MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

# Health Services for People with Haemoglobin Disorders

## West Midlands Sickle Cell Haemoglobinopathy Coordinating Centre Midlands Thalassaemia and RIA Haemoglobinopathy Coordinating Centre

## Birmingham Women's and Children's NHS Foundation Trust

Visit date: 17th May 2024

Report date: 19th September 2024

# Contents

# Introduction

This report presents the findings of the review of Birmingham Women's and Children's NHS Foundation Trust that took place on 17th May 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 Birmingham Women's and Childrens NHS Trust health economy. Appendix 2 contains the details of compliance with each of the standards and the percentage of standards met.

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

- Birmingham Women's and Children's NHS Foundation Trust
- NHS England West Midlands Region
- Birmingham and Solihull Integrated Care System
- Black County 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 Birmingham and Solihull Integrated Care Board.

## About the UKFHD and MLCSU

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

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

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

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

## Acknowledgements

The UKFHD and MLCSU would like to thank the staff and service users and carers of the Birmingham and Solihull 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

## West Midlands Sickle Cell Haemoglobinopathy Coordinating Centre and Midlands Thalassaemia and Rare Inherited Anaemias

## General Comments and Achievements

This review looked at the co-ordination of health services provided for children, young people and adults with sickle cell disorders across the West Midlands and those with Thalassaemia and Rare Inherited Anaemia (RIA) across the whole of the Midlands.

Birmingham Women's and Children's Hospital NHS Foundation Trust (BWCH) and Sandwell and West Birmingham Hospitals NHS Trust (SWBH) were collaboratively responsible for two Haemoglobinopathy Coordinating Centres (HCC) networks having gained designation in 2020, with BWCH managing the paediatric services and the adult services being managed by SWBH. The HCCs had evolved from West Midlands Sickle Cell and Thalassaemia Network (WMSTN) which had been in operation for several years and therefore relationships across the West Midlands were well established. The trusts were also designated providers of Specialist Haemoglobinopathy Teams (SHT) for their own catchment areas, adults at SWBH and children and young people at BWCH.

Although both HCCs were separate in their commissioned functions much of operational workings were joint across both HCCs, therefore the report below reflects this**.**

The West Midlands Sickle Cell HCC provided support across Herefordshire and Worcestershire, Staffordshire, Shropshire, Warwickshire and the West Midlands. There were two SHTs based at Birmingham Women's and Children's NHS Foundation Trust and Sandwell and West Birmingham Hospitals NHS Trust and local haemoglobinopathy teams (LHT) based at the following hospitals, some of which had services on more than one hospital site:- Dudley Group of Hospitals, The Royal Wolverhampton Hospitals NHS Trust, Shrewsbury and Telford Hospital NHS Trust, University Hospitals Birmingham NHS Foundation Trust, University Hospitals Coventry and Warwickshire, University Hospital North Midlands, Walsall Healthcare NHS Trust, Worcestershire Acute Hospitals NHS Trust, and Wye Valley NHS Trust.

Midlands Thalassaemia and RIA HCC covered the East and West Midlands and provided support and oversight across Derbyshire, Herefordshire and Worcestershire, Nottinghamshire, Northamptonshire, Leicestershire and Lincolnshire, Staffordshire and Shropshire. There were four SHTs based at Birmingham Women's and Children's NHS Foundation Trust Nottingham University Hospital NHS Trust, Sandwell and West Birmingham Hospitals NHS Trust and University Hospitals Leicester. Local Haemoglobinopathy Teams (LHT) were based at the following hospitals, some of which had services on more than one hospital site:- Dudley Group of Hospitals, Kettering General Hospital NHS Foundation Trust, Northampton General Hospital NHS Trust, The Royal Wolverhampton Hospitals NHS Trust, Shrewsbury and Telford Hospital NHS Trust, University Hospitals Birmingham NHS Foundation Trust University, University Hospitals Coventry and Warwickshire, University Hospitals of Derby and Burton, University Hospital North Midlands, Walsall Healthcare NHS Trust, Worcestershire Acute Hospitals NHS Trust and Wye valley NHS Trust.

As of May 2024, the total number of patients across the HCC catchment areas with hemoglobinopathies was 1768 made up of 1336 people with a sickle cell disorder (West Midlands) and 432 people with thalassaemia and rare inherited anaemias (Midlands).

Both HCCs had designated clinical leads all of whom had considerable expertise and provided representation at numerous boards and national groups. Each HCC had Leads who covered adults, children and young people to ensure that all ages had leadership representation.

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

- Adult Clinical Lead for the West Midlands Sickle Cell & Midlands Thalassaemia and RIA HCCs (3 PA but allocated to additional consultant haematologist post)
- Paediatric Lead for the West Midlands Sickle Cell & Midlands Thalassaemia and RIA HCCs (1PA)
- HCC Network Manager covering both HCCs (0.85 WTE)
- HCC Transcranial Doppler Lead (0.25 PA)
- Adult HCC Nurse Educator (0.5 WTE)
- Paediatric Nurse Educator ( 0.8 WTE)
- Paediatric HCC Network Coordinator (0.4 WTE)

Both HCCs held regular business meetings throughout the year to ensure coordinated and effective service delivery. The Sickle Cell Disease (SCD) HCC met three times a year, while the Thalassaemia & Rare Inherited Anaemias (RIA) HCC convened twice annually. These meetings were open to the entire HCC, including SHTs, LHTs, and commissioners.

During these meetings, the annual programme of work and audit programmes were agreed upon. Meetings were conducted remotely to enhance engagement across the region. The agendas included monitoring the Specialist Services Quality Dashboard (SSQD) data for both HCCs and SHTs, as well as reviewing action plans, policies, and audits to ensure continuous improvement and compliance with quality standards.

Patient engagement had been challenging for the HCCs, with difficulties in securing regular patient representatives at HCC meetings and disappointing attendance at other events. To address this, Patient Voice meetings were held quarterly. These meetings were attended by Lead Nurses and Managers, who shared information from the HCCs and gathered patient feedback to report at the HCC meetings. Despite these efforts, the overall level of patient involvement remains an area for improvement.

The HCCs had met with NHSE Midlands specialist commissioners to discuss their annual work plans and report on progress and any concerns. Meetings had also been held with local ICB commissioners.

The West Midlands SCD HCC had also completed an audit of transcranial doppler ultrasound competences during the previous 12 months which had identified issues that they had included as a risk in their gap analysis.

The West Midlands SCD HCC scheduled regional sickle cell multidisciplinary meetings (MDTs) for adults and paediatrics every two months but clinical pressures and staff vacancies had significantly impacted on joint MDT attendance. To mitigate, both SHTs, as part of their outreach work had implemented MDTs with specific LHTs on a regular basis.

The Thalassaemia and RIA HCC also held scheduled multidisciplinary meetings four times a year and had arrangements for regional teams to access advice at other times. The HCC had undertaken a review of all patients living with thalassaemia when first set up and continues to discuss issues with chelation at each meeting. The SHTs based in the East Midlands also had the opportunity to join the West Midland SHT meetings to discuss any patients with thalassaemia.

Both HCCs MDTs had arrangements for the clinical review of patients (morbidity and mortality meetings) and criteria in place for more complex patient cases to be referred to the National Haemoglobinopathy Panel MDT.

Newborn screening meetings were held biannually and regional Transcranial Doppler (TCD) meetings three times a year. The data managers met monthly to review NHR developments and discuss the practice of data entry, which had seen NHR registration across the network reaching 95%.

There was an active regional nurses forum and an adult network pharmacist had commenced in post in January 2024.

