# Health Services for People with Haemoglobin Disorders

## West London Haemoglobinopathy Coordinating Centre

## Imperial College NHS Trust

Visit Date: 22nd January 2025

Report Date: 23rd June 2025

# Contents

## Introduction

This report presents the findings of the review of Imperial College Healthcare NHS Trust that took place on the 22nd January 2025.

The purpose of the visit was to review compliance with the Health Service for People with Haemoglobin Disorders Quality Standards Version 5.2, November 2023 which were developed by the Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit were organised by the Nursing and Urgent Care Team (NUCT) at NHS Midlands and Lancashire (ML). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

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

A comprehensive peer review for Local Haemoglobinopathy Teams (LHT) against the Local Haemoglobinopathy Team Quality Standards were not part of the 2023-2025 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 the report identifies the main issues raised during the course of the visit. Any immediate risks identified will include the Trust and UKFHD/NUCT ML response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in Imperial College 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:

- Imperial College Healthcare NHS Trust
- NHS London Region
- North West London Integrated Care System
- South West London 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 are NHSE London and North West London Integrated Care Board.

## About the UKFHD and NHS ML

The UK Forum for Haemoglobin Disorders (UKFHD) is a multi-disciplinary group of healthcare professionals interested in all aspects of sickle cell disorders, 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 UKHFD 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 UKHFD 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.

NHS Midlands and Lancashire (NHS ML) 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 details about the work of the UKFHD and the NHS ML is available at https://haemoglobin.org.uk and https://www.midlandsandlancashirecsu.nhs.uk/our-expertise/nursing-and-urgent-care/

## Acknowledgments

The UKFHD and NHSML would like to thank the staff and service users and carers of the Imperial College 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 then contributed to this review

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## Review Visit Findings

## West London Sickle Cell Haemoglobinopathy Coordinating Centre

## General Comments and Achievements

The Imperial College Healthcare NHS Trust (ICHT) was the lead provider of the West London HCC (WLHCC) for sickle cell disorders. The coordinating centre for the care of those living with thalassaemia and rarer inherited anaemias was The Red Cell Thalassaemia HCC a partnership of all SHTs and based at University College London NHS Foundation Trust.

The WLHCC governance structure aimed to offer improved access to high quality care, improving patient experience and providing overarching administrative support, leadership, governance and education across a wide region of West London and incorporated three specialist haemoglobinopathy teams (SHTs): ICHT, London North West University Healthcare NHS Trust & St George's University Hospitals NHS Foundation Trust.

The West London HCC covered thirteen London boroughs, 289,932 residents were Black, Black British, Black Welsh, Caribbean or African: African, Caribbean, other Black population recorded on the 2021 Census giving a rough estimate of 23,195 Sickle Cell gene carriers. Approximately 1,840 patients living with a Sickle Cell Disorder (SCD) were seen by the providers of the West London HCC. Of these, 866 lived in North West London (NWL), 338 in South West London (SWL), 86 in Surrey, 90 in Hertfordshire. The majority of patients living with SCD in region lived in Index of Multiple Deprivation (IMD) ranked highly deprived areas (Brent, North Kensington, Wembley, parts of Ealing in NWL and Roehampton and Mitcham in SWL).

The HCC had unified previously separate Adult & Paediatric network structures in NW London (the North West London Haemoglobinopathy Managed Clinical Network launched in 2003 and the Imperial Paediatric Red Cell Disorders Network established in 2010) which served adult and paediatric patients across a smaller geographical area.

The HCC service had a dedicated team of network, quality, data and project managers to support effective delivery of care for those living with a sickle cell, thalassaemia and rarer inherited anaemia disorders across West London. The HCC was clear about their objectives to promote clinical excellence and improve outcomes and patient experience for patients with haemoglobin disorders, in particular to maintain joint working between specialist and local haemoglobinopathy teams and improve care pathways.

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

- Clinical Director (1PA)
- Deputy Clinical Director (0.1WTE)
- Network Manager (1 WTE)
- Transcranial Doppler Lead (0.025 WTE)
- Lead Nurse (0.025 WTE)
- Senior Data Manager (1 WTE)
- Local Data Managers ( 1 WTE for each SHT – adults and paediatrics)
- HCC Administrator (0.6 WTE)

The HCC had also designated leads for the following work programme areas

- HCC MDT Lead
- HCC Research Lead
- SHT Adult and Paediatric Clinical Leads

- HCC Education Lead and Adult Guideline Lead
- Paediatric Guidelines Lead
- HCC Patient and Public Voice Group (PPV) Lead

**Quality Management and Governance Framework**

The HCC had a full-time Network Manager to coordinate the agreed Quality Management programme. The HCC held a steering group each month which had oversight of the HCC subgroups and an additional operational meeting was held weekly with the lead team. Each role within the network had a designated lead as detailed above.

The HCC were clear about the challenges they faced in terms of workforce across the region and more recently an HCC risk log had been developed with members which would be reviewed as part of the usual HCC governance business agenda.

An agreed audit programme had covered time to analgesia and pain management in emergency settings, audit of the NICE guidelines and the number of patients who are on and have been asked about Hydroxycarbamide had been completed by all the SHTs and partially by the LHTs. Other audits completed by the SHTs within the HCC included the patient pathway for patients needing regular transfusion and some had completed the acute admissions to inappropriate settings, including patient and clinical feedback.

The HCC Transcranial Doppler (TCD) Lead had undertaken an annual review covering quality assurance of TCD provision and activity across the SCD HCC and had plans in place to address the five practitioners who did not meet the criteria of undertaking 40 scans per year.

HCC funding and monitoring was actively overseen by the HCC with support from ICHT finance and contracts departments.

HCC Network guidelines were overseen by a paediatric or adult led sub group which would met on an ad hoc basis to review and update policies and guidance.

The HCC had an extremely active clinical research programme with several clinical trials that were network wide. Details of areas participating and the trials available were discussed at the beginning of each MDT and a list sent to all teams after the meeting. The paediatric research leads recognised the challenges of delivering an equitable service to the paediatric population which also spanned a large geographical area.

The HCC linked to two main ICBs; North West London and South West London. The HCC had met with commissioners from both NHSE London and North West London ICB around their annual work plans and to report on progress and any concerns. Commissioners and the NWL ICB had conducted visits to the specialist services individually and across the region. However, reviewers were told that there was limited engagement of NW and SW London ICBs in governance, oversight, and quality systems of the HCC, they highlighted the need for stronger partnerships, particularly in NW London, where integration with ICB structures was considered limited.

**HCC Business Meetings**

Bi-annual business meetings were hosted, and open to the whole HCC including teams from their SHTs, LHTs, commissioners and HCC patient representatives. As part of these meetings the annual programme of work and audit programmes were agreed. Meetings were held remotely to promote engagement across the region. A range of other meetings and subgroups had been implemented to cover the work of the HCC, *see table 1.*

**TABLE 1**

| Meeting Title | Frequency |
|---|---|
| HCC Business Meeting | Every 6 months |
| HCC Steering Group Meeting | Every month |
| West London HCC MDT | Every Month<br>Quarterley to review any adverse events |
| Operational Meeting | Every week |
| MDT Leads Sub-group | Adhoc |
| Paediatric Sub-group | Adhoc |
| Adult Guidelines Sub-group | Adhoc |
| Training and Education Sub-group | Quarterley |
| Data Management Sub-group | Every month |
| Nurses, Midwives and counselling Health Visitors Subgroup | Every six weeks |
| Patient and Public Voice Group | Every month |

**HCC Multi-disciplinary Team Meetings**

Combined paediatric and adult multidisciplinary team meetings (MDTs) were held monthly, alternating between Wednesday and Friday afternoon, with an adverse event MDT held quarterly to facilitate effective reporting and dissemination of learning in Morbidity and Mortality cases. All members of the SHTs (ICHT, London North West Hospitals Trust (LNWH) and St George's Hospital (SGH) as well as Local Haemoglobinopathy Teams (LHTs) in the West London area and representatives were invited to submit cases for discussion against the agreed criteria. The North West London community team also attended HCC MDT to coordinate care and discuss best next steps for high-risk patients who needed to be seen outside of the acute hospital setting.

The West London HCC had also forged links with Welsh and Scottish haemoglobinopathy centres who were also invited and attended the HCC MDT meetings.

In 2024 a total number of thirteen paediatric cases and 60 adult cases had been reviewed by the HCC MDT. The HCC also had a clear process for onward referral to the National Haemoglobinopathy Panel Meetings.

**HCC Education, Staff Training and Resources**

The HCC education programme for 2024-5 had prioritised education programmes for community and staff and had run a number of online sessions for school nurses across the region which had proved very successful with stakeholders. The HCC had also hosted a Community of Practice event with other teams developing hyper acute units (HAU) including Manchester to share best practice.

The WLHCC website, which had been implemented in 2021, included a wide range of resources for patients and staff with links to their 'You Tube' channel which had 54 videos covering a wide range of topics. As the website had seen a significant increase in activity by users since its inception, work was underway to further develop their media and communication strategy.

A specialist nurse subgroup led by the HCC lead nurse had also been implemented to share good practice and provide support.

The HCC had also been able to fund 72 staff to attend the Annual Sickle cell and Thalassaemia Conference (ASCAT) and had committed funding to support nurse independent prescriber courses, with the first CNS due to undertake the course in 2025.

**HCC Patient Involvement and Support**

The HCC was active in improving stakeholder engagement and had been successful in developing a fully integrated Patient and Public Voice Group (PPV) into the governance work of the HCC. The group met every month and were remunerated. At the time of the visit the group had approximately 12 members representing children, families and adults. A two way process for the sharing of information was in place with the PPV chair attending business meetings and, on a regular basis, the HCC manger attended the PPV group meetings. The PPV group had been involved in a wide range of topics ranging from HCC educational programmes, input into projects, reviewing improvements identified from incident and other national reports and providing user and carer feedback on services.

