematologists. As the on call cover was not always a haematologist, this resulted in the Lead Consultant being phoned for advice when not on call.

b There was no evidence of future proofing across the SHT and limited arrangements in place for absence. Reviewers were told that during a long-term absence of the lead clinician, cover for the SHT had been provided by a peadiatric haematology specialist registrar alongside a consultant paediatric haematologist, the clinical lead of the paediatric haematology/oncology service, an oncologist, and a consultant paediatrician.

c The Lead consultant's job plan allowed insufficient time for haemoglobinopathy related CPD and the lead did not have capacity to attend the HCC MDTs on a regular basis.

Concern

1 Lead Nurse (CNS) Staffing

a. At the time of the visit, reviewers were concerned that the service had insufficient CNS staffing with only one CNS employed 0.8 WTE who also covered other conditions. This was compounded by the lack of support from other specialist services such as psychology, social care and welfare support leading to the CNS spending time on non-clinical activities and outside of the remit of her role.

b. There was no cover arrangements for the Paediatric CNS when absent. In practice the adult CNS would be available to contact for queries and advice

2 Access to psychology

Access to psychology was limited due to having no dedicated psychology support for the service. Waiting lists for the general psychology service were approximately one year unless the patient was awaiting a transplant (in which case there was a separate pathway). However, the general psychology service would not have the relevant experience in caring for patients and families with haemoglobin disorders. Reviewers were concerned as without a dedicated psychological practitioner individuals affected by these

disorders will have limited specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition.

3 Limited data support

The SHT had limited data support leading to clinical staff spending clinical time on administration and data collection. Reviewers were told that the lack of administrative support was on the Trust Risk Register but it was not clear what actions were planned to address.

4 Service isolation and lack of networking.

Attendance at the Regional and National MDTs was limited due to the lack of time within the Clinical Leads job plan. The broad geographical area covered by the SHT provided a challenge and the service identified the need to strengthen links and have more formal Service Level Agreements with the LHTs.

5 Access to analgesia and training for Emergency Department staff

The most recent service audit of compliance with the NICE clinical guideline on the management of acute pain (10 patients) showed that no patients had received analgesia within 30 minutes of arrival to the Emergency Department.

There had also been limited or no haemoglobinopathy specialist training provided for staff working within the Emergency Department.

6 Regional MDT decision-making

The review team were concerned that there did not appear to be good links between the SHT and all the local centres (LHTs) across the network area with no outreach clinics or regular MDT that the regional clinicians regularly attended/accessed.

Further Consideration

1 A repeat and full audit of the pain pathway should be undertaken to identify the blocks in providing timely pain relief for patients experiencing a Sickle Cell Crisis.

2 The first sickle cell support group for paediatric patients or their carers was due to take place the week after the visit. Feedback from the patients survey highlighted the value they felt they would gain from a regular support group.

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Specialist Haemoglobinopathy Team (Adult Services):

Newcastle Upon Tyne Hospitals NHS Foundation Trust

General Comments and Achievements

This was an enthusiastic small team who are clearly working hard towards achieving the Quality Standards. The team members were held in high regard and clearly well connected with key specialist colleagues including those from orthopaedic, pulmonary hypertension, renal and liver services.

The haemoglobinopathy cohort was rapidly expanding and mostly consisted of recent arrivals to the area including health workers and university students. The increasing activity for the team had been raised at management meetings.

An adult haemoglobinopathy CNS had joined the team in 2020, Nurse led telephone clinics for hydroxycarbamide monitoring had been implemented and the SHT had a well thought out transition plan.

There had been a significant improvement in the time to analgesia for those with a sickle cell disorder presenting with acute pain, but results showed that 53% of adults were receiving analgesia within the 30 minute timeframe.

A clear protocol and pathway for emergency manual red cell exchange was in place, with manual exchange being undertaken on the intensive care unit (ITU). Reviewers were told that there was always access to the ITU and support for line insertion when required. The nurses on the ITU performed the manual red cell exchange and about five patients had required manual exchange in the last 12 months

The SHT were aware that other local hospitals cared for red cell patients in local clinics, but due to the setup of the NHR database these hospitals were not listed on the NHR and the SHT had no way to record the patients as being local to a different trust. Other than patients seen at The James Cook University Hospital, all of these patients had annual reviews performed by the team at Newcastle and were included in the SHT patient numbers. The Lead Clinician had raised this issue with MDSAS and the NHR data committee, but the issue remained unresolved.