The HCC had established robust mechanisms for providing education, with dedicated education nurses for both adults and paediatrics who had developed a comprehensive education strategy. Training sessions were offered across the region to LHTs and SHTs. Education leads at both SHTs provided specialised training on

haemoglobin disorders to doctors in training and other specialty teams. However, engagement and uptake from LHTs were reported to be challenging due to workforce issues.

An annual education program was in place, which included pan-Midland virtual education resources and events. The HCCs also produced excellent educational videos for adult patients and their carers, enhancing the accessibility and quality of information available.

A regional transition program had been developed, with funding secured for an HCC transition nurse to support its implementation. This program aims to facilitate the smooth transition of patients from paediatric to adult care, ensuring continuity and consistency in their treatment.

The HCCs maintained a comprehensive website under the banner of the WMSTN, which served both HCCs. The website provided a wealth of information and resources for patients and carers, including news items and useful links. There was also a dedicated section for NHS professionals, ensuring easy access to relevant information and educational materials.

## Good Practice

1. Good working relationships across the HCC were clear and reviewers were impressed with the breadth of work and the flexibility of the HCCs to engage and support their constituent LHTS and SHTs. A range of engagement events had been held and the SCD HCC had invited the East Midlands SHTs to education sessions. Reviewers were particularly impressed with the proactive work by the clinical leads to support new consultants across the region, demonstrating their commitment to networking.
2. The regional nurses' network was very active and provided clinical support and personal mentoring for nurses either face to face or via virtual meetings. This had enabled networking across the region to be strengthened and support provided to existing and new members. The group had also worked to standardise network protocols. The meetings took place before the HCC network meetings and were well attended.
3. The HCCs demonstrated strong governance structures, including regular Multidisciplinary Team Meetings (MDTs) and a well-defined referral system. Additionally, they had developed a comprehensive annual work programme, indicating a proactive approach to service delivery and development. Reviewers commended the HCC for conducting a thorough analysis of gaps and risks, both within the HCC itself and in collaboration with the SHTs. This gap analysis, covering the period of 2024-25, identified pertinent issues and risks, enabling the HCC to implement targeted strategies for improvement and risk mitigation.
4. The HCC also had several initiatives planned to improve patient, clinical and service participation across the networks. Initiatives ranged from the recruitment of a patient engagement coordinator to work with patient groups and the funding of additional CNS time to enable them to liaise more with LHTs to support audit completion and networking. In addition, the HCC had been successful in obtaining funding for four other regional posts; two assistant psychologists, a regional transition nurse and welfare advisor.
5. The HCCs also encouraged their constituent LHTS to submit service improvement bids, which if successful, would be detailed in a service level agreement. The SLA would also include a requirement for the LHTS to engage with the HCCs and an understanding that funding could be removed should the commitment not materialise.
6. The education leads were also working on the development of an additional educational resource via Moodle, an online learning platform.
7. The WMSTN website included a wide range of educational videos for patients and their carers. Topics ranged from health tips, how to seek medical help for patients living with thalassaemia, how to manage a sickle cell crisis and sickle cell priapism, management of persistent pain and a tour video of SCAT unit at SWBH.

## Concerns

**1. LHT engagement**

Reviewers were concerned at the variability of LHT engagement across the HCCs which has the potential to lead to a lack of standardisation and assurance of care and ultimately health outcomes for patients. This will be particularly important to address as the LHTs provide services for an ever-increasing population of adults, children and young people with haemoglobin disorders with a limited workforce.

**2. 24hr Advice for adult patients across the HCC**

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

**3. Lead nurse role**

The HCC did not have a funded lead nurse role and whilst the nurse educators undertook education responsibility across both HCCs, they did not have capacity to cover other aspects of the lead nurse role. Development of a lead nurse for the HCCs would help with coordination and engagement across the HCC regions.

**4. Transcranial Doppler Ultrasound**

Reviewers were concerned that the 2022 -23 TCD annual report identified that competences were outstanding for three practitioners. There was also variable compliance with the minimum number of scans recommended that each operator carried out annually and variability in the quality of scans reported. Reviewers were also concerned that the TCD machine service status had expired at BCH. Reviewers were told that the HCC had plans to undertake an internal QA analysis and for TCD results to be available on the NHR.

## Further Consideration

1. Patient engagement was limited across the HCC and attendance at events had been reported by the HCCs as being disappointing with a theme from the regional patient survey reporting 'feedback fatigue' . Reviewers recognised the challenges faced by the HCC however improving patient engagement will be important to help improve services and promote equity for patients with haemoglobin disorders across the Midlands.
2. Patients from the LHTs had limited access to psychology via the regional referral pathway. two psychology posts had been created in 2021 (one at SWBH and one at BWCH) however, with the increase in patient numbers across the region, both psychological services did not have the capacity to offer a comprehensive service to these patients.
3. Reviewers were told that psychologists were not represented/ invited to regional network meetings.

# Birmingham Women's and Children's Hospital NHSFT

## Trust-wide General Comments

This review looked at the health services provided for children and young people with haemoglobin disorders at Birmingham Women's and Children's NHS Foundation Trust.

During the visit, reviewers attended the Birmingham Children's Hospital emergency department, wards and outpatient areas. They met with patients and carers, and with staff providing services for the local health economy.

Birmingham is the 7th most deprived local authority nationally and the most deprived local authority in the West Midlands, 42% of residents were non-white with 40% of the population were less than 25 years of age. Birmingham was also classed as a a high-prevalence area for Sickle Cell Disease, Thalassaemia, and Rare Inherited Anaemias (UK. Gov).

In total the Trust serves 755 patients with Haemoglobin Disorders, mostly sickle cell disease (SCD).

The paediatric Specialist Haemoglobinopathy Team (SHT) provided a service with LHTs in Sandwell General Hospital (Sandwell and West Birmingham Hospitals NHS Trust), The Royal Wolverhampton Hospitals NHS Trust, Shrewsbury and Telford Hospital NHS Trust, University Hospital North Midlands and University Hospitals Coventry and Warwickshire.

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 are detailed in the Children and Young People SHT section of the report.

## Trust-wide Good Practice

1. **Clinical Leadership and Team Cohesion:** The review team was impressed by the strong clinical leadership and the cohesive teamwork from clinical staff to senior management.
2. **Innovative Ophthalmology Screening Service:** The ophthalmology screening service for patients living with thalassaemia was identified as innovative practice, unique to this service.
3. **Emergency Care Pathway Development:** The development of an emergency care pathway was noted for improving the responsiveness and timeliness of pain relief for patients.
4. **Effective Emergency Care Alert Card:** The Emergency Care Alert Card was found to be well embedded and effective in practice, with positive feedback from service users.
5. **NHS England Act Now Initiative:** The NHS England Act Now initiative was being actively rolled out at BCH to enhance patient experience and clinical outcomes for children experiencing a Sickle Cell Crisis.
6. **Engagement with Other Trusts:** Engagement with other trusts across the HCC was very strong, with close collaboration, outreach clinics, and regular dialogue and meetings involving both medical and nursing staff.
7. **Outstanding Facilities:** The estates facilities were noted to be outstanding, with child-friendly and spacious environments.
8. **Day Pain Team:** The 7-Day Pain team provided an excellent service, including the provision of early patient-controlled analgesia (PCA) for patients in the ED.