**NHSE Funded Pilots**

The HCC in partnership with NW and SW London ICBs and community service providers had been instrumental in the mobilisation and governance of the NHSE funded pilot quality improvement programme for sickle cell disease within region comprising the following projects:

- North West London Community Improvement Project
- South West London Community Improvement Project
- Haemoglobinopathy Hyper Acute Units based at the following sites:-
    - Hammersmith Hospital (ICHT - Renal and Haematology Triage Unit)
    - St George's University Hospitals NHS Foundation Trust
- Universal Care Plans uploaded to online platform for streamlined, centralised access to patients' pain protocols during SCD emergencies

A London Sickle Cell Improvement Programme Board met bi-monthly which served as a forum for commissioners to be updated on the transformation projects being led by the HCC.

**Feedback from Stakeholders**

The reviewers met with three SHT representatives, two paediatricians and one adult haematologist. All commented that they were well supported by the HCC, they attended education events regularly and HCC funding had enabled them to attend the ASCAT conference in 2024. Those who met with the visiting team, who were linked to the paediatric SHT at ICHT, had high praise for the support and advice they received from the team. Attendance and quality of discussion at the complex HCC MDT was valued.

**Challenges**

The HCC were very aware of the challenges they faced.

The work the HCC had been required to undertake to lead on the quality improvement programme for sickle cell disease on behalf of ICB commissioners across the region had seriously impacted on the available HCC workforce to be able to drive the important improvements that the HCC had identified and had hoped to have progressed.

The SHTs were experiencing medical workforce challenges, particularly the stability of the senior medical workforce at London North West University Healthcare NHS Trust was of concern and the Paediatric ICHT SHT had been required to provide specialist oversight for patients based at St George University Hospitals NHS Foundation Trust to cover leave of the SGH lead clinician.

Demographic changes to the number of people with haemoglobinopathies residing in Hertfordshire and Bedfordshire, in part driven by movement out of London and immigration, was causing capacity pressures, particularly for paediatric services across the region.

Many of the LHTs were experiencing workforce capacity issues; consultant staffing, limited or no CNS and psychology support. Also of concern to the HCC was the limited engagement with Trust EDs around robust processes for alerting their

local haematology teams when patients living with a haemoglobin disorder accessed emergency care or were admitted under other clinical specialties.

## Good Practice

1. Reviewers were impressed with the collaborative work undertaken to ensure that the patient voice was incorporated in to the governance of the HCC. A two way process for the sharing of information was in place with the PPV chair attending business meetings and, on a regular basis, the HCC manager attended the PPV group meetings to share information and invite feedback and participation in HCC wide activities.
2. The quality of the HCC Multidisciplinary Team Meetings was very good, providing a commendable environment for shared learning, expert advice and support, as well as being highly educative for the participants. In particular was the HCC's ability to respond and hold ad hoc MDTs for discussion of urgent cases outside of the usual MDT timetable.
3. The HCC had good relationships with all the SHTs in the region. Representatives who met with the visiting team were highly appreciative of the advice and support they received from the HCC.
4. The HCC actively promoted research programmes led by the individual SHTs. The HCC had a good process for encouraging equitable access to research and trials across the network. Research trials were discussed at the beginning of all HCC MDTs in order to encourage clinicians to forward cases onto the respective trials. A listing of trials was also distributed to staff across the HCC following the MDT meetings
5. Staff had access to a range of HCC developed education. In particular significant work had been undertaken to provide an online education resource for school nurses. The HCC were also active in ensuring that education was available in a range of formats via their website and via 'You Tube.'
6. In addition to the HCC business meetings a number of subcommittees had been implemented which enabled more dedicated time to focus on the specific areas of work and the audit programme.

## Serious Concern

1. **ICB Commissioning of NHSE Funded Projects**

   The impact on the accrued work in a short timeframe to lead, provide governance and deliver on the NHSE funded pilots, which would normally have been delegated to the ICBs to oversee, should not be underestimated. The requirement to deliver on multiple projects had placed a significant workload for the HCC Operational Manager and the HCC core team and impacted on their ability to drive the important improvements that the HCC had planned. The oversight of the projects across the region had also impacted on acute and community trust service managers who were required to attend a significant number of external meetings for these projects.

   *This Serious Concern is also included in the Commissioning section of the report.*

## Concerns

1. **HCC Nursing Leadership**

   At the time of the visit the nominated lead nurse had insufficient time (1 hour per week) for their HCC leadership as well as other clinical commitments considering the size and extent of the HCC. The review team considered that a greater focus on nursing leadership across the HCC would support a longer-term vision for this workforce and prioritise wider nursing education.

2. **Inequity of provision across the SHTs and LHTs**

   There had been a significant increase in the number of patients requiring care within the SHTs and LHTs, with this growing patient population, there had also been changes in demographics across the HCC.

Whilst patients who were accessing their care through the SHTs were receiving comprehensive care, and there were escalation policies if appropriate to transfer the patients from LHTs to the SHT. The LHTs were struggling to provide holistic care for their patients due to the lack of infrastructure (CNSs, psychology and administration support), resulting in clinical staff spending time trying to support their patients as well spending time on non-clinical activity. The insufficient staffing levels within the LHTs to provide comprehensive holistic care raised concerns about the sustainability of these services in the future with the likelihood of ever increasing activity.

3. **Patient pathways at Bedfordshire NHS Foundation Trust**

   From discussions during the visit, reviewers were concerned about the pathway for paediatric patients residing in Bedfordshire. Historically paediatric patients seen at the Bedford Hospital would receive their specialist care at the London North West Hospital (LNWH) SHT and for those patients based at the Luton and Dunstable Hospitals, specialist care was from the ICHT SHT. Adult patients received their specialist care from the SHT based at Whittington Health NHS Trust. Since the Trust merger of Bedford Hospital with Luton and Dunstable Hospitals to become Bedfordshire NHS Foundation Trust in April 2020 the LNWH paediatric SHT had withdrawn its support, and patients had been informally cared for by ICHT.

   This potentially had issues for young people transitioning to two different adult services for their specialist care. The combined governance and the need to standardise guidance and policies had also become problematic for the LHTs with the newly formed Trust formally reporting to two SHTs. Reviewers considered that with these changes a review of the SHT and LHT pathways and commissioning arrangements for Bedfordshire NHS Foundation Trust should be re-evaluated with all parties to align with the changed operating model post-merger. *This issue is also documented in the ICHT Children and Young Peoples section of the report*

4. **Patient Feedback - Local Emergency Departments**

   Adult patients who met with the visiting team were very concerned about attending their local ED if the RHTU (hyper acute unit) did not have capacity for them to be assessed. As the activity for both hyper acute units across the HCC region increases (RHTU and unit at SGH) the likelihood is that other EDs and Trusts will see fewer patients requiring care in an emergency. It will be important that the HCC monitor and tailor their education provision for referring areas, particularly how to access specialist advice and support to ensure that patients attending as an emergency and requiring admission away from these units receive safe and timely care.

5. **Liaison with commissioners outside of London**

   There was very little or no engagement from ICBs responsible for covering the many LHTs outside of central London. As commissioning arrangements change over the next few years these relationships will be crucial to the provision of appropriately staffed services for patients and HCC involvement and advocacy will be key. *See also commissioning section of the report.*

## Further Consideration

1. Feedback from the LHTs was that their ability to provide education covering the care of patients with haemoglobin disorders was challenging due to workload pressures and limited staffing. They commented that they would value more HCC outreach support, particularly targeted education provided locally for Trust colleagues working in areas where patients with haemoglobin disorders may be cared for (ED and Wards).

2. From discussion with LHTs during the visit, data on the numbers of patients being cared for by the LHTs was not always consistent with the data available to the reviewers. There was a of lack data support to the LHTs which had resulted in delays registering patients on the National Haemoglobinopathy Register (NHR), this had resulted in a number of patients not being allocated to an SHT on the NHR. The reviewers acknowledged that the HCC was in the process of data cleansing across the region.

3. With the level of expertise and engagement in research across the HCC, the HCC should consider how it could support and include research involving nurses and Allied Health Professionals.
4. As there were good relationships for informal discussion of patients outside of the formal MDT meetings, the HCC should monitor that all patients who meet the criteria are being presented to the HCC MDT for wider discussion.

## Review Visit Findings

## Imperial College NHS Trust

## Trust-wide General Comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders at the Imperial College Healthcare NHS Trust (ICHT). ICHT is one of the largest acute trusts in the country. The Trust comprised of Charing Cross, Hammersmith, Queen Charlotte's and Chelsea, St Mary's and Western Eye Hospitals. In partnership with Imperial College London, the Trust formed one of the first Academic Health Science Centres which nests within Imperial College Health Partners, the Academic Health Science Network for North West London.

In total the Trust served approximately 940 patients with Haemoglobin Disorders, mostly sickle cell disorders (SCD). During the visit the reviewers attended the Hammersmith Hospital, and St Mary's Hospital. The review team at Hammersmith Hospital visited the Renal and Haematology Triage Unit , ward and outpatients departments and the review team at St Mary's Hospital visited the paediatric emergency department, assessment units and wards; they met with patients and carers, and with staff providing services for the local health economy.

The adult and paediatric Specialist Haemoglobinopathy Team ( SHT) provided a service to the region of West London.

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

## Trust -wide Good Practice

1. The Haematology Quality Team were very well organised and clearly valued by the Haemoglobinopathy SHTs for their widespread support to the clinic teams.
2. ICHT had been successful in being commissioned by NHSE as provider for gene editing therapy (Casgevy) and in 2024 the adult haematology service had been successful in their bid to provide Haematopoietic Stem Cell Transplantation (HSCT) for patients living with a sickle cell disorder.

## Trust -wide Serious Concerns - Adults

1. **RHTU/HAU expansion and inpatient capacity**

   The reviewers were seriously concerned about the planned RHTU/HAU expansion which would result in the HAU seeing patients diverted from LNW. The full implementation of the HAU was dependant on expanding the inpatient bed base at HH for patients attending the HAU who required an inpatient admission. Reviewers were told that discussions had been ongoing for several years with no clear resolution nor timeframe for achieving the additional bed capacity. Reviewers were seriously concerned that this could affect the success of the pilot and may result in the loss of ongoing funding for the HAU.

**Views of Service Users and Carers**

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

During the visit we met with three adults and a parent of an adult living with a sickle cell disorder and one adult living with thalassaemia. From the children's perspective we met with four families caring for children and young people living with a Sickle Cell Disorder.

The views of the users were wide-ranging and are documented in the children's and adult specialist haemoglobinopathy team sections.