SPECIALIST HAEMOGLOBINOPATHY TEAM - ADULTS	
SHT: Newcastle Upon Tyne Hospitals NHS Foundation Trust (NuTH): Royal Victoria Infirmary (inpatients at Freeman Hospital)	Linked Haemoglobinopathy Coordinating Centres (HCC)
	North East and Yorkshire Sickle Cell HCC Thalassaemia and Rare Inherited Anaemias : North of England HCC
	Linked Local Haemoglobinopathy Teams (LHT)
	The James Cook University Hospital (JCUH), Middlesbrough South Tyneside and Sunderland NHS Foundation Trust County Durham and Darlington NHS Foundation Trust Northumbria Healthcare NHS Foundation Trust North Cumbria Integrated Care NHS Foundation Trust
PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM	

Condition		Registered patients	Active patients *[2]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Adults	123 as SHT 84 as NUTH direct care	79/84	58/63 2022-2023	3	32/58	35
Thalassaemia and rare inherited anaemias	Adults	44 as SHT 39 as NUTH direct care	44/44	28/31	10	0	1

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant haematologist dedicated to work with patients with haemoglobinopathies	167	Total 3.25 PAs (plus on call) – no CPD Lead had 2.5 (1.75 clinical and 0.75 SPA) Deputy 1.5 PAs
Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies	167	0.8 WTE
Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies	167	0

Emergency Care

Patients with a haemoglobinopathy had open access out of hours to the emergency triage line for haematology patients at Freeman Hospital but in practice would generally be asked to attend via the Accident & Emergency department at the Royal Victoria Infirmary (RVI). Within normal working hours, patients were asked to contact the department of haematology for advice.

In-patient Care

Adult inpatient care was provided on Ward 35 at Freeman hospital and a shared care arrangement was also in place to admit patients to the adult medical wards at the RVI. The CNS would review all patients who had been admitted to any of the wards.

Ward 35 at the Freeman Hospital was an adult haematology/oncology ward. The ward had 22 inpatient beds (14 single rooms and 2 four bedded bays). There were no haemoglobinopathy inpatients on the day of the visit.

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

Staff were friendly and welcoming. Some of the staffing establishment had been more stable which had enabled these staff to support new staff joining the team and also build long lasting and supportive relationships with the patients.

Staff were trained in the use of patient controlled analgesia systems (PCA) and reviewers were told that patients with sickle cell disease would take priority for admission if they required a PCA.

Day Unit Care

There was no dedicated haematology day care unit at the trust. Transfusions took place in the medical day case unit at RVI. Due to the distance from NHS Blood and Transfusion services, arrangements were in place to access blood and patients were cross matched 24-48hrs beforehand. The unit had 12 patient spaces, (10 chairs and 2 rooms) and was open Mon-Fri 0730 – 1800. Some day care was also accessible on the ambulatory care unit at the Freeman Hospital (NACU) which had six chairs for treatments and was open 7 days/week.

Outpatient Care

Clinics and blood tests were undertaken in the haematology department at the RVI which was shared facilities with the haemophilia unit.

Community-Based Care

There were no formal community services for adults with haemoglobin disorders.

Views of Service Users and Carers

The visiting team met with only one adult with sickle cell disease during the visit.

- The patient articulated that they had learned a lot about their condition and self-management, through their own research and experiences, independent of acute hospital services, over several decades.
- The patient was nonetheless very positive about the care they get from the lead consultant and CNS.
- The patient was satisfied with their experiences in attending the Emergency Department.

The reviewing team would have liked to have met with several patients to hear from a wider range of experiences of adult services.