## Trust Wide Immediate Risk

### 1 Birmingham Community Paediatric Haemoglobinopathy Service[1]

Reviewers identified an immediate risk to the pathway for providing a community paediatric haemoglobinopathy service for children, young people, and families in Birmingham. Approximately five years ago, Birmingham Women's and Children's Hospital NHS Foundation Trust (BWCH) was asked by Birmingham Community Healthcare (BCHC) to temporarily take on their Thalassaemia and Rare Inherited Anaemias (RIA) caseload. This arrangement was intended to allow BCHC to focus on their care of children and young people with sickle cell disease while they recruited staff to the service. Birmingham and the Black Country is a high prevalence area for sickle cell disease, thalassaemia, and RIAs. Despite the temporary nature of this arrangement, the increasing caseload of patients with haemoglobinopathies were not repatriated to BCHC. The longstanding inability to recruit staff to deliver the service was highlighted as a significant risk. Consequently, BWCH's paediatric acute service had been managing various elements of the community caseload for several years, impacting their capacity to deliver outreach services to local haemoglobinopathy teams across the region. Additionally, some of the SHT specialised commissioning funding had been diverted to deliver Birmingham and Solihull Integrated Care Board (ICB) community services.

After BCHC provided notice to discontinue this service in March 2024, BWCH submitted a bid to Birmingham and Solihull ICB commissioners to provide a comprehensive service. However, this bid was not accepted, and no rationale for the decision was communicated to the SHT. The service and its funding were subsequently transferred to Sandwell and West Birmingham NHS Trust (SWBH) in April 2024, with the remit to provide a community paediatric haemoglobinopathy service, as well as antenatal screening and follow-up.

Since April, SWBH has not been able to provide a comprehensive haemoglobinopathy paediatric community service. This service should include newborn referrals and home visits, development of care plans for children and young people, attendance at patient annual reviews, GP and patient education—particularly around admission and readmission prevention—assistance with social challenges preventing hospital discharge, and welfare support.

Reviewers were clear regarding the necessity for BWCH and ICB commissioners to collaborate in establishing a robust community children's haemoglobinopathy service. System-wide cooperation and support between Trust management, the paediatric SHT, SWBH, and ICB commissioners will be crucial in resolving these issues.

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[1] *Trust response We acknowledge the gaps in service provision referred to which are related to the long-running challenges of service sustainability. Our recent proposal to commissioners to provide an expanded service, or part thereof, was unsuccessful. With the current demands placed on our service, we are seeking to balance the patient need with the service we are commissioned and funded to do. This inherently involves an element of best endeavours and prioritisation, whilst we anticipate the appropriately commissioned service. We would welcome any feedback which would help us prioritise our limited staff and resources in the face of the current challenges and clinical need.*
*We continue to work with partners to secure effective provision of services for people with haemoglobin disorders. In particular: • We are working with SWB to identify if a partnership model with commissioner support can be put in place to deliver the paediatric community haemoglobinopathy service; • We are engaging with our ICB who have plans to conduct a commissioning exercise during this year; • We further note that SWB have plans in place to resolve the service provision for antenatal haemoglobinopathy services.*
*As your letter indicates, BWC is not commissioned to provide all of the services to which your concern relates, and those concerns can only be addressed through all partners working together and creating a shared understanding of the risks and impacts involved, and the collective action in response. We remain committed to finding solutions and identifying how BWC can play our part in resolving the gaps identified. The Trust further looks forward to receiving your full report in due course.*

*BSOL ICB Response is included in commissioning section of the report*

## Trust-Wide Concern

1. **Psychology Support:** The psychology support for the services was inadequate. At the time of the visit the 0.8 WTE Psychologist was on maternity leave, which had left the service with 1.0 WTE psychology assistant. This was insufficient to provide psychological support for patients with haemoglobinopathies and did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE qualified practitioner psychologist for every 300 patients.
2. **Timeliness of Analgesia:** Compliance with the NICE guidance 'Sickle cell disease: managing acute painful episodes in hospital' in providing pain relief in the Emergency Department was poor with only 38.3% of patients receiving pain relief within 30 minutes. However, it was acknowledged that strategies aimed at improvement had been implemented following the last audit, such as the new emergency care pathway and the introduction of a nurse educator role.
3. **Impact on Day Care from Emergency Care Pathway:** Reviewers were concerned that the implementation of the emergency care pathway had negatively affected patients attending day care, primarily due to a lack of space and staff to effectively facilitate both the emergency pathway and day care services. The Acute admission pathway pilot requires formal evaluation before considering an expansion of its hours. This evaluation is essential to ensure that any potential negative impacts on both staff and patients attending the day unit are carefully considered and mitigated.

**Views of Service Users and Carers**

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

During the visit, the review team met with three families caring for children and young people with sickle cell disease and three families caring for children and young people with thalassaemia.

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

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

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# Specialist l Haemoglobinopathy Team (Children and Young People Services)

## General Comments and Achievements

The Specialist Haemoglobinopathy Team (SHT) at BCH demonstrated exceptional leadership, innovation, and dedication in delivering outstanding service to patients and families. The team was highly motivated and adaptable, maintaining a clear vision for their goals at both the local level and for their constituent Local Haemoglobinopathy Teams (LHTs), while being acutely aware of the challenges they faced.

The SHT managed the care of 755 children and young people diagnosed with haemoglobinopathies, all registered on the National Haemoglobinopathy Register. The team was led by a Paediatric Haematology Consultant, who also served as the Haemoglobinopathy Coordinating Centre's (HCC's) lead for SCD and Thalassaemia, supported by a deputy lead consultant and a lead nurse.

The multidisciplinary team included four consultants with a combined total of 14.5 PAs which were divided among other subspecialties to ensure comprehensive patient care both in inpatient and outpatient settings, 0.8 WTE ANP, 2.6 WTE Clinical Nurse Specialists, 1.8 WTE psychology posts (0.8WTE B8 psychologist & 1WTE B5 assistant psychologist).

There was a robust and collaborative relationship between the management team and clinicians, resulting in a highly effective service network. The team was proactive in developing business cases to enhance service provision, reflecting a strong commitment to continuous improvement.

The SHT was actively committed to providing training and education to a wide range of healthcare professionals. This included medical and nursing students, nurses, doctors in training, clinical fellows, emergency department staff, junior doctors, and consultant colleagues both within and outside of haematology. Their educational reach extended to the wider network and community. A clear strategy was in place to further enhance training efforts, exemplified by the introduction of a new Nurse Educator role.

Overall, the Specialist Haemoglobinopathy Team at BCH exemplified excellence in patient care, teamwork, and professional development, setting a high standard for haemoglobinopathy services.

| CARE OF CHILDREN AND YOUNG PEOPLE | | | |
|---|---|---|---|
| Birmingham Children's Hospital | Linked Haemoglobinopathy Coordinating Centres (HCC) | | |
| | West Midlands Sickle Cell HCC<br>Midlands Thalassaemia and Rare Inherited Anaemias HCC<br>*(Both hosted by Sandwell and West Birmingham Hospitals NHS Trust in partnership with Birmingham Women's and Children's Hospital NHS Foundation Trust)* | | |
| | Linked Local Haemoglobinopathy Teams (LHT) | Patient Distribution | |
| | | SCD | Thal. |
| | Sandwell Paediatric Hospital | 58 | 8 |
| | The Royal Wolverhampton Hospitals NHS Trust | 79 | 6 |
| | Shrewsbury and Telford Hospital NHS Trust | 37 | 9 |
| | University Hospital North Midlands, | 25 | 15 |
| | University Hospitals Coventry and Warwickshire | 104 | 25 |
| **PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM** | | | |