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

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

## General Comments and Achievements

Until 2000, paediatric and adult haematology services at Imperial College Healthcare NHS Trust (ICHT) were co-located at Hammersmith Hospital. Following re-configuration of paediatric services in West London, Paediatric Haematology relocated to St Mary's Hospital, Paddington in 2001.

In 2022, the West London Children's Healthcare (WLCH) partnership was formalised between Imperial College Healthcare and Chelsea and Westminster Hospital NHS Foundation Trust to improve quality, experience and outcomes across all aspects of child health. ICHT was a host site for WLCH which operated as an integrated healthcare system spanning across West London and had developed shared ways of working across the acute and specialist children's services. It also supported closer collaboration with community and primary care partners.

All paediatric haematology care was delivered from the St Mary's Hospital site. The Paediatric Haematology service was part of the Children's Services Division of the West London Children's Healthcare (WLCH).

Comprehensive paediatric haematology care was delivered by the team at ICHT. The haematology service was a tertiary and international referral centre offering care for blood and marrow transplantation for non-malignant haematological conditions, including: Haemoglobinopathies, Diamond Blackfan Anaemia, Fanconi Anaemia, Dyskeratosis Congenita and Aplastic Anaemia. The service hosted the Paediatric Oncology Shared Care Unit (POSCU); shared care level 2 for children with haematological malignancies and solid tumours in conjunction with Great Ormond Street Hospital. The department also benefited from its close relationship with the Paediatric Infectious Diseases Unit and Paediatric Intensive Care Unit (PICU), which had a wide experience of the management of children with opportunistic and life-threatening infections.

The paediatric haematology team comprised of five consultants, supported by four to five designated Haematology Specialist Registrars/Clinical fellows and a rotating group of ST2/3 paediatric trainees. The provision of medical care was delivered on a 24-hour consultant rota which included on-call and weekend cover.

Nursing staff included a lead nurse for Paediatric Haematology, Matron for Haemoglobinopathies and Apheresis, a dedicated Clinical Nurse Specialist, a Ward Link Nurse for Haemoglobinopathies, and Haematology trained nurses within the ward, day care and outpatient areas. The SHT had developed a Deputy Haemoglobinopathy CNS role and successfully recruited into this post.

The hospitals served specifically by Paediatric SHT at ICHT were:

- Chelsea and Westminster Hospital (West Middlesex Hospital Hospitals NHS Trust)
- Hillingdon Hospitals NHS Foundation Trust
- Luton & Dunstable University Hospital
- Bedford Hospital
- Watford General Hospital (West Hertfordshire Hospitals NHS Trust)

The above hospitals all received specialist support involving outreach annual reviews, telephone/email advice and emergency and elective (surgical) in-patient care. Patients also attended the ICHT for specialist investigations.

Paediatric Haematology at ICHT supported the LNWH SHT by providing specialist clinical care and advice to Northwick Park Hospital/Central Middlesex Hospital and Ealing Hospital. Over the past year ICHT has also provided support to St George's Hospital to help cover maternity leave.

As ICHT offered a 24/7 paediatric haematology consultant on call, specialist nurse apheresis rota and also had a dedicated PICU, many patients living with a sickle cell disorder from across London were transferred for emergency high dependency care.

**Transition**

Between the age of 14-18 years, paediatric patients were guided through adolescent transition to adult care. ICHT operated the 'Ready, Steady, Go, Hello' programme for transitioning care to adult services. The paediatric specialist nurse worked with the young person and parents from about the age of 14 to develop the skills and understanding of their condition. Young people had the opportunity to attend adolescent evening clinics which took place monthly where there was an opportunity to focus on relevant issues relating to the impact of living with a chronic illness during the teenage years. The adult clinical nurse specialist and red cell consultant also attended paediatric outpatient clinics to facilitate this programme and introduce the adult service. Patients and parents were invited for an adolescent care event at Hammersmith Hospital which was hosted biannually, this involved a guided tour of the facilities and red blood cell exchange procedures for adolescents at Hammersmith Hospital and an opportunity to meet key members of the adult team.

**Research**

The Paediatric Haematology Department had an active research programme predominantly focused upon further developments in bone marrow transplantation and gene therapy for patients with haemoglobinopathies. The adult red cell research team at Hammersmith had several open studies and adolescent patients were made aware of novel drug therapies which may be accessible to them. The paediatric research unit at ICHT had the expertise and infrastructure in place to support paediatric red cell studies.

| SPECIALIST HAEMOGLOBINOPATHY TEAM- CHILDREN AND YOUNG PEOPLE [1] | | | |
|---|---|---|---|
| | Linked Haemoglobinopathy Coordinating Centres (HCC) | | |
| | West London Sickle Cell HCC<br>*Hosted by Imperial College NHS Trust*<br>The Red Cell Network: Thalassaemia and Rare Inherited Anaemia HCC<br>*Hosted by University College of London Hospitals (UCLH)* | | |
| | Linked Local Haemoglobinopathy Teams LHT | Patient Distribution | |
| | | SCD | Thalassaemia |
| | West Hertfordshire Hospitals NHS Trust | 33 | 3 |
| | The Hillingdon Hospitals NHS Foundation Trust | 18 | 5 |
| | Chelsea and Westminster Hospitals NHS Foundation Trusts | 25 | 5 |
| | Bedfordshire Hospitals NHS Foundation Trust - Luton and Dunstable University Hospital | 77 | 9 |
| | Bedfordshire Hospitals NHS Foundation Trust (Bedford Hospital) *To note: - this hospital is formally under the remit of the London NW SHT however since the merger with Luton and Dunstable on 1st April 2020 this service has been served by the ICHT team.* | 18 | 4 |

[1] Note, data have been rounded to the nearest 5 and numbers of 5 or lower suppressed, to ensure that no patient can be identified through publication of small numbers.

| PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLONOAPTHY TEAM | | | | | | | |
|---|---|---|---|---|---|---|---|
| Condition | | Registered patients | Active patients*[2] | Annual Review ** | Long term transfusion | % Eligible patients on hydroxycarbamide | Inpatient admissions in the last year |
| Sickle Cell Disorder | CYP | 178 | 188 | 139 | 27 | 87 | 133 |
| Thalassaemia and RIA | CYP | 37 | 53 | 24 | 22 | 1 | 6 |

### Staffing

| Specialist Haemoglobinopathy Team | Number of patients | Actual PA or WTE (at the time of the visit) |
|---|---|---|
| Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies | 250 | 1.0 wte plus 2 deputy leads providing dedicated clinic input. |
| Clinical Nurse Specialist dedicated to work with paediatric patients living with haemoglobinopathies | 250 | 2.0 wte |
| Clinical Nurse Specialist dedicated to work with paediatric patients living with haemoglobinopathies in the community | N/A | 1WTE Band 7 & 6 employed by Central London Community Healthcare NHS Trust |
| Clinical Psychologist dedicated to work with paediatric patients living with haemoglobinopathies | 250 | 0.2 wte |

## Urgent and Emergency Care

The Paediatric Emergency Department (ED) was based on the first floor of the Queen Elizabeth Queen Mother (QEQM) building which was accessible by an external ramp or internally via lift or stairs. All patients both adult and children reported to the main reception where they were booked in and then signposted to the dedicated children's ED waiting area. The children were triaged and those living a with sickle-cell disorder were prioritised for early review. On booking in, the system had an alert so that the triage nurses were made aware of any haemoglobinopathy patients attending for prioritisation of care.

Medical staff in ED accessed guidelines via an app and they described a rolling training programme to capture doctors on rotation, new staff, and maintain competences. There was a dedicated ED link nurse for haemoglobinopathies alongside regular contact with the haematology team who in-reached into the ED. A joint Haemoglobinopathy and ED nurse education programme had been implemented.

A wall display to highlight awareness of specific conditions was visible: at the time of the visit the topic was bronchiolitis.

Priority for admission was given to those patients who required management of their sickle cell crisis, acute chest syndrome, urgent transfusions or exchange transfusions as well as other complications in relation to haemoglobin disorders. There was no automatic electronic alert on the system to inform the haematology team of an attendance with the ED contacting the team manually.

The Clinical Director and leads met weekly to discuss any pathway issues and once a month this had a haematology focus. The review team noted a positive attitude to continuous quality improvement within ED.

[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.

## In-patient Care

The Grand Union ward was dedicated to haematology care which included 12 single rooms and an on-site school to support continued education of the children. In-patients were cared for by a dedicated paediatric haematology team of medical staff separate from the general paediatrics and other paediatric specialities. There was resident haematology cover until 9pm with cover then provided by the general paediatric team.

When beds were not available on the Grand Union ward the children were cared for on the 25 bedded Great Western ward which included 11 single rooms. Co-located was a 15 bedded Paediatric Intensive Care Unit. Nursing staff were familiar with the care of haemoglobinopathy patients and training was received. The unit matron kept an active record of the number of haemoglobinopathy patients they cared for on the ward outside of the dedication haematology ward.

## Day Care

Day-care facilities were provided on the Paediatric Haematology Day Unit (PHDU), a purpose-built facility exclusively dedicated to the care of paediatric haematology patients, which was situated on the 6th floor of the QEQM building at St Mary's. This unit consisted of two clinical consultation rooms, a four bedded day unit, a HEPA-filtrated isolation room, a treatment room, a phlebotomy room, observations, weight and height room, a pantry, and ward office.

Two Paediatric Haematology specialist registrars and a Paediatric Haematology Clinical Nurse Specialist led this service and worked in conjunction with the haematology nurses.

In 2022, the apheresis service was relocated to a dedicated Apheresis Bay within the Grand Union Ward. Prior to this, the apheresis service operated from the PHDU. The Apheresis Bay consisted of three chairs for apheresis procedures including red cell exchange procedures and peripheral blood stem cell collection. Procurement of two additional Optia machines in the past 2 years including through successful MedTech funding in 2024, had resulted in a total of three Optia machines being available for procedures within the apheresis service.

The apheresis service was overseen by the Collection Facility Medical Director (Paediatric Haematology Consultant) and was operationally led by the apheresis Matron and staff nurses trained in red cell exchange and apheresis continuous mononuclear cell collections (CMNC).

## Outpatients

Children's outpatient haematology clinics took place on the PHDU, clinics were consultant led and supported by the CNS. Evening clinics for adolescents were held monthly. A team of play specialists moved with the children to provide support regardless of their location in the hospital.