Good Practice

1. Reviewers were impressed that patients could access complementary therapy services (aromatherapy, massage) when as an inpatient on ward 35 at the Freeman hospital.
2. For young people transitioning to adult care the CNS would meet with the young person and identify their specific needs and develop an individualised plan to help them adjust to the adult service. The CNS proactively attended the paediatric clinic to meet young people and as part of their first adult clinic, took them on a tour of the ED, outpatient department and inpatient wards. Parents were asked to wait outside the clinic room for part of the consultation to foster independence.
3. Patients attending for their 'new patient' appointment would see the CNS prior to the formal consultant clinic review. This enabled patients to receive information and support in a more relaxed environment.
4. There were systems in place to score and prioritise patients being seen in ED, enabling haemoglobinopathy patients to be flagged on arrival and triaged quickly. All patients were issued with a standardised care plan which was easily accessible on the Electronic Patient Record (EPR) system
5. Bair hugger warming blankets were available in the ED and on ward 35 at the Freeman Hospital for patients. Reviewers were told that the team had not analysed the use of Bair huggers either qualitatively or quantitatively, but informal patient feedback had been very positive.

6. The majority of blood transfusions were taking place at Freeman ambulatory care unit, feedback from patients had been very positive as the unit had been able to reduce the time to transfusion for patients. As the service was operational seven days a week patients also had more flexibility and choice as to when to attend for their transfusion.

7. Reviewers were impressed with the good relationships that the SHT had with a large range of speciality teams for seeking advice and referral for patients with acute and chronic complications of their disorder. In particular the SHT had implemented a joint endocrine and red cell MDT and held joint haemoglobinopathy and orthopaedic clinics. Reviewers were told that one stop echocardiography which had ceased during the Covid-19 pandemic was in the process of being re-established.

8. One stop eye screening had been implemented for patients with sickle cell disease. This meant that patients could be assessed as part of their normal review clinic appointment which would mean they did not have to attend the hospital for an additional appointment for an ophthalmology assessment.

9. The lead clinician had led on the design and agreement of a research trial looking at retinopathy in patients with a sickle cell disorder.

Immediate Risks: No immediate risks were identified at the time of the visit.

Serious Concern

1. 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 staffing for regular reviews, emergency care and clinics.

   a At the time of the visit the lead consultant had 1.5 programmed activities (PA) for 167 pts, and 0.75 PA for leadership of the SHT, liaising with local haemoglobinopathy teams and a 1:9 on call commitment. The deputy had only 1.5 PAs

   b The service also 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 and the lead clinician was contacted when not on call. In addition, the lead consultant was also providing advice for the paediatric service in the absence of the paediatric lead.

   c Reviewers were concerned that the lack of capacity will become more pronounced as the cohort of patients with haemoglobin disorders rapidly expands, with doubling of service users within a two year time frame likely to continue. The potential changes in the service provided at JCUH, Middlesbrough (see trust wide section of the report) is also likely to have a significant impact.

   d The lead could not easily commit to regular HCC network MDTs as these routinely clashed with prior clinical commitments or non-working day (Fridays). In practice the lead consultant would try and attend part of the MDT when required, by briefly leaving the thrombosis clinic or dialling in to an MDT on a non-working day

Concern

2. Access to Psychology

   There was no dedicated psychology service. In practice patients were referred to a generic service which had a significant wait (9-12 months) although patients deemed to be at high need could be prioritised for more urgent review if required. However, the general psychology service would not have the relevant experience in caring for patients and families with haemoglobin disorders. Reviewers were concerned as without a dedicated psychological practitioner individuals affected by these disorders will have limited

specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition.

3. Clinical Nurse Specialist Workload

The reviewers considered that the CNS workload was not sustainable in the long term, especially as patient numbers were increasing annually, for the following reasons: -

a The absence of a psychology service and community nursing support for patients with haemoglobin disorders had resulted in the trust CNS trying to cover the community requirement alongside supporting patients wellbeing, social and financial needs.

b Formal cover for absences was not in place. Reviewers were told that there were informal arrangements with the haemophilia nurse team.

c The CNS was also spending clinical time on administrative activities and had inadequate time for MDT working, training and audit.

Further Consideration

1 Reviewers did not see any signage for red cell services in any of the areas visited on both sites. It was notable that no part of any information displayed related to red cell conditions, which has the potential to make patients with haemoglobin disorders feel less important than patients with other conditions. Lack of signage/posters/patient information in the outpatient area which is heavily branded for haemophilia. Reviewers considered that there could be posters and patient information included in the haemophilia unit as this is where routine haemoglobinopathy clinics were held and there was available space on notice boards and leaflet holders where such information and posters could be placed.

2 Patient and GP information could be enhanced and added to the end of all new patient and annual review letters.

3 The length of stay and frequent attenders audit results were limited, and reviewers considered that repeating the audit would help with planning patient management and support to areas as well as identifying if there were any specific training needs for staff in these areas.

4 It was also not clear if consultants on the non- malignant on call rota had appropriate CPD especially as seven weeks out of nine they would be providing cover on the ward and regional training covered all emergencies and was not specific to haemoglobin disorders. Providing training and learning for all consultants covering the out of hours rota and all SpRs in training to cover emergencies in sickle cell disease, thalassaemia, and rarer anaemias should be considered as well as involvement of those on the out of hours rota in the wider discussion around mortality and morbidity and complex cases.

5 CNS and Ward nurses had training in haemoglobinopathies, but a formal competence framework was not yet in place. Nursing staff on the wards visited at the Freeman Hospital (ward 35 and the Ambulatory unit), and the Medical day case unit at the RVI had competences in transfusion and cannulation but staff commented that they would value more specific training in haemoglobin disorders. Reviewers commented that any future training should include the APPG report: No one's listening: an inquiry into the avoidable deaths and failures of care for sickle cell patients in secondary care, as not all those who met the reviewing team were aware of this report and its findings.

6 The SHT had completed an audit of transfusion times, but patients who spoke to reviewers on the RVI site commented that after transfusions commenced they often experienced delays in the starting of subsequent units. Reviewers suggested that the SHT may want to explore this issue further.

7 The CNS and lead consultant reported taking on the task of recording annual review details on the NHR, which reviewers considered may be better delegated to the data support to free up specialist haematology and CNS time for more relevant activities.

8 Access to automated exchange was only during working hours (9-5 Monday-Friday). A business case and funding (Med Tech and capital funding) had been agreed for a 24/7 service which was likely to be available as a 1:6 on call rota within the next 12 /18 months.

9 Attendance at the SHT multidisciplinary team meetings (MDT) was not clear as only about 1/3rd of participants listed appear to have attended as roles were not defined. The lead consultant and CNS attended regularly but the reviewers were unsure if others listed were routinely required. Reviewers considered that it may be helpful to add the roles to the names on the attendance list to clarify this, as well as audit MDM attendance. Widening the invitation to attend MDMs for all the consultants involved in patient care would allow wider discussion, sharing of approaches and learning as especially there did not seem to be regular attendance from the LHT's .

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Commissioning

The review team had discussions with a member of the Quality Team from NHS North East and Yorkshire. Several of the issues in this report will require the active involvement of the Trust and commissioners in order to ensure that timely progress is made.

Concerns

1 Lack of Formal Escalation to Commissioners

The reviewers were concerned about the lack of escalation of issues faced by the SHTs by the Trust. From discussions with trust and commissioners representatives at the time of the visit, it did not appear that commissioners were made aware/ were aware of the issues related to the service, such as the poor compliance with the NICE Clinical Guideline on the management of acute pain , other SSQD monitoring and the inadequate staffing levels for the patient population covered.

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Membership of Visiting Team

Visiting Team		
Matty Asante-Owusu	Community Sickle Cell Matron	Whittington Health NHS Trust
Lulu Awori	Devolution, Contracts and Performance Manager	NHS England
Liz Green	Haemoglobinopathy CNS Adult	Sandwell & West Birmingham Hospitals NHS Trust
Romaine Maharaj	User Representative	United Kingdom Thalassaemia Society
Heather Rawle	Consultant Clinical and Health Psychologist	Guy's and St Thomas' NHS Foundation Trust
Michele Salter	User Representative	Sickle Cell Society UK
Christine Wright	Consultant Adult Haematologist	Sandwell & West Birmingham Hospitals NHS Trust

Clinical Leads		
Sara Stuart-Smith	Consultant Adult Haematologist	King’s College 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
Rachael Berks	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	29	62%
Specialist Haemoglobinopathy Team (SHT) Adults	45	27	61%

Specialist Haemoglobinopathy Team for Children and Young People with Haemoglobin Disorders

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

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

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	Y	The environment and facilities were child friendly hosting a range of activities such as music and art therapy. There were play specialists on the wards and within the ED. There was also a 'teenage cancer unit' on the ward that patients can access. See good practice section of the report
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	Y	Operational policy in place. Joint meetings took place with the adult CNS for paediatric patients transitioning to adult services. No 16 years or older were allowed on inpatient paediatric wards – however flexibility was described for paediatric haemato-oncology cases. Access to the teenage cancer unit was less accessible for the non-malignant haematology patients.
HC-197	**Gathering Views of Children, Young People and their Families** The service should gather the views of children, young people and their families at least every three years using: a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder' b. UKTS Survey for Parents of Children with Thalassaemia	Y	Thalassaemia and Rare Inherited Anaemias HCC patient survey closed on 15.12.2023. Results were awaited from HCC. Standard met for Sickle Cell Disease (October 2023) 19 parents + 9 children responses received. Issues identified regarding access to psychology and support groups.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	N	There was no evidence of the SHT having mechanisms in place for involving children, young people and their families in decisions about the service (b). Other aspects of the QS were met.
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The Lead consultant had 2 PAs in total for work with the SHT including direct clinical care and network-wide role (service development and liaison with other services across the network). There was no formalised deputy in place therefore the Lead was not able to attend the HCC MDTs. This was of particular concern given the relative inexperience of the lead clinician.
HC-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The Paediatric Lead Nurse was employed as 0.8WTE. There was no formal cover for absence. The role encompassed additional duties as a result of a lack of investment in other roles such as 'psychology support'.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The Lead consultant had 2PAs and an additional paediatrician had 1 PA totalling 3 PAs for a total of 111 patients across the SHT (of which 69 were local to NUTH). There was limited cover for absence (required number of PAs 3.6).
HC-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of children and young people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	N	On call cover was not always a haematologist with experience in haemoglobinopathies therefore the Lead was phoned for advice when not on call. The 1:9 rota included seven oncologists and 2 haematologists.
HC-206	**Doctors in Training** If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders.	Y	
HC-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	General nursing competencies in place however there was no evidence that staff had completed these.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	A specific psychologist for the service was not in place and the waiting list for referrals to see a neuro-psychologist was approximately 12 months. Patients could be referred to a generic service which had a significant wait of 12 months. There was some access to psychology for patients awaiting a stem cell transplant.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N	Competence framework was seen for five staff however the data had not been submitted to the HCC for the annual TCD report. There was no evidence that all competencies were complete and data was not available to show that all practitioners had each performed 40 scans annually.
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	The SHT had limited data support The admin staffing was identified as a risk on the trust wide risk register.
HC-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required: a. Social worker / benefits adviser b. Play specialist / youth worker c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Child and adolescent mental health services	N	Access to support services was minimal resulting in additional responsibility of the CNS to undertake non clinical tasks outside of the remit of the role.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	All but 'f' was in place. Access to automated exchange was only during working hours. Funding for a 24/7 provision had been agreed but at the time of the visit not in operation.
HC-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	**Y**	
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders.	N	Paediatric ED staff were not provided with specialist HD training and pain audits reported very poor compliance with emergency treatment guidelines. All patients with a sickle cell disorder had an EHCP which was accessible on the electronic patient record system and staff were able to access clinical guidelines

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HC-195)	N	Guidance document was in place however this was generic guidance that did not cover the local process as outlined within the quality standard.
HC-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for children, young people and their families.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-504	**Transcranial Doppler Ultrasound Standard Operating Procedure** A Standard Operating Procedure for Transcranial Doppler ultrasound should be in use covering at least: a. Transcranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Transcranial Doppler ultrasound (QS HC-209) d. Arrangements for ensuring staff performing Transcranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	Y	
HC-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Arrangements for accessing staff with cannulation competences f. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion g. Patient pathway for Central Venous Access Device insertion, management and removal	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible	Y	
HC-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring complications e. Indications for discontinuation	Y	
HC-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred **For children and young people with sickle cell disorder:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration **For children and young people with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by an HCC / SHT b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hrs of acute admission c. Patient discussion at local multidisciplinary team meetings (QS HC-604) d. Referral of children for TCD screening if not provided locally e. 'Fail-safe' arrangements for ensuring all children and young people have TCD ultrasound when indicated f. Arrangements for liaison with community paediatricians and with schools or colleges g. Follow up of patients who 'were not brought' h. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care i. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together j. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	Y	
HC-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HC-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HC-503) d. National Haemoglobinopathy Registry data collection (QS HC-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HC-607) (if applicable) g. Participation in HCC-agreed audits (HC-706)	N	Not currently in place however the service had plans to implement this.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when required, representatives of support services (QS HC-301).	Y	Regular MDT meetings took place however they did not have regular attendance by the LHTs
HC-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of children and young people with haemoglobin disorders b. Two-way exchange of information between hospital and community services	N	No SLA was in place however sign- posting and collaborative working with Community Services was discussed.
HC-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each SCD HCC Business Meeting (QS HC-702).	Y	Despite compliance with this standard, the leads were unable to attend this meeting regularly
HC-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each thalassaemia HCC Business Meeting (QS HC-702).	N	The SHT representatives had only been able to attend 3 out of 5 HCC Thalassemia meetings from 2021
HC-608	**Neonatal Screening Programme Review Meetings** The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results, identify issues of mutual concern and agree action.	Y	The neonatal screening programme was identified as an area of good practice, with a 0.5WTE specialist midwife employed.
HC-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	
HC-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505) b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS HC-702d).	N/A	The HCC did not have an agreed list of audits
HC-707	**Research** The service should actively participate in HCC-agreed research trials.	N/A	There were no trials that the SHT could participate in.
HC-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HC-197) compared with other services c. Results of audits (QS HC-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	This standard had not been achieved at the time of the visit.
HC-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	N	There was no evidence of review and learning. Review and learning tended to be undertaken via HCC meetings rather than locally and the team did not attend unless they had patients to present. There was no forum for the SHT and LHTs to discuss feedback, complaints, incidents etc.
HC-799	**Document Control** All information for children, young people and their families, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	Guidelines controlled

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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** Written information should be offered to patients and their carers, and should be easily available within patient areas, covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Contact interpreter and advocacy services, Patient Advice and Liaison Service (PALS), spiritual support and Healthwatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HA-199)	Y	Haemoglobinopathy service information seen for adults and contact details. No information for haemoglobinopathy specific community or specialist psychology services as these did not exist locally.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-102	**Information about Haemoglobin Disorders** Patients and their carers should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	Clinic letters included contraceptive advice, prescription information and vaccination advice, but no general information on their condition or management of pain at home. Reviewers considered that clinic letters could be expanded to cover the aspects of the quality standard.
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	Y	
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	Emergency care plan template seen and there was a clear process for triaging as a priority in ED and emergency analgesia plans were easily accessible. The plans were clear about contact details for the haemoglobinopathy CNS in working hours and triage phone number to access advice via the haemato-oncology ward was in place with options to leave a voicemail message.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	N	Clinic letters sent to primary health care team included contraceptive advice, prescription information and vaccination advice, but no general information on their condition, management of pain at home. Reviewers considered that clinic letters could be expanded to cover the aspects of the quality standard.
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	Environment and facilities were spacious and in good order but signage, information posters and patient information leaflets for patients with haemoglobin disorders were absent/not visible.
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	Y	Guidance covering transition was included in the service operational policy and trust Haemoglobinopathy Guidelines. Some information was also on the Trust website.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	Y	Sickle Cell survey last undertaken in November 2023. Eight responses were received. 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. Changes to accommodate patient feedback was the request to accommodate 7 day a week access to transfusions.
HA-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback b. Mechanisms for involving patients and their carers in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HA-797) c. Examples of changes made as a result of feedback and involvement	Y	Mechanisms for feedback were in place.
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The Lead consultant had insufficient PAs for local care and management of the SHT network, and could not easily commit to regular network MDMs as these routinely clashed with prior clinical commitments or non-working day (Fridays). In practice the lead consultant would try and attend part of the MDM when required, by briefly leaving thrombosis clinic or dialling in to an MDM on a non-working day. A named deputy was in place.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	The lead nurse (0.8 wte CNS) was post.
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The consultant on-call rota is 1:9 with ~7:9 covered by other non-malignant haematologists with no specified interest or CPD commitment to haemoglobinopathies. The on-call consultant also ward attended when on-call, meaning that the day to day management on haemoglobinopathy inpatients was primarily not covered by a haematology consultant with a specialist interest and adequate CPD in haemoglobinopathies, and patients were not usually managed by their usual consultant when admitted. Reviewers considered that the lead consultant has insufficient time in their Job Plan for haemoglobinopathies, especially as the cohort of patients with haemoglobin disorders was expanding.
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	N	On call cover was not always a haematologist with an interest in haemoglobinopathies therefore the Lead was phoned for advice when not on call. Patients were triaged out of hours by senior nurses on haemato-oncology ward . In realty most patients were then directed to the Emergency Department

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	Recent changes to the training rota had ensured a consistent 4-month attachment for SpRs including regular weekly outpatient clinic attendance.
HA-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	CNS and Ward nurses had training in haemoglobinopathies, but a formal competence framework was not yet in place. Nursing staff at the wards visited at the Freeman Hospital, PIU and Ambulatory unit had competences in transfusion and cannulation. There was no community service.
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	There was no dedicated psychology service, patients could be referred to a generic service which had a significant wait (9-12 months) although patients deemed to be at high need could be prioritised for more urgent review if required. There was no neuropsychology pathway.
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	Data support for the adult services was available. The CNS and lead consultant reported taking on the task of recording annual review details on the NHR, which reviewers considered should be delegated to data team to free up specialist haematology and CNS time for more relevant activities.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	Y	Most services were available generically through the mainstream hospital services.
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	N	All but 'f' was in place. Access to automated exchange was only during working hours. Funding for a 24/7 provision had been agreed but at the time of the visit not in operation.
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	N	Training as provided to staff working the Emergency Departments, but it was unclear about the frequency of specific haemoglobinopathy training An audit of compliance with NICE Clinical Guideline on the management of acute pain showed that 53% of patients were given pain relief within 30 mins. Compliance had increased from the previous year of 38% but was still low.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HA-195)	N	The guidance was included in the guideline compendium but was generic and had not been localised. Reviewers considered the SHT may want to develop a network guideline as the LHTS were all using different approaches to transitioning their young people to adult services. The service operational policy included the transition arrangements in place and a more detailed pathway was included in the paediatric transition guidance.
HA-502	**New Patient and Annual Review Guidelines** Guidelines or templates should be in use covering: a. First outpatient appointment b. Annual review Guidelines should cover both clinical practice and information for patients and carers.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	Y	
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	Y	

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

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	N	Guidelines did not appear to cover 'ii' and 'v'
HA-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, admission units, clinic and ward areas.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hrs of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	Y	Service organisation SOP covered' a-d' Key specialities were all co-located so 'e-f' were not relevant
HA-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HA-503) d. National Haemoglobinopathy Registry data collection (QS HA-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HA-607) (if applicable) g. Participation in HCC-agreed audits (HA-706)	N	There were no written agreements with the LHTs. In practice there was a referral guide outlining scenarios which require urgent referral and contacts to arrange advice and transfer. Clinical pathways were in place with Sunderland and Durham with the majority of annual reviews being carried out by the SHT. The Middlesborough haemoglobinopathy team appeared to function as a separate independent entity.
HA-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when requested, representatives of support services (QS HA-301).	Y	SHT MDM seemed rather poorly attended by about 1/3rd of listed participants, but no roles were defined, so it was not clear if all those listed were routinely required. The lead consultant and CNS attended regularly.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services	N	No SLA were in place covering role of community services in the care of patients with haemoglobin disorders. A north east health recover model was in the process of being developed. There was clear communication with General Practice facilitated by clinic letters and the CNS.
HA-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each Sickle Cell Disorder HCC Business Meeting (QS HA-702).	N	SHT representatives had only been able to attend 5 out of 7 meetings.
HA-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each thalassaemia HCC Business Meeting (QS HA-702).	N	The SHT representatives had only been able to attend 3 out of 5 HCC Thalassemia meetings from 2021
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	The data team registered all patients, but the clinical team were updating annual review, serious adverse events, pregnancies etc which reviewers considered could be delegated to the data team
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	Y	
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	N/A	The HCC did not have an agreed list of audits
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	A sickle retinopathy research project was in progress

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HA-197) compared with other services c. Results of audits (QS HA-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	This standard had not been achieved at the time of the visit.
HA-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	N	It was unclear from the evidence seen of MDM discussions and whether these also related to learning from complaints, serious adverse events, incidents and near misses. Staff when asked reported that these events would be discussed locally and then escalated to network or national MDM if required.
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	Version control by document date

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