| CARE OF CHILDREN AND YOUNG PEOPLE | | | | | | | |
|---|---|---|---|---|---|---|---|
| Birmingham Children's Hospital | Linked Haemoglobinopathy Coordinating Centres (HCC) | | | | | | |
| | West Midlands Sickle Cell HCC<br>Midlands Thalassaemia and Rare Inherited Anaemias HCC<br>*(Both hosted by Sandwell and West Birmingham Hospitals NHS Trust in partnership with Birmingham Women's and Children's Hospital NHS Foundation Trust)* | | | | | | |
| | Linked Local Haemoglobinopathy Teams (LHT) | | | | | Patient Distribution | |
| | | | | | | SCD | Thal. |
| | Sandwell Paediatric Hospital | | | | | 58 | 8 |
| | The Royal Wolverhampton Hospitals NHS Trust | | | | | 79 | 6 |
| | Shrewsbury and Telford Hospital NHS Trust | | | | | 37 | 9 |
| | University Hospital North Midlands, | | | | | 25 | 15 |
| | University Hospitals Coventry and Warwickshire | | | | | 104 | 25 |

| Condition | | Registered patients | Active patients *[2] | Annual review ** | Long-term transfusion | Eligible patients - hydroxycarbamide | In-patient admissions in last year |
|---|---|---|---|---|---|---|---|
| Sickle Cell Disease | CYP | 593 (290 BCH only) | 593 | 397 (39pts <1yr not required) | 17 | 290/410 (additional 90 offered) | 162<br>3x 20+ days (22/23) |
| Thalassaemia | CYP | 162 (97 BCH only) | 162 | 102 (9pts <1yr) (93 on NHR (67 BCH) | 115 (72 BCH only) | na | 7<br>1x 20+ days (22/23) |

**Staffing**

| Specialist Haemoglobinopathy Team | Number of patients | Actual WTE (at time of visit) |
|---|---|---|
| Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies | 755 | 4 Consultants (14.5WTE) contribute to the HBO service but have split posts with other subspecialities. |
| Clinical Nurse Specialist for paediatric patients dedicated to work with patients with hemoglobinopathies | 755 | 2.6WTE B7<br>0.8 WTE ANP |
| Clinical Psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies | 755 | 1.8WTE<br>0.8WTE B8a Psychologist (of that 0.2WTE uplift to B8b for service development)<br>1.0WTE B5 (assistant psychologist) |

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

## Urgent and Emergency Care

Prior to September 2023, all children and young people requiring acute assessment or admission at Birmingham Children's Hospital (BCH) were seen via the Emergency Department (ED). The 2022-2023 Pain Audit revealed that only 38.3% of patients received pain relief within 30 minutes of presenting with a Sickle Cell Crisis in the ED. This prompted a focus on improving education and reviewing pathways for emergency presentations.

Recognising that evidence shows centres offering direct access to haematology units can deliver pain relief more efficiently than EDs, BCH began piloting a new pathway for acute admissions to their Day Unit in September 2023. Under this pilot, patients were asked to call the haemoglobinopathy day unit between Monday and Friday from 0900-1400. Nursing staff triaged these calls using a triage proforma. If the patient needed to attend, they were assessed by a member of the haemoglobinopathy medical team or Advanced Nurse Practitioner (ANP). The triage sheets were reviewed weekly at the Multidisciplinary Team (MDT) meeting and informal feedback from patients had been very positive, leading the service to plan an extension of the operational hours during 2024. However, feedback from day unit staff indicated concerns about the impact on patients receiving day care. With no additional staffing resources allocated for this service, there were increased demands on existing staff, affecting their capacity to carry out normal duties.

In addition to the pilot, a plan to increase education for staff within the ED had been implemented. A practice education facilitator had been recruited to develop and roll out an education programme across the SHT, with ED being one of the key focuses of this initiative.

Outside of the pilot operational hours, patients presented to the ED, where they were asked to show an alert card for correct triage. Patients were initially assessed either by ED staff or by the Haemoglobinopathy (HBO) advanced nurse practitioner or benign haematology middle grade doctor before a decision to admit or discharge was made. For out-of-hours care from 1700-2100, the on-call long-day paediatric haematology middle grade doctor managed sickle and thalassaemia patient care. From 2100-0900, the hospital at night medical team took over. Every day at 8 AM, the haemoglobinopathy specialist team received an email list of patients who had attended the ED in the previous 24 hours.

General patient feedback regarding acute presentations at BCH was very positive. Patients who needed to attend the ED reported that showing their alert card ensured they were seen quickly, and they felt the ED pathway worked well, with prompt attention from a haematology team member. The only issue identified was delays in being admitted to an appropriate ward.

Most unwell patients were admitted via the haemoglobinopathy day unit or the ED to an inpatient paediatric ward. Others were transferred directly to ward 18 or intensive care from local centres.

## In-patient Care

Emergency admissions for haemoglobinopathy patients were directed to Ward 18, though bed capacity had often necessitated the use of other wards throughout the hospital. A recent audit of admissions to inappropriate wards had revealed that haemoglobinopathy patients were admitted to the haematology wards (Wards 18/19) in 32% of cases, paediatric medicine wards in 57% of cases, and surgical wards in 11% of cases. The service identified two non-haematology wards, Ward 15 and the Paediatric Assessment Unit (PAU), for targeted education due to the higher concentration of patients admitted there. Feedback from families treated on non-haematology wards was less positive compared to those on the haematology wards.

Children admitted to BCH were regularly reviewed by the advanced nurse practitioner and the paediatric haematology ward medical team, supervised by one of the Paediatric Haematology Consultants. All patients were seen by a senior haematology decision-maker within 14 hours of admission. For complications requiring specialist input, advice from an Haemoglobinopathy Consultant was sought if they were not carrying out ward duties. Dedicated middle-grade haematology on-site cover is available from 0900-2100 each day, while Consultant Haematology cover is provided 24/7, including daily weekend ward rounds. The hospital pain team

offers seven-day cover and daily ward rounds, with out-of-hours cover provided by the on-call anaesthetic team.

During the review, the reviewers visited the wards and observed that the facilities were new, clean, child-friendly, and spacious, offering excellent amenities for children. Visiting hours were unrestricted during the day, and one parent was allowed to stay overnight with their child. The environment was welcoming, and staff were very friendly. The ward sister was very passionate about patient care and supporting families through difficult times.  Play specialists were observed actively engaging children in the play area of the ward.

Feedback from patients regarding ward care was generally very positive. However, one patient noted that on occasions some professionals made discouraging comments such as "you don't look as though you are in that much pain" or "you don't look that unwell."

## Day care

The haemoglobinopathy Day Unit operated Monday to Friday, providing dedicated nurse-led care. It serves 6-7 patients on a transfusion programme daily, managing their crossmatch, cannulation, and transfusions. Additionally, patients requiring regular exchange transfusions also attend this unit. As detailed earlier, the unit has been utilised for the "unwell pathway" pilot from Monday to Friday 9am to 2pm.

Located within the haematology area of the hospital, the unit was child-friendly and inviting. It featured play specialists and facilities to keep children occupied during their treatment. Parents accompanying their children provided extremely positive feedback about the service. They appreciated the opportunity to socialise with other parents, forming lifelong friendships and support networks. The unit offered refreshments and a comfortable area for parents to sit and observe their children while they played and received treatment.

Staff were knowledgeable, supportive, and flexible in accommodating the needs of patients and their families. However, they did raise concerns about the impact on their capacity to deliver day care services due to the additional demands of the new 'unwell patient' pathway pilot.

## Outpatients

The SHT offered a comprehensive range of outpatient clinics, operating from the outstanding facilities within the haematology area at Birmingham Children's Hospital (BCH). These clinics were designed to provide specialised care and support for patients with haemoglobinopathies.

Weekly annual review clinics were an essential component of the outpatient services. These included dedicated clinics for thalassaemia, which took place in the first week of each month, and for sickle cell disorders, held every week. These review sessions were conducted by a Haematology or Haemoglobinopathy Consultant and a Clinical Nurse Specialist (CNS), ensuring thorough and expert evaluations.

In addition to the annual review clinics, the SHT held weekly consultant clinics, which were available both face-to-face and virtually, providing flexible options for patient consultations. Weekly nurse-led hydroxycarbamide clinics were conducted virtually, offering patients ongoing management and support for their treatment regimens. Moreover, the team facilitates Transcranial Doppler (TCD) clinics three times a month, focusing on the prevention and early detection of complications related to sickle cell disorders. Specialist clinics in collaboration with the endocrinology and neurology departments further enhance the comprehensive care provided to patients.

Beyond the primary BCH location, the SHT extended its services through joint outreach clinics. These clinics, held at varying frequencies, were conducted in partnership with LHTs in Coventry, Wolverhampton, Sandwell, Stoke, and Telford. This outreach service ensured that patients across the region had access to the specialised care they needed, reinforcing the SHT's commitment to comprehensive and accessible patient care.

## Community-based Care

**Birmingham/Solihull:** Birmingham/Solihull Community-based Care provision was identified as an immediate risk in the HCC region during the visit (see immediate risk section).

**Sandwell, Stoke-on-Trent, and Worcester**: There was no dedicated community nursing support in Sandwell therefore outreach services were provided by the BCH team. At the time of the review, funding applications had been submitted for additional hospital-based CNSs to fill these gaps.

**Shropshire:** The local hospital CNS in Shropshire provides some outreach for local patients. A funding application for a 0.5 WTE hospital-based CNS to fill this gap has been submitted.

**Coventry**: In Coventry, the hospital CNS team provided outreach for local patients.

**Wolverhampton/Walsall:** For patients in Wolverhampton and Walsall, the hospital CNS team provided outreach in conjunction with community support from the Wolverhampton Sickle Cell and Thalassaemia Support Project.

## Views of Service Users and Carers

**Service user Feedback**

The review team met three families caring for children and young people with sickle cell disease and three families caring for children and young people with thalassaemia.

**Sickle Cell Service User Feedback**

The SCD feedback was provided by three parents, two parents with children with sickle cell disease and one parent of three young adults who had experience of service at BWCH. Some of those who joined the meeting for adults also provided some feedback of their experience at BWCH.

- **Informed Care:** Parents reported feeling fully informed about their children's conditions, receiving letters following consultations that were also sent to their child's GP, along with text message updates.
- **Positive Experiences:** One parent praised the continuity of care from diagnosis to the present, describing it as "absolutely excellent" and noting effective pain management for their child.
- **Ward Care**: While care on the ward was generally good, some parents encountered professionals making unhelpful comments such as "you don't seem to be in that much pain" or "you don't look that unwell."
- **Empowerment:** One parent emphasised the importance of empowering their child to cope with their condition, encouraging them to engage in activities they felt capable of doing.
- **Support Groups:** The local support group, OSCAR, was mentioned as a useful and supportive resource.
- **Transition to Adult Care:** The transition from paediatric to adult care was generally well planned. Children visited the adult service at SWBH, and while parents of young adults noticed a decrease in support levels, they understood this shift to adult care. However, some parents found it challenging when they were no longer allowed to attend appointments once their child turned 16.
- **Care Plans and Community Nurse Support**: All children had care plans, and parents spoke highly of the CNS (Susie), who provided valuable advice and support.
- **Annual TCDs**: The process for booking and receiving results of annual TCDs worked well. For those with HSS, TCDs ceased at age 12 due to a lower risk of stroke, which parents understood but still caused some concern, perceiving it as a resource issue.

- **Emergency Department (ED) Pathway**: When attending the ED, parents would show an alert card and be seen quickly by a member of the haematology team. However, delays in being admitted to an appropriate ward were noted as an issue.
- **Psychology Services**: Parents were uncertain about the availability of psychology services

**Thalassaemia Service User Feedback**

The Thalassaemia feedback was provided by three Parents, one with two children living with thalassaemia and two with one child living with thalassaemia.

- **Information and Understanding**: Patients and parents feel well-informed and understand their conditions. They report that necessary investigations and monitoring have been conducted.
- **Positive Experiences**: Feedback on the care received has been overwhelmingly positive. The BCH ED pathway is highlighted as effective, often bypassing local services for more direct care.
- **Support from CNS**: Patients and parents are satisfied with the ability to contact the Clinical Nurse Specialist (CNS) for any queries.
- **Communication**: Patients receive copies of all communications sent to their GPs, ensuring they stay informed about their medical care.
- **Satisfaction and Suggestions**: When asked what they would change, respondents stated they wouldn't change a thing. They praised the nurses, found the facilities comfortable, and appreciated the option for food vouchers from the canteen. However, they suggested that more activities for young people would be beneficial, especially since DVDs are no longer available.
- **Transition to Adult Care**: One child transitioning to adult care expressed concerns about their visit to City Hospital due to the clientele and police presence at the ED entrance. The young person also suggested that more visits and opportunities to meet with peers of similar age or those recently transitioned would be helpful.

## Good Practice

1. **Clinical Leadership and Team Cohesion:** The review team was impressed by the strong clinical leadership and the cohesive teamwork from floor staff to senior management.
2. **Innovative Ophthalmology Screening Service:** The ophthalmology screening service for thalassaemia patients was identified as innovative practice, unique to this service.
3. **Regional Transitional Video:** The use of a regional transitional video to assist patients moving from paediatric to adult services was highlighted as an example of good practice.
4. **Wolverhampton Model:** The Wolverhampton model within the Haemoglobinopathy Coordinating Centre (HCC), which provides collaborative support with acute trust providers, was recognized as an exemplary service, especially for its coverage of Wolverhampton and Walsall.
5. **Emergency Care Pathway Development:** The development of an emergency care pathway was noted for improving the responsiveness and timeliness of pain relief for patients.
6. **Effective Emergency Care Alert Card:** The Emergency Care Alert Card was found to be well embedded and effective in practice, with positive feedback from service users.
7. **NHS England Act Now Initiative:** The NHS England Act Now initiative is being actively rolled out at BCH to enhance patient experience and clinical outcomes for children experiencing a Sickle Cell Crisis.

8. **Engagement with Other Trusts:** Engagement with other trusts across the HCC is very strong, with close collaboration, outreach clinics, and regular dialogue and meetings involving both medical and nursing staff.
9. **Outstanding Facilities:** The estates facilities were noted to be outstanding, with child-friendly and spacious environments.
10. **Nurse Educator Role:** A nurse educator role had been introduced across the HCC, focusing on educating key areas about haemoglobinopathies. Significant progress had been made in planning and training development since the Clinical Nurse Specialist (CNS) took on the Patient Education role, with commendable performance.
11. **7-Day Pain Team:** The 7-Day Pain team provided an excellent service, including early patient-controlled analgesia (PCA) for patients in the ED.
12. **Proactive Development of Services:** There was clear evidence of efforts to achieve outstanding practice and address gaps proactively through the development of business cases and new initiatives. An example was the new welfare/benefits advisor post that has been funded and was actively being recruited.
13. **Innovative Use of Virtual Reality (VR) Headsets:** The provision of VR headsets for patient distraction during transfusions and venepuncture was identified as an innovative and evidence-based practice.
14. **Nurse Forum:** The lead nurse had established a forum specifically for nurses across the HCC. While nurses already attended other HCC meetings, the purpose of this dedicated nurse forum was to provide targeted support and facilitate open discussions among Clinical Nurse Specialists (CNSs). This setting encouraged more specific and candid conversations, ensuring that nurses had a platform where they felt comfortable sharing their insights and concerns.

## Immediate Risk: See trust wide immediate risk section of the report

## Concerns

1. **Psychology Support for the service**: The psychology capacity for the service was inadequate. At the time of the visit the 0.8 WTE specialist psychologist was on maternity leave, leaving only a 1.0 WTE psychology assistant with support from the general psychology team. If the service was at full establishment, it was still insufficient to provide a comprehensive psychological service and did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE qualified practitioner psychologist for every 300 patients. Reviewers were concerned that the lack of specialist psychology for children and young people may result in them having difficulties in coping with challenges associated with their condition'.
2. **Access to Analgesia in the ED:** Compliance with providing pain relief standards in the Emergency Department was poor with only 38.3% of patients receiving pain relief within 30 minutes. Work had been undertaken to improve compliance since the last audit by implementing a new emergency care pathway and the introduction of a nurse educator role, however compliance remained sup optimal.
3. **Impact on Day Care from Emergency Care Pathway**: Reviewers were concerned that the implementation of the emergency care pathway had negatively affected patients attending day care, primarily due to a lack of space and staff to effectively facilitate both the emergency pathway and day care services. The Acute admission pathway pilot required formal evaluation before considering an expansion of its hours. This evaluation is essential to ensure that any potential negative impacts on both staff and patients attending the day unit are carefully considered and mitigated.
4. **Transcranial Doppler Ultrasound:** Reviewers expressed concerns regarding the 2022-23 TCD annual report, which indicated that three practitioners had not yet achieved the required competences. Additionally, compliance with the recommended minimum number of annual scans varied among operators. Another issue highlighted was that the service status of the TCD machine at the trust had expired in in March 2024.

Reviewers were informed that the SHT plans to conduct an internal quality assurance analysis and ensure that TCD results are accessible on the NHR.

## Further Considerations

No further considerations were identified

# Commissioning

The review team had discussions with the regional NHSE regional specialist commissioner and three representatives from local commissioners from the Birmingham & Solihull and Black Country ICBs. The NHSE regional specialist commissioner had a good relationship with the HCC/SHTs in terms of agreeing the work programme and review of the APPG report findings. This had resulted in additional funding to support LHTs. Further collaboration was planned between NHSE and ICB commissioners to ensure the seamless delegation of specialist commissioning for the HCC/SHTs.

Several of the issues in this report will require the active involvement of the Trust leadership team, with clinical involvement and commissioners to ensure that timely progress is made.

## Commissioning Immediate Risk

**Birmingham Community Paediatric Haemoglobinopathy Service[3]**

Reviewers identified an immediate risk to the pathway for providing a community paediatric haemoglobinopathy service for children, young people, and families in Birmingham. Approximately five years ago, Birmingham Women's and Children's Hospital NHS Foundation Trust (BWCH) was asked by Birmingham Community Healthcare (BCHC) to temporarily take on their Thalassaemia and Rare Inherited Anaemias (RIA) caseload. This arrangement was intended to allow BCHC to focus on their care of children and young people with sickle cell disease while they recruited staff to the service. Birmingham and the Black Country is a high prevalence area for sickle cell disease, thalassaemia, and RIAs. Despite the temporary nature of this arrangement, the increasing caseload of patients with haemoglobinopathies were not repatriated to BCHC. The longstanding inability to recruit staff to deliver the service was highlighted as a significant risk. Consequently, BWCH's paediatric acute service had been managing various elements of the community caseload for several years, impacting their capacity to deliver outreach services to local haemoglobinopathy teams across the region. Additionally, some of the SHT specialised commissioning funding had been diverted to deliver Birmingham and Solihull Integrated Care Board (ICB) community services.

After BCHC provided notice to discontinue this service in March 2024, BWCH submitted a bid to Birmingham and Solihull ICB commissioners to provide a comprehensive service. However, this bid was not accepted, and

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*[3] As noted in the letter, the service for the Sickle Cell and Thalassemia Service transferred from Birmingham Community Healthcare NHS Trust (BCHC) to Sandwell and West Birmingham NHS Trust (SWB), after BCHC had served notice on the service. The transfer occurred on 1st March 2024. Our intention has always been to enable a transfer of the existing service initially, with a view to undertaking a commissioning exercise to review the service, and ultimately deliver improvements to it. The proposed commissioning process will include:*
*•Needs assessment. Options appraisal. Specification development.• Engagement.• Review of engagement and finalise specification.• Mobilisation plan.*
*The plan is to still carry out the commissioning exercise in partnership with the system as originally intended. This will commence by August 2024, allowing time for us to engage with SWB on their early experiences of running the service. The aim is that the needs assessment and options appraisal will be completed by November 2024, ready for system and stakeholder engagement in December 2024. This is about setting the long-term strategy and plan for the service to meet current and future population need.*
*Clearly the Peer Review has highlighted specific immediate challenge about the antenatal and paediatric community service. This had already been identified and SWB are committed to finding a solution with partners. An interim solution to stabilise the service is being explored with SWB as the provider of the service.*
*We look forward to receiving a full copy of the draft report and are committed to responding to the findings as appropriate, and a clear system action plan. As part of sharing the draft report, we would appreciate some clarity regarding the publication arrangements.*

BWCH Response is included in the trust wide section of the report

no rationale for the decision was communicated to the SHT. The service and its funding were subsequently transferred to Sandwell and West Birmingham NHS Trust (SWBH) in April 2024, with the remit to provide a community paediatric haemoglobinopathy service, as well as antenatal screening and follow-up.

Since April, SWBH has not been able to provide a comprehensive haemoglobinopathy paediatric community service. This service should include newborn referrals and home visits, development of care plans for children and young people, attendance at patient annual reviews, GP and patient education—particularly around admission and readmission prevention—assistance with social challenges preventing hospital discharge, and welfare support.

Reviewers were clear regarding the necessity for BWCH and ICB commissioners to collaborate in establishing a robust community children's haemoglobinopathy service. System-wide cooperation and support between Trust management, the paediatric SHT, SWBH, and ICB commissioners will be crucial in resolving these issues.

## Commissioning Concern

From discussions with trust staff and commissioners, reviewers were concerned that decisions around some of the serious issues raised in this report were the result of the lack of collaborative decision making. To address the issues in this report, it will require active collaboration between the clinical team, trust management, integrated care boards and NHSE specialised commissioners, ensuring that timely progress is made.

# Appendix 1 - Membership of Visiting Team

## Birmingham Women's and Childrens NHS Foundation Trust & HCCs

| Visiting Team | | |
|---|---|---|
| Janine Younis | Paediatric Consultant Haematologist | Whittington Health NHS Trust |
| Louise Smith | Sickle Cell, Thalassaemia & RIA CNS | Alder Hey Children's Hospital NHS Foundation Trust |
| Edith Aimiuwu | Roald Dahl Paediatric Haemoglobinopathy CNS | Whittington Health NHS Trust |
| John James | User Representative | Sickle Cell Society |
| Gabriel Theophanous | User Representative | UK Thalassaemia Society |

## Sandwell and West Birmingham Hospitals Trust & HCCs

| Visiting Team | | |
|---|---|---|
| Emma Drašar | Consultant Haematologist | Whittington Health NHS Trust |
| Carol Edwards | Paediatric and Antenatal Sickle Cell Clinical Nurse Specialist | Croydon Health Services NHS Trust |
| Ioanna Ampati | Principle Psychologist | North East London NHS Foundation Trust |
| Funmi Dairo | User Representative | Liverpool Sickle Cell and Thalassaemia Support Group |
| Roanna Maharaj | User Representative | UK Thalassaemia Society |

| Clinical Leads | | |
|---|---|---|
| Sabiha Kausar | Paediatric Consultant Haematologist | Manchester University NHS Foundation Trust |
| Clare Samuelson | Consultant Haematologist | Sheffield Teaching Hospital NHS Foundation Trust |

| MLCSU Team | | |
|---|---|---|
| Rachael Berks | Clinical lead | NHS Midlands & Lancashire |
| Sarah Broomhead | Professional Lead | NHS Midlands & Lancashire |

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# Appendix 2 - Compliance with the Quality Standards

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

## Percentage of Quality Standards met

| Service | Number of Applicable QS | Number of QS Met | % Met |
|---|---|---|---|
| West Midlands Sickle Cell Haemoglobinopathy Coordinating Care Centre - All Ages | 13 | 11 | 77% |
| Midlands Thalassaemia and Rare Inherited Anaemias Haemoglobinopathy Coordinating Care Centre - All Ages | 11 | 9 | 82% |
| Specialist Haemoglobinopathy Team (SHT) Children and Young People | 49 | 44 | 90% |

## West Midlands Sickle Cell - Haemoglobinopathy Coordinating Care Centre - All Ages

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-198S | **Network-wide Involvement of Children, Young People and Families (SCD)**<br>The Sickle Cell Disorder HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702). | Y | Regular patient voice meetings had been held and the HCC were relaunching their patient engagement strategy to encourage wider representation at HCC meetings. |
| H-201 | **Lead Consultant**<br>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available. | Y | Lead consultants had been designated for both adults and paediatrics |
| H-202 | **Lead Nurse**<br>A lead nurse should be available with:<br>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders<br>b. Responsibility for liaison with other services within the network<br>c. Competences in caring for people with haemoglobin disorders<br>The lead nurse should have appropriate time for their leadership role and cover for absences should be available. | N | See HCC concern, page 10 |
| H-202A | **Lead Manager**<br>A lead manager should be available with:<br>a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs<br>b. Responsibility for liaison with other services within the network | Y | |

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| | c. The lead manager should have appropriate time for their role. | | |
| H-203 | **Lead for Transcranial Doppler Ultrasound**<br>The HCC should have a nominated lead for Transcranial Doppler Ultrasound screening. | Y | |
| H-602S | **HCC Service Organisation (SCD)**<br>A Sickle Cell Disorder HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including:<br>a. Telephone or email advice for outpatient and inpatient care<br>b. Advice on emergencies outside of normal working hours | N | For adults there was no formal arrangement to provide advice out of normal working hours. In practice the adult consultants at SWBH would be contacted.<br>A service operational policy was in place. There were arrangements in place to provide advice from the paediatric team at BWCH. |
| H-605S | **HCC Multidisciplinary Discussion (SCD)**<br>MDT meetings for the discussion of more complex patients with sickle cell disorder should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use. | Y | HCC MDTS where LHTS could discuss more complex patients took place every two months though the annual report suggested that clinical pressures and staff vacancies had impacted on attendance. To mitigate the LHTs also had the option to seek advice via the SHT led MDTs which were held with specific LHTs around the region. |
| H-609 | **NHS Blood and Transplant Liaison**<br>The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies. | Y | |

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

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-704 | **Transcranial Doppler (TCD) Monitoring Report**<br>The HCC TCD lead should monitor and review at least annually:<br>a The list of staff undertaking TCD ultrasound and whether they have undertaken 40 procedures in the last year (QS HC-209)<br>b Results of internal quality assurance systems (QS HC-504)<br>c Results of National Quality Assurance Scheme (NQAS) for TCD ultrasound (when established) or local peer review arrangements (until NQAS established)<br>d Number of TCD ultrasounds performed and the number of abnormal TCDs across the network<br>e Whether any changes to the TCD Standard Operating Procedure (QS HC-504) are required | N | TCD Annual Report 2022/23 had been completed but identified a number of issues around recording of competences, quality assurance and service status of machines. |
| H-707 | **Research**<br>The HCC should have agreed a list of research trials available to all patients within the network and SHTs should actively participate in these trials. | Y | |
| H-799 | **Document Control**<br>All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | |

## Midlands Thalassaemia & RIA Haemoglobinopathy Coordinating Care Centre - All Ages

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-198T | **Network-wide Involvement of Children, Young People and Families (Th)**<br>The Thalassaemia HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702). | Y | Regular patient voice meetings had been held and the HCC were relaunching their patient engagement strategy to encourage wider representation at HCC meetings. |
| H-201 | **Lead Consultant**<br>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available. | Y | Lead consultants had been designated for both adults and paediatrics |
| H-202 | **Lead Nurse**<br>A lead nurse should be available with:<br>a Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders<br>b Responsibility for liaison with other services within the network<br>c Competences in caring for people with haemoglobin disorders<br>The lead nurse should have appropriate time for their leadership role and cover for absences should be available. | N | See HCC concern page 10 |

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-202A | **Lead Manager**<br>A lead manager should be available with:<br>a Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs<br>b Responsibility for liaison with other services within the network<br>c The lead manager should have appropriate time for their role. | Y | |
| H-602T | **HCC Service Organisation (Th)**<br>A Thalassaemia HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including:<br>a Telephone or email advice for outpatient and inpatient care<br>b Advice on emergencies outside of normal working hours | N | For adults there was no formal arrangement to provide advice out of normal working hours. In practice the adult consultants at SWBH would be contacted.<br>A service operational policy was in place.<br>There were arrangements in place to provide advice from the paediatric team at BWCH. |
| H-605T | **HCC Multidisciplinary Discussion (Th)**<br>MDT meetings for the discussion of more complex patients with thalassaemia should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use. | Y | Four HCC MDTs had taken place. |
| H-609 | **NHS Blood and Transplant Liaison**<br>The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies. | Y | |

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-702T | **HCC Business Meetings (Th)**<br>The Thalassaemia HCC should organise at least two meetings each year with its referring SHTs and LHTs to:<br>a Agree network-wide information for patients and carers of all ages<br>b Agree network-wide policies, procedures and guidelines, including revisions as required<br>c Agree the annual network education and training programme<br>d Agree the annual network audit plan, review results of network audits undertaken and agree action plans<br>e Review and agree learning from any positive feedback or complaints involving liaison between teams<br>f Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams<br>g Review progress with patient experience and clinical outcomes (QS H-797) across the network and agree any network-wide actions to improve performance<br>h Consider the TCD annual monitoring report and agree any actions required (QS H-704) | Y | |
| H-703 | **HCC Annual Programme of Work**<br>The HCC should meet with their commissioners at least annually in order to:<br>a Review progress on the previous year's annual programme of work<br>b Review progress with improving patient experience and clinical outcomes across the network (QS H-797)<br>c Agree the annual programme of work for the forthcoming year | Y | |

| Ref. | Quality Standards | Met? Y/ N | Reviewer Comment |
|---|---|---|---|
| H-707 | **Research**<br>The HCC should have agreed a list of research trials available to all patients within the network and SHTs should actively participate in these trials. | Y | |
| H-799 | **Document Control**<br>All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | Trust governance of polices had required the SHT/HCC to develop SWBH versions the guidance that was available to stakeholders across the region. |

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## Specialist Haemoglobinopathy Team for Children and Young People with Haemoglobin Disorders

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

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

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

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-194 | **Environment and Facilities**<br>The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients. | Y | |
| HC-195 | **Transition to Adult Services**<br>Young people approaching the time when their care will transfer to adult services should be offered:<br>a. Information and support on taking responsibility for their own care<br>b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services<br>c. A named coordinator for the transfer of care<br>d. A preparation period prior to transfer<br>e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care<br>f. Advice for young people leaving home or studying away from home including:<br>i. Registering with a GP<br>ii. How to access emergency and routine care<br>iii. How to access support from their specialist service<br>iv. Communication with their new GP | Y | |
| HC-197 | **Gathering Views of Children, Young People and their Families**<br>The service should gather the views of children, young people and their families at least every three years using:<br>a. 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder'<br>b. UKTS Survey for Parents of Children with Thalassaemia | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-199 | **Involving Children, Young People and Families**<br>The service's involvement of children, young people and their families should include:<br>a. Mechanisms for receiving feedback<br>b. Mechanisms for involving children, young people and their families in:<br>i. Decisions about the organisation of the service<br>ii. Discussion of patient experience and clinical outcomes (QS HC-797)<br>c. Examples of changes made as a result of feedback and involvement | Y | |
| HC-201 | **Lead Consultant**<br>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available. | Y | |
| HC-202 | **Lead Nurse**<br>A lead nurse should be available with:<br>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders<br>b. Responsibility for liaison with other services within the network<br>c. Competences in caring for children and young people with haemoglobin disorders<br>The lead nurse should have appropriate time for their leadership role and cover for absences should be available. | Y | |
| HC-204 | **Medical Staffing and Competences: Clinics and Regular Reviews**<br>The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
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| HC-205 | **Medical Staffing and Competences: Unscheduled Care**<br>24/7 consultant and junior staffing for unscheduled care should be available.<br>**SHTs and HCCs only:**<br>A consultant specialising in the care of children and young people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available. | Y | |
| HC-206 | **Doctors in Training**<br>If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders. | Y | |
| HC-207 | **Nurse Staffing and Competences**<br>The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including:<br>a. Clinical nurse specialist/s with responsibility for the acute service<br>b. Clinical nurse specialist/s with responsibility for the community service<br>c. Ward-based nursing staff<br>d. Day unit (or equivalent) nursing staff<br>e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | N | A competence framework was not yet in place to assess competences. The adapted RCN competencies framework was in place and there was a training plan to achieve within the next two years. |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
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| HC-208 | **Psychology Staffing and Competences**<br>The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including:<br>a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care<br>b. Time for input to the service's multidisciplinary discussions and governance activities<br>c. Provision of, or arrangements for liaison with and referral to, neuropsychology<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | N | There was insufficient psychology time for the number of patients |
| HC-209 | **Transcranial Doppler Ultrasound Competences**<br>Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available. | N | Not all the practitioners had up to date competences in place |
| HC-299 | **Administrative, Clerical and Data Collection Support**<br>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service. | Y | |
| HC-301 | **Support Services**<br>Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required:<br>a. Social worker / benefits adviser<br>b. Play specialist / youth worker<br>c. Dietetics<br>d. Physiotherapy (inpatient and community-based)<br>e. Occupational therapy<br>f. Child and adolescent mental health services | N | Agreement had been agreed to fund a welfare advisor however at the time of the visit this support was not in place for children young people and their families |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
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| HC-302 | **Specialist Support**<br>Access to the following specialist staff and services should be easily available:<br>a. DNA studies<br>b. Genetic counselling<br>c. Sleep studies<br>d. Diagnostic radiology<br>e. Manual exchange transfusion (24/7)<br>f. Automated red cell exchange transfusion (24/7)<br>g. Pain team including specialist monitoring of patients with complex analgesia needs<br>h. Level 2 and 3 critical care | Y | |
| HC-303 | **Laboratory Services**<br>UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available. | Y | |
| HC-304 | **Urgent Care – Staff Competences**<br>Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders. | Y | |
| HC-501 | **Transition Guidelines**<br>Guidelines on transition to adult care should be in use covering at least:<br>a. Age guidelines for timing of the transfer<br>b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care<br>c. Allocation of a named coordinator for the transfer of care<br>d. A preparation period and education programme relating to transfer to adult care<br>e. Communication of clinical information from paediatric to adult services<br>f. Arrangements for monitoring during the time immediately after transfer to adult care<br>g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable)<br>h. Responsibilities for giving information to the young person and their family or carer (QS HC-195) | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-502 | **New Patient and Annual Review Guidelines**<br>Guidelines or templates should be in use covering:<br>a. First outpatient appointment<br>b. Annual review<br>Guidelines should cover both clinical practice and information for children, young people and their families. | Y | |
| HC-504 | **Transcranial Doppler Ultrasound Standard Operating Procedure**<br>A Standard Operating Procedure for Transcranial Doppler ultrasound should be in use covering at least:<br>a. Transcranial Doppler modality used<br>b. Identification of ultrasound equipment and maintenance arrangements<br>c. Identification of staff performing Transcranial Doppler ultrasound (QS HC-209)<br>d. Arrangements for ensuring staff performing Transcranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year<br>e. Arrangements for recording and storing images and ensuring availability of images for subsequent review<br>f. Reporting format<br>g. Arrangements for documentation and communication of results<br>h. Internal systems to assure quality, accuracy and verification of results | Y | |

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

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

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

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

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-603 | **Shared Care Agreement with LHTs**<br>A written agreement should be in place with each LHT covering:<br>a. Whether or not annual reviews are delegated to the LHT<br>b. New patient and annual review guidelines (QS HC-502) (if annual reviews are delegated)<br>c. LHT management and referral guidelines (QS HC-503)<br>d. National Haemoglobinopathy Registry data collection (QS HC-701)<br>e. Two-way communication of patient information between HCC / SHT and LHT<br>f. Attendance at HCC business meetings (HC-607) (if applicable)<br>g. Participation in HCC-agreed audits (HC-706) | Y | |
| HC-604 | **Local Multidisciplinary Meetings**<br>MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when required, representatives of support services (QS HC-301). | Y | |
| HC-606 | **Service Level Agreement with Community Services**<br>A service level agreement for support from community services should be in place covering, at least:<br>a. Role of community service in the care of children and young people with haemoglobin disorders<br>b. Two-way exchange of information between hospital and community services | N | A service level agreement with the community service was not in place to provide community care, see immediate risk section of the report |
| HC-607S | **HCC Business Meeting Attendance (SCD)**<br>At least one representative of the team should attend each SCD HCC Business Meeting (QS HC-702). | Y | |
| HC-607T | **HCC Business Meeting Attendance (Th)**<br>At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HC-702). | Y | |
| HC-608 | **Neonatal Screening Programme Review Meetings**<br>The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results, identify issues of mutual concern and agree action. | Y | |

| Ref. | Quality Standards (Children) | Met? Y/ N/ | Reviewer Comment |
|---|---|---|---|
| HC-701 | **National Haemoglobinopathy Registry**<br>Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed. | Y | |
| HC-705 | **Other Audits**<br>Clinical audits covering the following areas should have been undertaken within the last two years:<br>a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HC-505)<br>b. Acute admissions to inappropriate settings, including feedback from children, young people and their families and clinical feedback on these admissions | Y | |
| HC-706 | **HCC Audits**<br>The service should participate in agreed HCC-specified audits (QS HC-702d). | Y | |
| HC-707 | **Research**<br>The service should actively participate in HCC-agreed research trials. | Y | |
| HC-797 | **Review of Patient Experience and Clinical Outcomes**<br>The service's multidisciplinary team, with patient and carer representatives, should review at least annually:<br>a. Achievement of Quality Dashboard metrics compared with other services<br>b. Achievement of Patient Survey results (QS HC-197) compared with other services<br>c. Results of audits (QS HC-705):<br>i. Timescales and pathway for regular transfusions<br>ii. Patients admitted to inappropriate settings<br>Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored. | Y | |
| HC-798 | **Review and Learning**<br>The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'. | Y | |

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

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