Trans Cranial Doppler Ultrasound (TCDs) were undertaken outside the PHDU within the imaging department. The children and their families were escorted by the CNS team on initial visits to ensure the families are familiar with the routine and where to go.

## Community- based care

Community care was provided by Central London Community Healthcare (CLCH). A number of community nurse specialists supported the haemoglobinopathy service which covered a broad area of West London. The community haemoglobinopathies specialist nurse team provided outreach services to patients, supporting their needs at home and school.

This team met prospective mothers to offer prenatal genetic testing and visit the families of new-born babies with a haemoglobinopathy diagnosis to offer support, education and provide a link to primary and secondary care services.

Other key roles involved outreaching to nurseries and schools to provide healthcare plans and visiting schools to advocate for the child's needs when this was needed. The community teams also communicated with families of frequently non-attending patients to facilitate improvement in engagement with healthcare services.

A community nurse visited all newly diagnosed babies and their parents to discuss the condition and provide information, liaised with families and developed nursery/school care plans. The community team would liaise with the child's or young person's school and would undertake school visits if necessary. There was a regular bimonthly meeting to discuss patients with the community nurse.

## Views of Service Users and Carers

The review team met with two children and their parents receiving apheresis on the Grand Union Ward and two further parents on the visit day via MS Teams. All families concerned had children living with a Sickle Cell Disorder. The review team did not speak to any parents of children, or children living with thalassaemia.

**Feedback**

- In general, the feedback was highly positive with both the patients and their parents very content with the care and support they received.
- The children and parents all confirmed that they knew who to contact if they had any questions and that the team were very responsive. They knew what to do in a crisis.
- They felt the schools were aware of and understood their child's needs.
- One child reported that the use of ultrasound had really improved their experience of cannulation.
- Translation services were used where appropriate, and information was provided in the parents' first language.
- One child described how they felt they had not much to do with the community team within their area of Hillingdon.
- Clinic appointments were spread out and not batched, this enabled the parents to allocate the time to attend effectively.
- One parent reported that they had spent a whole day in ED and felt that they had been forgotten between shifts. The doctors in ED were knowledgeable but they would like to wait less time in ED.
- Parents spoke about how culturally sensitive the lead CNS at St Mary's was and that this sensitivity was important in making them feel understood.
- There was no psychology support for parents via the service.
- They described that they had good support from the team and the local authority in terms of benefit claims however it was felt that this process was easier for children with better known conditions such as autism than for sickle cell which was less understood.
- Good community support was received, and they were aware of the wider support groups they could access.

## Good Practice

1. The review team were impressed by the dedication of the team to support a smooth, structured, and supportive transition of young people into the adult services. The Paediatrics CNS maintained contact with the young person for support until the age of 21, or until the young person felt comfortable to transition.
2. Doctors in the ED could easily access the haemoglobinopathy guidelines via app at the point of need.
3. The LHTs all commented that the SHT team provided good support to both their elective and emergency pathways.

4. There were robust emergency care pathways, and the identification and engagement of the ED link nurse has supported awareness of the condition among ED practitioners with excellent time to analgesia results in the latest audit.
5. There was a strong research portfolio which was well disseminated to LHTs.
6. The review team were impressed by the expanded apheresis service which had enabled an increase in the number of patients on red blood cell exchange programme along with a robust vascular access service supported by good links with surgical colleagues. Work had been undertaken to develop the skills and competency of the apheresis team so that they were able to offer procedures for patients <20kg weight.
7. The patients and their families the review team spoke to on the day of the visit specifically highlighted the cultural awareness of the lead CNS. The patients and families commented that this cultural awareness made them feel understood.
8. There had been improvement and sustainability of the 30 minutes time to analgesia metric (October 2024 – 80%, November 2024 – 100%).
9. The haematology service had reduced delays in recording the end date of blood products- which had improved blood product traceability and reducing wastage.
10. Reduction in waiting time for cross-match/ transfusion through training of more staff in venepuncture/cannulation competences and ultrasound guided cannulation.
11. Divisional management where aware of the challenges and were proactively involved with the service, the Divisional Team reported good and open communication with the Executive team.

## Immediate Risks

There were no immediate risks identified during the course of the visit

## Concern

**1. Consultant Workload**

There was one WTE consultant responsible for leadership of both the HCC and SHT who was also providing support to St Georges Hospital to cover maternity leave. Informal support was also being provided to Bedford Hospital *(see concern 3).* Two additional consultant colleagues provided clinic resource with ICHT and the LHTs. The review team were concerned that the consultant resource was not adequate to provide the service requirements. The team were visionary and were keen to support the expansion of service however this would be hampered if not appropriately resourced to be achieved in a safe and sustainable way.

**2. Access to psychology**

There was only 0.2 wte psychology support available for children and families which was insufficient for the 250 patients registered with the service and given the growth of the service and Bone Marrow Transplant programme did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE HCPC Senior Psychologist for every 300 patients. Reviewers were concerned that individuals affected by these disorders will have limited specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition.

The review team heard that a further 0.5 wte funding was available with the post out to recruitment. Reviewers considered that the SHT should explore alternatives should recruitment not be successful such as the use of psychology assistants, cognitive behavioural therapists and consideration of youth worker support for the older paediatric cohort.

**3. Bedfordshire NHS Foundation Trust Pathway**

From discussions during the visit reviewers were concerned about the pathway for paediatric patients residing in Bedfordshire. Historically paediatric patients seen at the Bedford Hospital would receive their specialist care at the London North West Hospital (LNWH) SHT and for those patients based at the Luton and Dunstable Hospitals, specialist care was from the ICHT SHT. Adult patients received their specialist care from the SHT based at Whittington Health NHS Trust. Since the Trust merger of Bedford Hospital with Luton and Dunstable Hospitals to become Bedfordshire NHS Foundation Trust in April 2020 the LNWH paediatric SHT had withdrawn its support, and patients had been informally cared for by ICHT.

This potentially had issues for young people transitioning to two different adult services for their specialist care. The combined governance and the need to standardise guidance and policies had also become problematic for the LHTs with the newly formed Trust formally reporting to two SHTs. Reviewers considered that with these changes a review of the SHT and LHT pathways and commissioning arrangements for Bedfordshire NHS Foundation Trust should be re-evaluated with all parties to align with the changed operating model post-merger. *This issue is also documented in the WLHCC section of the report.*

***4.*** **Local Haemoglobinopathy Team support for Young People**

The was no service provision within the LHTs for those age 16 and 17 years. ICHT take over the care of these young people as an informal arrangement however the review team were concerned that this did not provide a good patient experience and there was a danger that some young people may not be picked up without formal safety netting procedures.

**5. Lack of CNS support at the LHTs**

There was limited CNS support in the LHTs with minimal resource for the ICHT CNS to provide the level of outreach support. The review team considered that there was an urgent need to look at the provision of CNS support to LHTs including CNS succession planning.

## Further Consideration

1. The Trust had six TCD practitioners however only the lead practitioner had achieved over 40 scans per annum. The review team spoke to the lead for the TCD service on the day of the visit who explained that practitioners peer reviewed each other's TCD scans to both provide a quality assurance check and establish exposure to further numbers. The review team felt that there was good internal quality assurance in place however the use of additional external quality assurance should be considered due to the small numbers.
2. The review team heard from the LHTs that the SHT team were supportive and responsive. Outreach clinics were provided and the SHT team were accessible for advice. This support to the LHTs however was on the goodwill of the team and more formalised processes may support a greater visibility of resource requirements.
3. The LHTs were concerned about the training and exposure for their teams, especially with the successful outcome of hydroxycarbamide treatment. The SHT should consider putting on an annual event bringing together LHTs to network, gain knowledge, and share best practice.
4. The children and young people could access social work support via the adult service however the social work resource available to them did not have parity with the adult service. Access to a paediatric social worker dedicated to families would provide equity and ensure their specific needs were met.
5. The review team noted a particularly good acute pain management service but highlighted that additional support for chronic pain would benefit the children and young people with complex pain issues.
6. Procurement of a dedicated ultrasound machine for cannulation for those attending for apheresis would further improve the apheresis service.

7. There were two CNSs dedicated to providing haemoglobinopathy care in the community employed by CLCH. There was however need for growth in the community service provision in line with increasing patient numbers.
8. The review team felt that there should be a greater focus on engaging with thalassaemia representatives to strengthen the input of this group of patients. Different methods should be considered including virtual options.
9. The review team were impressed by the time to analgesia results and commended the work and effort to achieve these. Consideration should however be given to the move away from ED being the single point of access to the provision of direct access into specialist care.
10. Consideration should be given to the implementation of an automatic electronic alert on the Trust system to inform the haematology team of an attendance. This would negate the ED staff needing to contact the team manually.

## Specialist Haemoglobinopathy Team (Adult Services)

## General Comments and Achievements

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

Clinical Haematology was part of the Division of Surgery and Cancer. Its services encompassed the full range of blood diseases, including malignancies, haemostasis and thrombosis, anaemias, haemoglobinopathies, immune haematological conditions and haemolytic disorders provided by separate sub-specialty teams. There was a comprehensive cellular therapies programme which included hematopoietic stem cell transplantation for sickle cell disease and delivery of exagamglogene autotemcel (Casgevy).

Haematology services were based at the Hammersmith Hospital (HH) and St Mary's Hospital (SMH) sites, with the majority including all inpatient care centralised on the Hammersmith site.

The Red Cell team provided comprehensive care to over 600 adult patients living with sickle cell, thalassaemia and other inherited red cell disorders (454 SCD/ 76 Thal /157 RIA) within a specialised multidisciplinary service model. Not all patients living with a sickle cell condition were registered on the NHR (437 out of 454 patients); however, work was being undertaken to address this.

The team consisted of seven consultants, who all had dedicated haemoglobinopathy sessions in their job plans to manage the care of inpatients and attended the SHT MDTs. There were two dedicated haemoglobinopathy specialist nurses, a dedicated psychologist, one WTE dedicated social worker, a dedicated pharmacy technician and more recently a specialist pharmacist for sickle cell disease had joined the team.

There were dedicated outpatient clinics for red cell patients at HH and SMH. A joint obstetric haematology clinic for women with haemoglobin disorders was held at Queen Charlotte's Hospital (on the Hammersmith site). Within the Trust there was access to a full complement of specialist services to support the medical needs of patients with haemoglobin disorders. Key adjacencies included the National Pulmonary Hypertension Service and West London Renal and Transplant Centre co-located at the Hammersmith Hospital.

Care for young people transitioning to adult services was delivered jointly with the paediatric SHT based at SMH.

The clinical service benefited from access to nationally renowned laboratory services for investigation of haemoglobin and other red cell disorders. There was a weekly lab meeting for the integrated review of Haemoglobinopathy cases and a separate haemato-pathology meeting where red cell cases were reviewed on alternate weeks.

The Trust had implemented the depletion exchange programme which had resulted in a significant reduction in blood usage.

The haematology wards and service had minimal nursing vacancies and had been able to develop staff and target training, the wards had also been recognised and received two 'Daisy Awards' for nursing excellence.

The Red Cell team had an extensive portfolio of research studies and was the largest non-malignant haematology clinical trials unit in the country. There was a dedicated team of research nurses and clinical research practitioners who supported patient enrolment into clinical trials and observational studies.

The SHT had recently partnered with the Sickle Cell Society to pilot their peer mentoring programme for patients across the SHT. This initiative was funded initially for two years.

| SPECIALIST HAEMOGLOBINOPATHY TEAM- ADULT [3] | | | | | | | |
|---|---|---|---|---|---|---|---|
| | Linked Haemoglobinopathy Coordinating Centres (HCC) | | | | | | |
| | West London Sickle Cell HCC<br>*Hosted by Imperial College NHS Trust*<br>The Red Cell Network: Thalassaemia and Rare Inherited Anaemia HCC<br>*Hosted by University College of London Hospitals (UCLH)* | | | | | | |
| | Linked Local Haemoglobinopathy Teams LHT | | | | Patient Distribution | | |
| | | | | | SCD | Thalassaemia | |
| | Chelsea & Westminster Hospitals NHS Foundation Trust | | | | 42 | 0 | |
| | The Hillingdon Hospitals NHS Foundation Trust | | | | 27 | <=5 | |
| | West Hertfordshire Hospitals NHS Trust- Watford Hospital | | | | 31 | 0 | |
| PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLONOAPTHY TEAM | | | | | | | |
| Condition | | Registered patients | Active patients*[4] | Annual Review ** | Long term transfusion | % Eligible patients on hydroxycarbamide | Inpatient admissions in the last year |
| Sickle Cell Disorder | Adults | 454 | 435 | 384 | 114<br>110 - Red cell exchange 4 - Red cell exchange and hydroxycarbamide | 85 | 528 |
| Thalassaemia and RIA | Adults | 233<br>76 thalassaemia and 157 RIA | 183 | 60 | 23<br>20 - Top up 3- Red cell exchange | <=5 | 9 |

### Staffing

| Specialist Haemoglobinopathy Team | Number of patients | Actual PA or WTE (at the time of the visit) |
|---|---|---|
| Consultant haematologist dedicated to work with patients with haemoglobinopathies | 687 | 20 PAs for direct clinical care activities |
| Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies | 687 | 2 WTE |
| Clinical Nurse Specialist dedicated to work with patients living with haemoglobinopathies in the community | 687 | 2 WTE band 7 and 1 WTE band 8 Provided by Central London Community Healthcare NHS Trust |
| Clinical Psychologist dedicated to work with patients living with haemoglobinopathies | 687 | 1 WTE |

[3] Note, data have been rounded to the nearest 5 and numbers of 5 or lower suppressed, to ensure that no patient can be identified through publication of small numbers.

[4] *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

The Renal and Haematology Triage Unit (RHTU) had been set up when the ED at HH had closed and enabled haemoglobinopathy patients to bypass the emergency departments on other sites and access urgent care directly on a 24/7 basis. The RHTU was based on the HH site and provided access to rapid specialist assessment diagnosis and treatment for patients. A service level agreement was in place with the London Ambulance Service (LAS) which enabled patients to be conveyed directly to the RHTU where clinically appropriate.

The unit had eleven treatment spaces, including six side-rooms and was located on the ground floor of B Block, in HH near the Du Cane Road main entrance with direct ambulance access. The capacity of the service had recently been expanded as part of the National Health Inequalities Improvement Programme funded Sickle Cell Disorder ED bypass pilot project with the intention of providing access to patients with a sickle cell disorder from across North West London.

Red cell patients under the care of the SHT were provided with a Patient Access Card ('passport') with details and information on how to contact and access the RHTU service if they required urgent assessment for pain or other symptoms related to their condition. For patients living with a sickle cell disorder there was a standardised triage tool for initial telephone assessment by the RHTU nursing team. Data showed that the Nurse led Telephone triage service activity was approximately 2,800 patients in the last year with 60% of those with a haemoglobinopathy disorder (612 with an acute pain crisis) and over 90% of non-elective haemoglobinopathy admissions had occurred via this route.

Other medical emergencies which did not meet the criteria for attendance at the RHTU were diverted to the nearest ED or specialist team. All patients had a 'Sickle Cell icon' on their care records to alert ED departments to patients who presented via this route.

Medical cover was provided by a dedicated haematology SHO and SpR during the day and via the on-call SHO and SpR out of hours. Senior medical input was provided by the attending/on call red cell consultant seven days a week with provision for review of emergency attendances twice a day if necessary.

The RHTU provided emergency assessment for any patient with a renal or haematological condition. Those attending in an acute vaso-occlusive crisis were able to receive two doses of analgesia and, if capacity allowed a third dose of analgesia before a decision to admit for inpatient care. The implementation of remote prescribing had increased compliance with the timeliness of analgesia within 30 minutes of presentation. Training of RHTU nurses in the use of patient controlled analgesia had recently been undertaken with plans to introduce this for patients in whom this is the preferred option for acute pain management.

Nursing staff working in this area were appropriately skilled for acute assessment and diagnosis, treatment and ongoing care. Staff undertook mandatory training and completed competences in the care of patients with haemoglobin disorders.

## In-patient Care

Inpatient services were based on three dedicated haematology wards; Dacie, Weston and Fraser Gamble. Patients with haemoglobin disorders were primarily managed on Fraser Gamble Ward located on the third floor of the Renal Building, which had 29 beds including five neutral side rooms (en-suite). The medical team providing care for haemoglobinopathies and other non-malignant blood disorders (excluding haemostasis and thrombosis) comprised of seven haematology consultants who attended on a weekly basis supported by a rotating group of haematology SpRs and SHOs. Nursing provision included two CNSs and ward link nurses for haemoglobinopathies. Additional members of the multidisciplinary team supporting haemoglobinopathy inpatients included a clinical psychologist, social worker and specialist pharmacist for sickle cell disease. Attending consultants had provision in their weekly timetable for twice daily review of emergency admissions. Full MDT ward rounds were conducted three days a week with board rounds on other days and senior review of new admissions and where clinically indicated seven days a week.

Patients received a follow up call from the CNS following discharge and the CNS team would refer to the community team for further follow up as required.

High dependency care, including non-invasive ventilation & Level 2 and 3 critical care were available on the HH site. High dependency care was provided by the Critical Care Service and the Adult Intensive Care Unit was located one floor below Fraser Gamble Ward. There was an established standard operating procedure for escalation of acutely unwell patients with a haemoglobin disorder to critical care.

## Day Care

Ambulatory care for haematology patients was provided in a dedicated facility on the ground floor of the Catherine Lewis and Garry Weston buildings, with apheresis services located on Constance Wood Ward, 2nd floor of the Garry Weston building. The Haematology Day Care Unit had four beds and six reclining chairs, with an additional six chairs allocated for routine infusions including blood transfusion. The unit was open from 08:00 to 20:30, seven days a week. A designated link nurse supported haemoglobinopathy patients who attended the unit.

The apheresis service operated under the direction of the senior apheresis nurse coordinator from a three bedded unit with access to five Spectra Optia apheresis machines. An additional side room if required was available. The service provided elective red cell exchange six days a week and 24/7 provision for emergency red cell and plasma exchange. Medical oversight was provided by a designated red cell consultant. At the time of the visit the nursing team comprised of one band 8, two band 7 and two band 6 posts.

## Outpatients

There were dedicated outpatient clinics for red cell and non-malignant haematology at HH and SMH. The Haematology Outpatient Department (HOPD) was located on the ground floor of the Catherine Lewis Centre and incorporated its own phlebotomy service and hot lab FBC analyser. Consultant led haemoglobinopathy clinics were held weekly. In addition, a weekly CNS led hydroxycarbamide clinic was held and more recently, a medication management clinic led by the sickle cell pharmacist, was held in parallel with the main red cell clinic for patients to discuss any medication issues. The team also had plans to extend the pharmacist led medication review clinic for patients residing in North West London. A joint obstetric clinic and monthly transition clinics were also held with staff from the paediatric SHT.

A sickle cell pain management group with patients suffering from complex pain issues had also been established and meetings were held virtually. The meeting was supported by colleagues from ICHT and SGH and had a number of regular attendees. Feedback from those attending had been reported as positive.

A vascular access ANP provided support for any patient with a haematology condition requiring vascular access.

## Community- based care

Community haemoglobinopathy services were provided primarily by Central London Community Healthcare NHS Trust whose specialist haemoglobinopathy nurses attended the outpatient clinic and multi-disciplinary team (MDT) meetings on a regular basis. Direct referrals were made to the Specialist Community Haemoglobinopathy team by the haemoglobinopathy team using the agreed referral form. The specialist community haemoglobinopathy nursing team aimed to facilitate avoidance of hospital admission where possible and support early discharge by working collaboratively with health and social care services to provide a link between hospital and community services. The community team ran an outreach service, nurse-led clinics and provided telephone contact to support and educate patients.

Additional support for users and carers was also available through the Brent Sickle Cell & Thalassaemia Centre.

**Feedback from Linked LHTs**

The visiting team met with representatives from the Adult LHTs based at Watford (West Hertfordshire NHS Trust), West Middlesex University and Chelsea and Westminster Hospitals (Chelsea & Westminster Hospitals NHS Foundation Trust).

All commented about having easy access to the SHT for help and advice and also responsive if patients needed to be transferred for emergency red cell exchanges. They valued the LHT/ SHT MDT meetings which were clinically and educationally helpful.

At Watford, transition meetings were held locally and all annual reviews delegated to the LHT. They did not have access to psychology but could refer within the network. They had been able to recruit a part time band 6 CNS who had been well supported by the HCC and would contact the ICHT team for advice. The CNS had delivered some haemoglobinopathy training locally.

West Middlesex University and Chelsea and Westminster Hospitals did have linked Trust-wide protocols and cared for approximately 50 adult patients across both sites, although the majority of patients attended the West Middlesex site. In an emergency patients would attend either ED prior to being admitted to the acute medical units for ongoing care. The LHTs did not have capacity to provide any targeted haemoglobinopathy training for staff groups at the Trust. Patients did not have access locally to a CNS or AHPs to provide specialist support. They commented that as HH did not have an ED, patients would attend their EDs and it was difficult to care for these patients as their 'red cards' were not accessible and they did not have access to day units where patients could receive analgesia.

## Views of Service Users and Carers

Meetings were arranged before the visit to meet with patients and the visiting team, but unfortunately none of those registered attended the meetings. During the visit we met with three adults and a parent of an adult living with a sickle cell disorder and one adult living with thalassaemia.

**Service User Feedback**

- All those who met with the visiting team praised the SHT staff. They commented that the CNS team were easy to contact for help and advice.
- They highly valued the RHTU and commented that usually a bed was available to them when needed.
- The apheresis service was excellent and they considered that staff were knowledgeable and helpful.
- They felt having the specialist bone marrow transplantation service on site meant that care was coordinated and they liked that they would already have existing relationships with some of the haemoglobinopathy team members.
- Patients commented that they were offered access to the psychology service when attending their routine clinic appointments. Those who had experience of the service were highly appreciative of the care and support they received.
- Some did not consider that they had up to date knowledge of the services on offer and asked if they could receive more communication about service changes, especially changes in staff as they were not sure who everyone was.
- If they called the RHTU and there was no capacity for them to be assessed, they all commented that they would not attend their Emergency Department as this was so stressful and they would risk staying at home as long as possible.
- If attending for a face to face clinical appointment, they experienced long waiting times between phlebotomy and their clinic appointments.
- The also commented that they experienced long waiting times for the clinical team to issue prescriptions. This was also the case if even if they had contacted the team in advance that a prescription would be required.
- As inpatients they commented on the process of being discharged which they described as lengthy.
- A comment was received that the staff on Fraser Gamble were not always compassionate as they could be.

- Reviewers were told that the staff on Fraser Gamble would not access their existing 'ports' for access and they would either have to wait for a member of the apheresis team or have additional peripheral venous access.
- The three patients who met with the reviewing team were not aware of the alert/ access cards to show staff/depts when seeking emergency care and not all were sure whether they had care plans.
- They did not consider that feedback was always acted upon.

## Immediate Risks

There were no immediate risks identified during the course of the visit

## Good Practice

1. The SHT had been successful in the HAU expansion in RTHU through the National Health Inequalities Improvement Programme funded Sickle Cell ED bypass pilot project.
2. The RHTU was consistently achieving over 90% with the 30 mins time to analgesia metric and the team had also implemented remote prescribing which had reduced the time patients waited for analgesia.
3. Sickle Cell Pain Management Group Programme was very good. It ran as a weekly virtual group led by the Consultant Psychologist at ICHT with the Lead Physiotherapist for Sickle Cell conditions based at SGH. Patients could opt into to the various sessions which consisted of a rotating list of topics. Early evaluation of the programme had been positive with patients commenting how important the group was to keeping them well.
4. All the LHTs felt supported by the SHT and in particular valued the SHT responsiveness in facilitating and holding additional MDTs with them to discuss patients.
5. CNS and link nurses on Fraser Gamble Ward undertook ward rounds to review any patients living with a haemoglobin disorder who had been admitted. Feedback was that these ward rounds were evaluated as being useful to identify where additional support may be needed. The ward also had three designated link nurses all of which had dedicated time for their link work so there was usually link nurse cover on most days.
6. Training in the care of people with haemoglobin disorders and achievement of associated competences had been made mandatory for nursing staff working in areas where most people with a haemoglobin disorder were cared for. Work was also underway to change over and assess staff with the recently published RCN competence framework.
7. The apheresis service had extended their opening times to accommodate patients who were in full time education or employment. The unit was now open Monday to Friday 8am to 8pm and 8am to 4 pm on Saturdays.
8. The appointment of Advanced Nurse Practitioner to support vascular access and the introduction of ultrasound guided cannulation for automated red cell exchange had significantly reduced the need for femoral line insertion and had improved patients' experience.
9. The SHT had appointed a specialist sickle cell pharmacist and, prior to the visit a weekly pharmacist-led medication management clinic had been launched, which ran in parallel with one of the haemoglobinopathy outpatient clinics.
10. The Trust had implemented the blood depletion exchange programme and reported an annual reduction of red cell usage by 1372 units, as well as resulting in a significant financial saving.
11. The Red Cell team had an extensive portfolio of research studies and was the largest non-malignant haematology clinical trials unit in the country. There was a dedicated team of research nurses and clinical research practitioners who supported patient enrolment into clinical trials and observational studies.
12. Divisional management were aware of the challenges and proactively involved with the service, the Divisional Team reported good and open communication with the executive team.

## Serious Concerns

1. **RHTU/HAU expansion and inpatient capacity**

   From discussions during the visit, the reviewers were seriously concerned about the progress in the RHTU/HAU expansion which will result in the HAU seeing an increase in patients with haemoglobinopathy disorders being diverted from LNW. The full implementation of the HAU was also dependant on expanding the inpatient bed base at HH for patients attending the HAU who would then require an inpatient admission. Reviewers were told that discussions had been ongoing for several years with no clear resolution nor timeframe for achieving the additional bed capacity. Reviewers were seriously concerned that this could impact on the capacity available in the RHTU, affect the success of the pilot and may result in the loss of ongoing funding for the HAU.

## Concern

1. **Lack of SHT Lead Nurse and CNS Workload**

   The Trust did not have a nominated lead nurse with responsibility, for guidelines, protocols, training and audit relating to haemoglobin disorders and responsibility for liaison with other services, especially the LHTs linked to the SHT. This had resulted in the absence of nursing voice in the leadership team and was also reflected in the lack of nurse led research and initiatives other than clinics.

   Only two WTE CNS were in post which was insufficient to provide care for 687 patients with a range of haemoglobin disorders and provide nurse led clinics. The CNS time was spent mainly on direct clinical care with little time to be fully involved in the management and work of the SHT.

   Taking into account the changes in patient flow from LNW with the development of the HAU, ensuring that nurse leadership of the SHT is clearly defined will be important as well as addressing the capacity within the CNS team with the ever increasing activity and complexity of patients requiring SHT support.

   Reviewers were told that there was some early work to develop existing staff to a band 6 role to complement the team which reviewers considered should be progressed.

2. **Access to Chronic Pain Service**

   Patients with haemoglobin disorders living with complex chronic pain did not have access to a chronic pain specialist.

3. **Access to Psychology**

   The service had one WTE consultant psychologist which was insufficient for the 685 patients registered with the service and did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE HCPC Senior Psychologist for every 300 patients. The SHT were aware of the need to expand the service especially given the growth of the service and the Bone Marrow Transplant Programme.

4. **Patient Feedback**

   All the patients who met with the visiting team commented that they would rather delay seeking emergency help if there was no capacity at the RHTU rather than attend their local ED. Reviewers were concerned about the potential detrimental effects to patients' health and wellbeing that may be caused by this delay. They were also concerned that once the diversion from LNW to RTHU was implemented, the issues of capacity in the RHTU may be exacerbated.

## Further Consideration

1. At the time of the visit the hydroxycarbamide clinics were not fully nurse led as the CNSs were not yet nurse prescribers. Therefore, the benefit of the nurse led clinics could not be fully realised as they were dependant on the medical team to review and prescribe medication. Reviewers considered as an interim measure that the utilisation of

the existing specialist pharmacy workforce may be a solution to support the clinics, with the longer term strategy for the nursing workforce to make the service fully nurse led.

2. The designated Lead Clinician did not have SHT leadership specified in their job plan with their PAs allocated for direct clinical care which would result in clinical work always taking priority and leadership of the SHT undertaken out of goodwill.
3. Patients who met with the visiting team commented that when they were admitted to the wards staff were either not trained or allowed by the apheresis service to access their existing vascular access ports and they complained that they had to wait for a member of the apheresis team to attend or were subjected to unnecessary peripheral cannulation.

## Commissioning

The review team had discussions with the regional NHS England Specialist Commissioners and the local commissioners from North West London ICB, South West London ICB, and Surrey Heartlands ICB. Several issues in this report will require the active involvement of the Trust leadership team and commissioners to ensure timely progress is made.

## Serious Concern

1. **ICB Commissioning of NHSE Funded Projects**

   Reviewers were seriously concerned that the oversight, governance and project delivery for the NHSE funded pilots, which would normally have been overseen by the ICBs, had been delegated to the HCC. Reviewers were told that this was due to a period of structural change within the ICBs which had resulted in no capacity to support these projects. The requirement to deliver on multiple projects in such a short timeframe had placed a significant workload on the HCC and impacted on their ability to drive the important improvements that the HCC had planned. The oversight of the projects across the region had also impacted on Trust executive leads who were required to attend a significant number of external meetings for these projects.

## Concern

1. **North West London and South West London ICB Engagement with the HCC**

   There was little governance oversight or engagement from the NW and SW London ICBs in the business of the HCC. The HCC was facing many challenges particularly around activity and workforce and it will be important that ICBs are able to provide the level of support required.

2. **Engagement of LHT linked ICBs**

   There was very little or no engagement from ICBs responsible for covering the many LHTs outside of central London. As commissioning arrangements change over the next few years these relationships will be crucial to the provision of appropriately staffed services for patients and HCC involvement and advocacy will be key.

# Appendix 1 Membership of Visiting Team

| Visiting Team | | |
|---|---|---|
| David Simcox | Adult Haemoglobin Consultant | Liverpool University Hospital NHS Trust |
| Hannah Jerman | Clinical Nurse Specialist | Guys and St Thomas' NHS Foundation Trust |
| Paula Lindo | CNS Sickle Cell & Thalassaemia | Croydon Health Services |
| Joy Nwaozo | Network Manager | Barts Health NHS Trust |
| Ruth Anderson | Consultant Psychologist | University College London Hospitals |
| Emma Astwood | Consultant Paediatric Haematologist | Sheffield Children's Hospital NHS Foundation Trust |
| Susan Crawford | Haemoglobinopathy Liaison CNS | Birmingham Women and Children's Hospital |
| Grace Adjei-Clinton | Haemoglobin Specialist Nurse | Whittington Health NHS trust |
| Zoe Hamilton | National Programme of Care Senior Manager – Blood and Infection, Specialised Commissioning | NHS England |
| Cherryl Westfield | User Representative | |
| Rajpal Singh | User Representative | |

| Clinical Leads | | |
|---|---|---|
| Dr Rachel Kesse-Adu | Consultant Haematologist | Guys and St Thomas' NHS Foundation Trust |
| Dr Sabiha Kausar | Consultant Paediatric Haematologist | Manchester University NHS Foundation Trust |

| NHS Midlands and Lancashire | | |
|---|---|---|
| Kelly Bishop | Assistant Director of Nursing and Urgent Care | NHS Midlands and Lancashire |
| Sarah Broomhead | Professional Lead | NHS Midlands and Lancashire |

# Appendix 2 – Compliance with the Quality Standards

Analyses if 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 London Sickle Cell Haemoglobinopathy Coordinating Care Centre | 13 | 11 | 85% |
| Specialist Haemoglobinopathy Team (SHT) Children and Young People | 49 | 43 | 88% |
| Specialist Haemoglobinopathy Team (SHT) Adults | 45 | 38 | 84% |

# Quality Standards – West London Sickle Cell Disorder HCC - All Ages

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| H-198 S | **Network-wide Involvement of Children, Young People, Families, Patients and Carers (SCD)**<br>The Sickle Cell Disorder HCC should have mechanisms for involving children, young people, families, patients and carers, including representation at HCC Business Meetings (QS H-702). | Y | The Patient and Public Voice Group was integrated into the governance of the HCC. The Chair and work of the West London HCC Patient and Public Voice group was included in the HCC website information. |
| 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 | The nominated Lead had 1 PA for leadership of the HCC. A nominated deputy was in place. |
| 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<br>c. Competences in caring for people with haemoglobin disorders<br>The lead nurse should have appropriate time for their leadership role and cover for absences should be available. | N | The Lead Nurse had nominal time for the leadership of the HCC (1 hr per week). |
| H-202A | **Lead Manager**<br>A lead manager should be available with:<br>a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs<br>b. Responsibility for liaison with other services within the network<br>The lead manager should have appropriate time for their role. | Y | |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| 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 | Informal arrangements were in place to provide tertiary support including telephone emergency/email advice and emergency and elective (surgical) inpatient care to local SHTs and LHTs.<br>The process for escalation of patients was included in the SLAs between the SHTs, LHTs and HCC. |
| 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 | Meetings were held monthly alternating between Wednesday and Friday afternoon. |
| 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 | The last meeting between the HCC and NHSBT had been held in November 2024. |

| Ref | Standard | 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 children, young people, families, 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 | Two sets of minutes provided for meetings held in July 24 and January 25 with attendance from participating SHTs and some LHTs. |
| 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 | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| H-704S | **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 | Y | NQA for TCD HCC- TCD service information was provided showing that out of six practitioners – five across the HCC had not completed the required number of 40 scans per annum.<br>*See also CYP section of the main report* |
| 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 | The HCC had a significant and extensive research programme. |
| H-799 | **Document Control**<br>All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | |

## Quality Standards – Care of Children and Young People

| Ref | Standard | 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 | Standard | 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 | Standard | 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>Immunisations<br>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 | Standard | 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 | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HC-199 | **Involving Children, Young People and Families**<br>The service's involvement of children, young people and their families should include:<br>a. Mechanisms for receiving feedback<br>b. Mechanisms for involving children, young people and their families in:<br>i. Decisions about the organisation of the service<br>ii. Discussion of patient experience and clinical outcomes (QS HC-797)<br>c. Examples of changes made as a result of feedback and involvement | N | The service used Trust feedback mechanisms to gain views and patient/carer experience via user experience surveys including the Friends & Family Test and the national Picker Surveys (for SCD and thalassemia).<br>For b) and c) there were plans to strengthen pathways for user feedback and engagement through organising information and educational events for patients/families of both SCD and thalassemia patient groups. These however were not in place at the time of the review. |
| HC-201 | **Lead Consultant**<br>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session(s) identified for the role within their job plan and cover for absences should be available. | N | The lead consultant had insufficient dedicated time for leadership of the SHT. |
| 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 | |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| 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 | |
| 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. | Y | |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HC-208 | **Psychology Staffing and Competences**<br>The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including:<br>a. An appropriate number of regular clinical session(s) for work with people with haemoglobin disorders and for liaison with other services about their care<br>b. Time for input to the service's multidisciplinary discussions and governance activities<br>c. Provision of, or arrangements for liaison with and referral to, neuropsychology<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | N | Only 0.2 wte psychology support was available for patients at the time of the visit although the review team acknowledged the funding for an additional 0.5 wte, with recruitment was underway. |
| 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 | Only one of the six practitioners on the register achieved over 40 scans per year.<br>The review team acknowledged the quality assurance in place by the team to mitigate this. |
| 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 | Y | |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HC-302 | **Specialist Support**<br>Access to the following specialist staff and services should be easily available:<br>a. DNA studies<br>b. Genetic counselling<br>c. Sleep studies<br>d. Diagnostic radiology<br>e. Manual exchange transfusion (24/7)<br>f. Automated red cell exchange transfusion (24/7)<br>g. Pain team including specialist monitoring of patients with complex analgesia needs<br>h. Level 2 and 3 critical care | Y | |
| HC-303 | **Laboratory Services**<br>UKAS/CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available. | Y | |
| HC-304 | **Urgent Care – Staff Competences**<br>Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders. | 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 | Standard | 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 | Standard | 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>a. Indications for chelation therapy<br>b. Choice of chelation drug(s), dosage and dosage adjustment<br>c. Monitoring of haemoglobin levels prior to transfusion<br>d. Management and monitoring of iron overload, including management of chelator side effects<br>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2<br>f. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible | Y | |

| Ref | Standard | 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>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 | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HC-510 | **Clinical Guidelines: Chronic Complications**<br>Guidelines on the management of the chronic complications listed below should be in use covering at least:<br>I. Local management<br>II. Indications for discussion at the HCC MDT<br>III. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred<br>IV. Arrangements for specialist multidisciplinary review<br>a. Renal disease, including sickle nephropathy<br>b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease<br>c. Eye problems, including sickle retinopathy and chelation-related eye disease<br>d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease<br>e. 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 | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HC-601 | **Service Organisation**<br>A service organisation policy should be in use covering arrangements for:<br>a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by an HCC / SHT<br>b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 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 | |
| HC-603 | **Shared Care Agreement with LHTs**<br>A written agreement should be in place with each LHT covering:<br>a. Whether or not annual reviews are delegated to the LHT<br>b. New patient and annual review guidelines (QS HC-502) (if annual reviews are delegated)<br>c. LHT management and referral guidelines (QS HC-503)<br>d. National Haemoglobinopathy Registry data collection (QS HC-701)<br>e. Two-way communication of patient information between HCC/SHT and LHT<br>f. Attendance at HCC business meetings (HC-607) (if applicable)<br>g. Participation in HCC-agreed audits (HC-706) | N | Shared care agreements were not in place for the Bedfordshire Hospitals NHS Foundation Trust. There was specifically confusion over the SHT ownership of the patients at Bedford Hospital since its merger with Luton and Dunstable on 1st April 2020. |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| 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 | Y | |
| HC-607S | **HCC Business Meeting Attendance (SCD)**<br>At least one representative of the team should attend each 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 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 | |
| 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 | |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HC-706 | **HCC Audits**<br>The service should participate in agreed HCC-specified audits (QS H-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. | N | The service used Trust feedback mechanisms to gain views and patient/carer experience via user experience surveys including the Friends & Family Test and national Picker Surveys (for SCD and thalassemia).<br>There were plans to strengthen pathways for user feedback and engagement through organising information and educational events for patients/families of both SCD and thalassemia patient groups. These however were not in place at the time of the review. |
| 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 | |
| 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 | |

## Quality Standards – Care of Adults

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

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

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-105 | **Information for Primary Health Care Team**<br>Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and:<br>a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD)<br>b. Side effects of medication, including chelator agents (SCD and Th)<br>c. Guidance for GPs on:<br>Immunisations<br>Contraception and sexual health<br>d. What to do in an emergency<br>e. Indications and arrangements for seeking advice from the specialist service | Y | |
| HA-194 | **Environment and Facilities**<br>The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. | Y | |
| HA-195 | **Transition to Adult Services**<br>Young people approaching the time when their care will transfer to adult services should be offered:<br>a. Information and support on taking responsibility for their own care<br>b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services<br>c. A named coordinator for the transfer of care<br>d. A preparation period prior to transfer<br>e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care<br>f. Advice for young people leaving home or studying away from home including:<br>i. Registering with a GP<br>ii. How to access emergency and routine care<br>iii. How to access support from their specialist service<br>iv. Communication with their new GP | Y | |
| HA-197 | **Gathering Patients' and Carers' Views**<br>The service should gather patients' and carers' views at least every three years using:<br>a. 'Patient Survey for Adults with a Sickle Cell Disorder'<br>b. UKTS Survey for Adults living with Thalassaemia | Y | Both surveys had been undertaken in November 2024 and met the 10% response rate<br>Sickle Cell Disorders: 52/454 pts.<br>Thalassaemia: 9/76 pts. |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-199 | **Involving Patients and Carers**<br>The service's involvement of patients and carers should include:<br>a. Mechanisms for receiving feedback<br>b. Mechanisms for involving patients and their carers in:<br>i. Decisions about the organisation of the service<br>ii. Discussion of patient experience and clinical outcomes (QS HA-797)<br>Examples of changes made as a result of feedback and involvement | Y | |
| HA-201 | **Lead Consultant**<br>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available. | N | Leadership time for the SHT was not specifically allocated and the Lead had the same number of PAs (5) and clinical commitments as all the other red cell consultants. |
| HA-202 | **Lead Nurse**<br>A lead nurse should be available with:<br>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders<br>b. Responsibility for liaison with other services<br>c. Competences in caring for people with haemoglobin disorders<br>The lead nurse should have appropriate time for their leadership role and cover for absences should be available. | N | There was no lead nurse with designated responsibility for 'a' and 'b'. |
| HA-204 | **Medical Staffing and Competences: Clinics and Regular Reviews**<br>The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD.<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | Y | Four Consultants had a primary interest in haemoglobinopathies (20 PAs for the care of 687 pts) and had responsibility for the care of inpatients with haemoglobin and other red cell disorders on a rotational basis.<br>Outpatient activity was at pressure with extended waiting times for follow up but being ameliorated with the recruitment of an additional consultant. |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-205 | **Medical Staffing and Competences: Unscheduled Care**<br>24/7 consultant and junior staffing for unscheduled care should be available.<br>SHTs and HCCs only:<br>A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available. | Y | Seven full time consultants (four of whom had a primary interest in haemoglobinopathies) had responsibility for unscheduled care of patients with haemoglobin and other red cell disorders. |
| HA-206 | **Doctors in Training**<br>If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders. | Y | |
| HA-207 | **Nurse Staffing and Competences**<br>The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>a. Clinical nurse specialist(s) with responsibility for the acute service<br>b. Clinical nurse specialist(s) with responsibility for the community service<br>c. Ward-based nursing staff<br>d. Day unit (or equivalent) nursing staff<br>e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion.<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | N | The SHT had only two WTE CNS for the 687 patients. *See main report.* |
| HA-208 | **Psychology Staffing and Competences**<br>The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care<br>b. Time for input to the service's multidisciplinary discussions and governance activities<br>c. Provision of, or arrangements for liaison with and referral to, neuropsychology<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available. | N | One WTE Psychologist in post for 687pts.<br>The trust was in the process of appointing to one WTE community outreach psychologist post but this was part of the community project for North East London. |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-299 | **Administrative, Clerical and Data Collection Support**<br>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service. | Y | The team had administrative and clerical support as well as a Quality Lead (0.3 WTE) and a Quality Manager (1.0 WTE) to support the Red Cell Service |
| HA-301 | **Support Services**<br>Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required:<br>a. Social worker / benefits adviser<br>b. Leg ulcer service<br>c. Dietetics<br>d. Physiotherapy (inpatient and community-based)<br>e. Occupational therapy<br>f. Mental health services | Y | The SHT had a dedicated Social Worker and access to a Specialist Haematology Physiotherapist and Dietetics service. |
| HA-302 | **Specialist Support**<br>Access to the following specialist staff and services should be easily available:<br>a. DNA studies<br>b. Genetic counselling<br>c. Sleep studies<br>d. Diagnostic radiology<br>e. Manual exchange transfusion (24/7)<br>f. Automated red cell exchange transfusion (24/7)<br>g. Pain team including specialist monitoring of patients with complex analgesia needs<br>h. Level 2 and 3 critical care | Y | |
| HA-303 | **Laboratory Services**<br>UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available. | Y | |
| HA-304 | **Urgent Care – Staff Competences**<br>Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders. | Y | Compliance with the NICE guidance on analgesia with 30 mins of arrival ranged between 80 -100% . |

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

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-505 | **Transfusion Guidelines**<br>Transfusion guidelines should be in use covering:<br>a. Indications for:<br>i. Emergency and regular transfusion<br>ii. Use of simple or exchange transfusion<br>iii. Offering access to automated exchange transfusion to patients on long-term transfusions<br>b. Protocol for:<br>i. Manual exchange transfusion<br>ii. Automated exchange transfusion on site or organised by another provider<br>c. Investigations and vaccinations prior to first transfusion<br>d. Recommended number of cannulation attempts<br>e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion<br>f. Patient pathway for Central Venous Access Device insertion, management and removal | Y | |
| HA-506 | **Chelation Therapy**<br>Guidelines on chelation therapy should be in use covering:<br>a. Indications for chelation therapy<br>b. Choice of chelation drug(s), dosage and dosage adjustment<br>c. Monitoring of haemoglobin levels prior to transfusion<br>d. Management and monitoring of iron overload, including management of chelator side effects<br>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2<br>f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible | Y | |
| HA-507 | **Hydroxycarbamide and Other Disease Modifying Therapies**<br>Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering:<br>a. Indications for initiation<br>b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide<br>c. Documenting reasons for non-compliance<br>d. Monitoring of complications<br>e. Indications for discontinuation | Y | |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-508 | **Non-Transfusion Dependent Thalassaemia (nTDT)**<br>Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering:<br>a. Indications for transfusion<br>b. Monitoring iron loading<br>c. Indications for splenectomy<br>d. Consideration of options for disease modifying therapy | Y | |
| HA-509 | **Clinical Guidelines: Acute Complications**<br>Guidelines on the management of the acute complications listed below should be in use covering at least:<br>i. Local management<br>ii. Indications for seeking advice from the HCC/SHT<br>iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred<br>For patients with sickle cell disorder:<br>a. Acute pain<br>b. Fever, infection and overwhelming sepsis<br>c. Acute chest syndrome<br>d. Abdominal pain and jaundice<br>e. Acute anaemia<br>f. Stroke and other acute neurological events<br>g. Priapism<br>h. Acute renal failure<br>i. Haematuria<br>j. Acute changes in vision<br>For patients with thalassaemia:<br>k. Fever, infection and overwhelming sepsis<br>l. Cardiac, hepatic or endocrine decompensation | Y | |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-510 | **Clinical Guidelines: Chronic Complications**<br>Guidelines on the management of the chronic complications listed below should be in use covering at least:<br>i. Local management<br>ii. Indications for discussion at the HCC MDT<br>iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred<br>iv. Arrangements for specialist multidisciplinary review<br>a. Renal disease, including sickle nephropathy<br>b. Orthopaedic problems, including the management of sickle and thalassaemia-related bone disease<br>c. Eye problems, including sickle retinopathy and chelation-related eye disease<br>d. Cardiological complications, including sickle cardiomyopathy and iron overload related heart disease<br>e. Pulmonary hypertension<br>f. Chronic respiratory disease, including sickle lung disease and obstructive sleep apnoea<br>g. Endocrine problems, including endocrinopathies and osteoporosis<br>h. Neurological complications, including sickle vasculopathy, other complications requiring neurology or neurosurgical input and access to interventional and neuroradiology<br>i. Chronic pain<br>j. Hepatobiliary disease, including sickle hepatopathy, viral liver disease and iron overload-related liver disease<br>k. Urological complications, including priapism and erectile dysfunction<br>l. Dental problems | N | 'l' Dental was not covered in the guidance. |
| HA-511 | **Anaesthesia and Surgery**<br>Guidelines should be in use covering the care of patients with sickle cell disorder and thalassaemia during anaesthesia and surgery. | Y | |

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

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-601 | **Service Organisation**<br>A service organisation policy should be in use covering arrangements for:<br>a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission<br>b. Patient discussion at local multidisciplinary team meetings (QS HA-604)<br>c. Follow up of patients who 'did not attend'<br>d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care<br>e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together<br>f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations | Y | Reviewers considered that Red Cell Operational Policy could be clearer in places.<br>Guidance for 'f' was covered in a Trust wide policy |
| HA-603 | **Shared Care Agreement with LHTs**<br>A written agreement should be in place with each LHT covering:<br>a. Whether or not annual reviews are delegated to the LHT<br>b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated)<br>c. LHT management and referral guidelines (QS HA-503)<br>d. National Haemoglobinopathy Registry data collection (QS HA-701)<br>e. Two-way communication of patient information between HCC/SHT and LHT<br>f. Attendance at HCC business meetings (HA-607) (if applicable)<br>g. Participation in HCC-agreed audits (HA-706) | Y | SLAs were in place with all the SHT linked LHTs - Hillingdon, West Hertfordshire, Chelsea & Westminster. |
| HA-604 | **Local Multidisciplinary Meetings**<br>MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when requested, representatives of support services (QS HA-301). | Y | |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-606 | **Service Level Agreement with Community Services**<br>A service level agreement for support from community services should be in place covering, at least:<br>a. Role of community service in the care of patients with haemoglobin disorders<br>b. Two-way exchange of information between hospital and community services. | Y | An SLA was in place with Central London Community Healthcare NHS Trust. |
| HA-607 S | **HCC Business Meeting Attendance (SCD)**<br>At least one representative of the team should attend each HCC Business Meeting (QS HA-702). | Y | |
| HA-607 T | **HCC Business Meeting Attendance (Th)**<br>At least one representative of the team should attend each HCC Business Meeting (QS HA-702). | Y | The Red Cell Network – Thalassaemia HCC |
| HA-701 | **National Haemoglobinopathy Registry**<br>Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed. | Y | |
| HA-705 | **Other Audits**<br>Clinical audits covering the following areas should have been undertaken within the last two years:<br>a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505)<br>b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions | N | 'a' had not been completed but scheduled to commence in February 2025. |
| HA-706 | **HCC Audits**<br>The service should participate in agreed HCC-specified audits (QS H-702d). | Y | |
| HA-707 | **Research**<br>The service should actively participate in HCC-agreed research trials. | Y | The SHT had an extensive research programme. |

| Ref | Standard | Met Y/N | Reviewer comment |
|---|---|---|---|
| HA-797 | **Review of Patient Experience and Clinical Outcomes**<br>The service's multidisciplinary team, with patient and carer representatives, should review at least annually:<br>a. Achievement of Quality Dashboard metrics compared with other services<br>b. Achievement of Patient Survey results (QS HA-197) compared with other services<br>c. Results of audits (QS HA-705):<br>i. Timescales and pathway for regular transfusions<br>ii. Patients admitted to inappropriate settings<br>Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored. | N | 'c i' was planned for February 2025. Some of the patients who met with the visiting team were not clear about what happens as a result of feedback. All other aspects of the QS were met. |
| HA-798 | **Review and Learning**<br>The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'. | Y | |
| HA-799 | **Document Control**<br>All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | |