MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

West Midlands Sickle Cell Haemoglobinopathy Coordinating Centre

Midlands Thalassaemia and RIA Haemoglobinopathy Coordinating Centre

Sandwell and West Birmingham Hospitals NHS Trust

Visit date: 17th May 2024

Report date: 19th September 2024

Contents

Introduction

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

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

A comprehensive peer review of Local Haemoglobinopathy Teams (LHT) against the Local Haemoglobinopathy Team Quality Standards were not part of the 2024 -2026 programme, however Haemoglobinopathy Coordinating Centres were given the option to request a review visit for any of their Local Haemoglobinopathy Teams in their review visit programme.

The aim of the standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Any immediate risks identified will include the Trust and UKFHD/MLSCU response to any actions taken to mitigate against the risk. Appendix 1 lists the visiting team that reviewed the services in Birmingham 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:

- Sandwell and West Birmingham Hospitals NHS Trust
- NHS England -Midlands Region
- Birmingham and Solihull Integrated Care System
- Black County Integrated Care System

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioners in relation to this report is NHS Birmingham and Solihull Integrated Care Board.

About the UKFHD and MLCSU

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

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

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

Acknowledgements

The UKFHD and MLCSU would like to thank the staff and service users and carers of the Birmingham Health economy for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks, are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

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Review Visit Findings

West Midlands Sickle Cell Haemoglobinopathy Coordinating Centre

Midlands Thalassaemia and Rare Inherited Anaemias

General Comments and Achievements

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Good Practice

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

Concerns

1. Local Haemoglobinopathy Team engagement

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

2. 24hr Advice for adult patients across the HCC

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

3. Lead nurse role

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

4. Transcranial Doppler Ultrasound

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

Further Consideration

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

Sandwell and West Birmingham NHS Trust – Trust-wide

General Comments and Achievements

This review looked at the health services provided for adults with haemoglobin disorders at Sandwell and West Birmingham NHS Trust. During the visit, reviewers attended the City Hospital and visited the emergency department, Sickle Cell and Thalassaemia Centre (SCaT) and wards. They met with patients and carers, and with staff providing services for the local health economy.

Sandwell and West Birmingham Hospitals NHS Trust was an integrated care organisation and responsible for the care of 530,000 local people from across North-West Birmingham and Sandwell. Many of the services were preparing to move to the Midland Metropolitan University Hospital in the autumn of 2024.

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

The adult SHT provided a service to the regions of Hereford and Worcestershire, Shropshire, Staffordshire, Warwickshire and the West Midlands. In total the Trust serves 792 patients with Haemoglobin Disorders, mostly sickle cell disorders (SCD).

Some issues in this report relate specifically to the Trust as a whole and have been included in the Trust-wide section of the report. Other issues are detailed in the adult SHT section of the report.

Trust wide Immediate Risk

1 Antenatal and Paediatric Community Haemoglobinopathy Service

Reviewers identified an immediate risk in the pathway for providing timely antenatal support, which is crucial for enabling informed decision making during pregnancy and ensuring affected babies receive appropriate follow-up and treatment. This risk could result in lack of parental choice, an increase in number of births of affected children, and delays in identifying and transitioning affected newborns into clinical care.

The provision of antenatal screening is a national mandate (Antenatal screening - GOV.UK (www.gov.uk). Likewise there are very clear measures for neonatal screening (Newborn screening - GOV.UK (www.gov.uk) which require prompt identification and counselling of affected newborn children so that appropriate treatment can be initiated.

Following the notice in March 2024 from Birmingham Community Healthcare NHS Trust (BCHC) to transfer the service, Sandwell and West Birmingham NHS Trust (SWBH) assumed responsibility in March 2024. The commissioned service aimed to provide antenatal screening, follow-up, and a community paediatric haemoglobinopathy service across Birmingham, a high-prevalence area for Sickle Cell Disease, Thalassaemia, and Rare Inherited Anaemias. Notably, there was no consultation with the clinical staff within the SHT who were expected to deliver these services.

At the time of the visit, the service comprised a 0.6 WTE nurse with administrative support, and reviewers were informed that the nurse was scheduled to leave the service the following week. The current SHT staff lacked the necessary training and competencies to provide this level of care. While they were undergoing relevant training for genetic risk assessment and counselling, they also did not have the capacity to deliver a comprehensive antenatal or paediatric community service.

It was unclear how the management and executive teams at SWBH (who currently held the contract for delivering this service) has escalated and responded to the significant risk posed by the lack of provision of this mandated service.

Since April, SWBH had been unable to provide a paediatric community haemoglobinopathy service, which includes newborn referrals, home visits, development of care plans, patient annual reviews, GP and patient education (particularly around admission/readmission prevention), assistance with social challenges, and welfare support for children and young people.

Reviewers were unable to explore the antenatal service arrangements in place across the rest of Birmingham.

Discussions during the visit made it clear to reviewers that system-wide cooperation and support is required between the Trust management and the SHT, working with BCH and commissioners to collaboratively address the issues surrounding antenatal screening, follow-up, and the provision of both an antenatal and paediatric haemoglobinopathy community service.[1]

Trust-wide Serious Concern

1 Emergency Department Pathway

Reviewers were seriously concerned about the pathway for patients with haemoglobin disorders for the following reasons:-

a. Access to analgesia

Compliance with the NICE guidance on the timeliness of analgesia audit undertaken showed that only 38% who attended the ED, had their analgesia administered within 30 mins of presentation.

b. Care in the Emergency Department

The SHT team had been very proactive in reviewing the ED pathway with ED staff from triage to developing a prescribing bundle and had developed posters and other resources for the department. Despite this reviewers were concerned that the experience of some patients was less than optimal.

Three patients who met with the reviewers reported that their experience in ED was very poor, often having to wait a long time to be assessed and not receiving timely analgesia as they were not viewed as being an emergency. Patients felt that staff did not have sufficient knowledge about their condition and the level of pain they experienced during a vaso-occlusive crisis (VOC). One of the patients new to the area hoped they would never have to visit the ED at City hospital again.

c. Sickle Cell Red Information Boxes

Reviewers were concerned about the governance of the contents of the sickle cell boxes and whether they were actually in use. The contents of the box seen in the ED had guidelines which were dated for review in 2022 and were not the latest trust version. The box also contained some printed individualised care plans, but it would not be clear to staff whether these were the latest versions of the patient's care plan. From discussions it was not clear that the ED had robust processes in place to ensure that the information contained in the boxes was correct and up to date.

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[1] Trust response: Sandwell and West Birmingham NHS Trust (SWB) fully accept and recognise this finding. We are actively engaged in conversations with University Hospitals Birmingham and Birmingham Women's and Childrens service to mutually agree an interim support solution to enable continuity of service for antenatal counselling. SWBH have implemented a training program with internal staff that will allow us to fully deliver this service from Q4 23/24. This risk has routinely been raised with the BSOL commissioning team and thought to be fully understood. SWB have in good faith and with the best interests of the patients we serve regionally taken on the community Haemoglobinopathy Service. This was following a request from the BSOL ICB team as the previous provider was struggling with sustainability. This service was known to have significant challenges on transfer and a recover plan was agreed with the ICB team. It is our belief that the present commissioning model does not support ongoing safe
provision of service for the age range required within the financial envelope provided. Following the pending recruitment to inherited vacancies we will be in a position to deliver adult community services and antenatal counselling as per the commissioned requirements. We are not able to develop the specific skills to deliver the paediatric Community Haemoglobinopathy Service and are in discussions with Birmingham Women's and Children's NHS Foundation NHS Trust on a potential partnership model with commissioner support.

BSOL ICB Response is included in commissioning section of the report

Five members of ED staff spoken to during the visit were not aware of where the resources could be located or that processes were in place to optimise time to analgesia with regard to the NICE standard.

Trust-Wide Concern

1 Collaborative working

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

2. Patients on outlying wards and Midland Metropolitan Hospital capacity

Reviewers were told that the planned bed base for haematology was reduced from 32 beds that were initially allocated, to 16 beds when the haematology service moves to MMUH. At the time of the visit there were patients with haemoglobin disorders on six outlying wards due to the lack of available haematology beds.

Reviewers were concerned about the inpatient capacity when the service moves in the autumn. From discussions with staff and commissioners during the visit, reviewers heard mixed views about how the bed base had been calculated, some thought it had been calculated on recent bed occupancy whereas others were of the view that it was old data. Reviewers were concerned that it was highly likely that capacity would be insufficient for the activity now and in the future and they were not assured that any plans were in place to mitigate the risks. Commissioners reported that a reduction of inpatient capacity would be mitigated by more care in the community. At the time of the visit there were no plans to commission increased care in the community for adult patients with haemoglobin disorders and the existing service was already at significant risk (see immediate risk section of the report).

An audit of acute admissions to inappropriate settings had not been completed and reviewers considered that if undertaken it would provide a more up to date position on patient activity and identify any pathway issues that should be taken into consideration as part of the preparation to the move. Following the visit the trust commented that the haemoglobinopathy flow and pathway would be reviewed as part of the preparedness to the move to the MMUH.

Trust-Wide Further Consideration

1. Reviewers also identified other issues for patients attending the ED.

a. There appeared to be an attitude that patients with haemoglobin disorders were viewed differently to others attending the ED with the view that they were 'SCAT' patients rather than a patient of the hospital. Often SCAT was contacted as soon as the centre opened to transfer the patient for management, which should have been commenced in the ED and at other times staff were pressurised to attend the ED when there was no capacity in the centre.

b. Patients living with thalassaemia did not have alert 'flags' on the ED system. Although attendances were low reviewers considered that it was important that the haematology team were also alerted if patients with thalassaemia had attended the ED. Alert 'flags' were in place for patients with a sickle cell disorder.

c. In view of the feedback from patients, adding as mandatory, training on haemoglobin disorders for ED staff may help with raising awareness of these conditions and improve the patient pathway, particularly access to analgesia.

Views of Service Users and Carers

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

Throughout the visit, the reviewers had the opportunity to meet and interact with a total of fourteen individuals, consisting of seven individuals living with transfusion dependent thalassaemia, six individuals living with sickle cell disease, as well as one caregiver.

The views of the users were extensive and wide-ranging and are documented in the adult specialist haemoglobinopathy team section. 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 (Adult Services)

General Comments and Achievements

This was a well organised, dedicated team who were working incredibly hard and flexibly to meet the needs of their patients and families. The SHT were insightful and were clear about what they wanted to achieve both locally and for their constituent LHTs as well as the challenges they faced.

The adult haemoglobinopathy service at SWBH managed the care of 792 adults with haemoglobinopathy diagnoses who were registered on the National Haemoglobinopathy Register. The SHT had seen an 165% increase in patient numbers over the last 5 years.

Since the last peer review visit in 2016 the trust had 24/7 access to red cell exchange provided by NHSBT.

The team consisted of two consultants, who had a total of 11 PAs for dedicated haemoglobinopathy sessions in their job plans to manage the care of both inpatients and outpatients. There were two dedicated haemoglobinopathy specialist nurses/liaison sisters (1.3 WTE band 6) and 0.8 WTE psychologist with support from a 1 WTE band 4 psychology assistant. The SHT had some support from the 0.8WTE B6 Network Coordinator along with funding for an additional B3 data administrator 0.6WTE which at the time of the visit was vacant and covered by long-term bank.

The team was proactive in conducting annual reviews, often completing them for transfused patients on transfusion days. For patients with thalassaemia and RIA, 60% of annual reviews were completed at SWBH, with 43% of patients having completed reviews across the network. For those living with a sickle cell disorder, 77% of annual reviews were completed at SWBH, and a total of 58% across the West Midlands network.

The SHT/ West Midlands Sickle Cell HCC published a quarterly newsletter - SCAT News which provided useful information on self-care and news items.

As an SHT, they considered a measure of success to be ensuring that all high-risk patients had care plans and were offered disease-modifying treatments. Additionally, they emphasised the importance of having consistent treatment pathways across local hospitals. They expressed a strong interest in engaging with patient groups to develop their own bite-sized educational tools.

CARE OF ADULTS			
Sandwell and West Birmingham Hospitals NHS Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)		
	West Midlands Sickle Cell HCC Midlands Thalassaemia and Rare Inherited Anaemias HCC *(Both hosted by Sandwell and West Birmingham Hospitals NHS Trust in partnership with Birmingham Women's and Children's Hospital NHS Foundation Trust)*		
	Linked Local Haemoglobinopathy Teams (LHT)	Patient Distribution	
		SCD	Thal.
	Dudley Group of Hospitals,	13	1
	The Royal Wolverhampton Hospitals NHS Trust	126	9
	Shrewsbury and Telford Hospital NHS Trust	26	2
	University Hospitals Birmingham NHS Foundation Trust	16	11
	University Hospitals Coventry and Warwickshire	104	36
	University Hospital North Midlands,	32	20
	Walsall Healthcare NHS Trust	7	2
	Worcestershire Acute Hospitals NHS Trust	13	5
	Wye Valley NHS Trust	2	3

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *2	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Adults	624 (510 SWBH + shared care 114 LHT)	624	443	44	140 (SWBH and LHT pts)	234. Of those 9= 20+ days (2022-23)
Thalassaemia	Adults	168 (34 shared care LHT)	168	131	90	N/A	Not reported

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant haematologist dedicated to work with patients with hemoglobinopathies	792	11PAs/ 1.1 WTE
Clinical Nurse Specialist for adult patients dedicated to work with patients with hemoglobinopathies	792	1.3 WTE
Clinical Nurse Specialist for adult patients dedicated to work with patients with hemoglobinopathies in the community	792	Liaison sisters (0.6WTE & 0.5WTE) Antenatal 0.8wte *(vacant from end of June 24)*
Clinical Psychologist for adult patients dedicated to work with patients with hemoglobinopathies	792	0.8 WTE -band 8a & 1WTE - band 4

Emergency Care

Patients presenting with acute complications of their haemoglobin disorder could either present to the SCAT centre during normal working hours; or to the Emergency Department (ED) out of normal working hours. Patients who presented to the ED during working hours were assessed by the SCAT outreach nurse and medical team to expedite treatment. The majority of patients who presented to the Emergency Department attended City Hospital.

A process was in place for an email alerts to be sent to the team if patients with a sickle cell disorder or thalassaemia attended the ED.

An on-call haematologist (Consultant or haematology registrar) was available out of hours via switchboard for emergency advice.

Inpatient Care

SWBH Trust had two main hospitals, City Hospital where the SCAT centre was located and Sandwell General Hospital. There were emergency departments and critical care services on both sites. Certain medical specialities were located on each site; clinical haematology was located on the City Hospital site along with maternity services whereas elective surgery was based at Sandwell Hospital. From Autumn 2024 many of the inpatient services were due to move to the new hospital site - Midland Metropolitan University Hospital (MMUH).

[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 .

At the time of the visit, patients were admitted either to Ward D12, a 9 bedded ward shared between Haematology/Oncology or D27 which had 21 beds and was shared with acute medicine.

Nurses on both wards had received training in the management of sickle cell disease and could implement and monitor patient control analgesia devices. Depending on bed capacity, patients were also admitted to other wards. In this setting the outreach nurse, once notified, would aim to support the clinical teams.

Sickle Cell and Thalassaemia Centre (SCAT)

The Sickle Cell and Thalassaemia Centre (SCAT) was the hub of the haemoglobinopathy service having been in operation for more than 22 years. The centre was open Monday to Friday between the hours of 9am – 5 pm with a Saturday service two to three times per month though weekend opening was not funded, this was through good will of the nurses to support school, university and work going patients. Some appointments were booked; but the service was predominantly a walk-in service. The team were active in providing training and education for patients and staff.

The centre consisted of consulting rooms, four beds for patients to receive blood transfusions and four beds for patients requiring management of acute complications. There were dedicated rooms for haemoglobinopathy patients to see the psychologist and for phlebotomy.

If capacity allowed patients with sickle cell disorders who presented with acute painful VOC crises were able to attend for pain management. Patients were also able to attend for post discharge and ad hoc reviews.

The team provided outreach support for inpatients, and in-reach for patients presenting to ED when the SCAT centre was at full capacity.

Outpatient Care

Outpatient clinics were held in the SCAT centre. There were two consulting rooms used on a daily basis for clinics as well as daily/ ad hoc reviews in the SCAT centre.

Patients could be referred from multiple sources- primary care, secondary care, transition patients (predominantly from Birmingham Women's and Children's Hospital NHS Foundation Trust), voluntary sector, other haematology colleagues.

Routine clinics were held on Tuesday afternoons and Thursday mornings. Both were attended by one or both of the haemoglobinopathy consultants , haematology specialist registrar, and SCAT nursing team. Processes were in place for the admin team to identify those patients requiring an annual review. Remote/virtual reviews were also available. Reviews outside of scheduled clinic times were arranged as per clinical need/ ad-hoc, and on occasions would occur at weekends.

Clinic capacity was in the process of being reviewed prior to the move the MMUH with the plan that there would be the option for more face to face consultant appointments.

Community-Based Care

Community support for patients was very limited. The trust had two part time specialist/liaison sisters (0.6WTE & 0.5WTE) who could support patients with admission and readmission prevention, patient education, transition as well as offering welfare and social assistance. Following the transfer of the antenatal screening service from the local community trust, the acute trust lead nurse was having to coordinate the antenatal screening follow up *(see immediate risk section of the report).*

Views of Service Users and Carers

Patient surveys had been undertaken in 2023 for both those living with a sickle cell disorder and thalassaemia and rare inherited anaemias. Responses had been relatively low (23 and 4 respectively). The results and themes had been analysed and the majority of those who responded were satisfied or very satisfied with the level of care they received.

Feedback from Service Users and Carers

Before and during the visit, the visiting team met a total of fourteen adults, six were living with a sickle cell disorder and one care giver, and seven were living with transfusion dependent thalassaemia. The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences.

Patient feedback from Sickle Cell Disorder meetings

The visiting team received positive feedback from everyone they spoke to regarding the SHT. They expressed their satisfaction with the strong rapport they had with the staff, who were seen as approachable and responsive in addressing any concerns or questions.

- Three of those who were at the meeting were concerned that as the SCaT was a day service they did feel quite vulnerable when the centre was closed.
- There were different experiences expressed about care in the ED. Four reported that their experience in ED was very poor, often having to wait a long time to be assessed and not receiving timely analgesia as they were not viewed as being an emergency and staff did not understand their pain. One of the patients new to the area hoped they would never have to visit the ED at City hospital again. Two others spoke highly of their care in the ED, as they had been seen quickly and analgesia was given promptly and they kept in the 'majors' section of the ED and then transferred to ward
- Parents of young adults also commented about the poor care in the ED and that they would rather go to their local hospital in Coventry where staff had more understanding of their condition.
- One parent spoke of their young adult's experience of receiving a manual exchange transfusion out of hours during the Covid Pandemic. The relative felt it was a high risk intervention at the best of times and made worse by being undertaken by less experienced staff and the experience had clearly traumatised the patient and the family.
- There were mixed views about the care received with some saying that the shared care when their children were at University was often better.
- The transition pathway worked well, and they had felt supported.
- One patient who met with the reviewing team commented that the sinks and toilets on Ward 12 were dirty and they did not think they had been cleaned for two days.
- Patients were very complimentary of the pharmacist who they felt was very knowledgeable about hydroxycarbamide.

Patient feedback from Thalassaemia meetings

All were extremely positive about the service they received and although had a few comments where improvements could be made overall, they felt well cared for.

Everyone expressed extreme satisfaction with the service they received, and although they had a few suggestions for improvement, overall, they felt they were well cared for by a knowledgeable and empathetic team.

- All individuals mentioned that they had the option to speak with their consultant if necessary and could easily contact the CNS when needed.
- They regularly received copies of their clinic letters and felt they had access to additional information if they needed it.
- Many appointments were conducted over the phone with members of the MDT and this arrangement worked well. However, some patients expressed a desire for occasional face-to-face appointments with their consultant. The general consensus was that if their condition was stable, they would not need to see the consultant face to face.
- Patients felt they were able to establish a rapport with the staff, but it was evident that new nurses lacked experience and knowledge sometimes resulting in treatment delays. However, they understood that new clinical staff needed time to learn. All the nurses were accommodating, especially when faced with difficult cannulation. New staff and trainee doctors always had a senior nurse nearby for assistance when cannulation problems occurred.
- All patients had access to their care plans through an app.
- Patients felt if they had any issues or concerns, they could express them to the team in confidence.
- When they attended SCaT), they received updates and other news, leaving them feeling well-informed.
- Those who had transitioned from BWCH found it to be a positive experience. They initially felt overwhelmed and needed time to adapt, but ultimately, they were happy with the service.
- Patients commented that it would be nice to have access to entertainment at times, but they acknowledged that planning their visits often allowed them to attend with 'friends'.
- The food was not great on weekends, but they considered this a minor inconvenience compared to not having the option available. During the week, they could have a hot meal from the canteen.
- Access to transfusions was flexible, allowing them to arrange them around their work schedule. They suggested having tables available for those trying to work, as balancing laptops was challenging. Patients also had the option of Saturday transfusions a few times a month.
- Patients expressed the need for more psychological input, they commented that they didn't know
- psychological service was available and would value group sessions as well as the option to a

  have one to one time.
- Patients were very complimentary of the pharmacist who they felt was very knowledgeable of thalassaemia and their chelation needs. They also commented that they felt very well listened to.
- The team asked for feedback every year, and they understood the importance of this. However, they suggested receiving the feedback form via email as it was difficult to complete when being transfused and having only one hand available.

Good Practice

1 Reviewers were impressed that the SHT had undertaken an audit of all high-risk patients living with thalassaemia which had shown that patients were being appropriately screened and monitored for complications of their condition. The audit had particularly considered the cohort of patients who were over 35 years of age and every patient known to have cardiac iron loading.

2 The work of the pharmacist was impressive. The post holder had only been in position for a few months but had been extremely proactive in building relationships with patients and was planning to commence hydroxycarbamide and disease modifying treatment monitoring clinics. The pharmacist had also completed an audit covering iron chelation for patients with thalassaemia.

3 An audit of presentations to SCAT for pain relief during a sickle cell crisis, from April 2021 – March 24 showed that 98% of had received analgesia with 30 mins of presentation.

4 Despite the shortfall in workforce the SHT were providing a good range of targeted education about haemoglobin disorders for ED, ward staff, doctors in training, and for primary care colleagues. As part of the staff nurse development programme, the ward sister on Ward D27 was working with staff to manage cultural attitudes and perceptions about haemoglobin disorders. There was a good training plan for doctors in training and the team commented that doctors in training had the opportunity to be involved in all aspects of HBO. The SHT had also developed some very good educational videos which could be accessed via the WMSTN website.

5 The ward signage and information available and displayed in areas was very well balanced between sickle cell disorders and thalassaemia as noted by reviewers who observed this was not consistently the case in other services and areas visited during this peer review programme. Of note was the poster of the APPG "No one's listening Report".

6 Recognising the poor experience of patients with sickle cell disorder attending the City ED and the low compliance with the NICE Clinical Guideline on the management of acute pain, the team had reviewed the triage process, prescribing bundle in ED, developed posters and other resources for the department. 'Sickle boxes', which were red boxes with sickle cell guidelines, complex patients' individualised care plans, SCAT contact detail, easy step-by-step guideline for management of care and escalation had been implemented. Regular meetings were held between the SCAT lead nurse and matrons for ED and haematology which had seen the development of 'sickle champions' in ED and more proactive in- reach support.

7 The process for transitioning young people to adult service was very good. Transition information and the process was based on 'The Ready Steady Go' transition programme and the transition leaflet for those living with thalassaemia was very well written and informative. The service held quarterly transition evenings for patients and families to come and look around the service and meet some of the staff. Pre-transition reviews were held with the young person and nursing staff and transition meetings were also offered in the in-school holidays after young people had completed their exams. Nurses from the service also delivered regular presentations outlining the key stages in the transition process.

8 A good range of sub-specialist clinics were in place for patients. Clinics ranged from orthopaedic, endocrine, obstetric, teenage transition and chronic pain. A joint sub specialist renal MDT was also in place.

9 The condition specific information leaflets for GPs were novel and very informative.

10 The SHT had been successful in gaining an additional clinical registrar post on rotation via the deanery. This will improve access to specialist haemoglobinopathy training for regional registrars, as well as improve capacity and resilience within the specialist team. The reviewing team felt it would be important that both registrar posts continue to be protected for the service in order to improve regional haemoglobinopathy training and increase the likelihood that trainees consider this underrepresented subspecialty as a future career or special interest option.

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

Serious Concern

1 Maintaining services due to staffing and capacity

a. Consultant Staffing

Reviewers were seriously concerned that the service had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care and clinics for the 792 patients under their care.

i At the time of the visit, the two consultants had only 11 programmed activity (PA) sessions rather than the recommended 29.2 PAs required for work with the service which included work with the SHT network, audit, research and leadership of both HCCs.

ii Some available HCC programmed activity funding had been added to create an additional consultant haematologist post which would provide 0.5wte for the care of patients with haemoglobinopathies however the trust had not been able to recruit to this vacancy.

iii Although the team was proactive in liaising with their constituent local haemoglobinopathy teams (LHTs), their clinical commitments limited the time available to develop and support these teams as expected of SHT and HCC providers. The LHTs also faced a significant increase in patient numbers and reported increasing pressure in trying to care for this cohort with a limited number of experienced staff in haemoglobinopathies.

iv The lack of available time had also resulted in key audits not being undertaken and limited time to access research opportunities.

The Trust was aware of the situation; however, reviewers were concerned that the lack of capacity will become more pronounced with the increase in the number of service users which is likely to continue year on year. There was no evidence of a plan in place to remedy the situation should recruitment to the vacant consultant post not be successful.

b. Clinical Nurse Specialist Workload

The Lead CNS role included a significant clinical workload and in practice did not have sufficient time for leadership of the SHT in terms of oversight of guidelines, training, and audit or for liaison with other services.

In addition, the Lead CNS was supporting the transferred antenatal screening and community paediatric services (see immediate risk section of the report).

c. Weekend Working

The SCAT provided a Saturday service two to three times per month which enabled patients who were not able to attend during normal working hours to attend for their transfusion. This service was just for transfusions, patients who were unwell and required an assessments or pain management would have to present to the ED. Reviewers were told that this provision had grown out of the goodwill of staff to provide a patient centred service and had not been formally funded.

2 Access to Psychology

Access to psychology was insufficient for the 792 pts registered with the service. There was only 0.8 WTE postholder in place with support from a psychology assistant (1 WTE band 4) which did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of 1 WTE HCPC Senior Psychologist for every 300 patients.

At the time of the visit the psychologist had insufficient time to join patient annual reviews and attend the haemoglobin disorders clinics.

It did not appear that the team were using any clinical outcome measures to assess patients' underlying psychological needs and/or as appropriate using the 'step care model' to refer patients to more specialised input should they have underlying mental health concerns. In addition, there was no clear reference as to how they supported people who experienced mental health crises and the referral pathway for those patients to access urgent mental health risk support.

Even though there were psychology service leaflets at the SCAT centre and the SHT promoted in the SCAT newsletter, the reviewers considered that the psychology service could be more proactive in raising

awareness of the psychology provision and ensuring equity of access to the service. Feedback from a number of patients who met with the reviewers reported that they were not aware that there was a psychology service even though the service had commenced in 2021.

Reviewers were concerned as without sufficient dedicated psychologist support 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. In cases where patients may also have underlying mental health needs, the reviewers were concerned that if they didn't have access to psychological input in timely manner, it may compromised their safety and have significant impact on their overall experience, treatment, and recovery.

Concern

1. IT Issues

The version of the Trust electronic patient records system (Cerner) in use was not able to 'flag' patients when they attended the hospital which meant that key information for example patient care plans and annual reviews were not available to staff. This had the potential to delay starting of treatment and to delay prompt referral to the haematology service.

Further Considerations

1 From discussions with patients and staff there appeared to be different approaches to transition to the adult services and reviewers considered that implementing a specific transition MDT clinic with the addition of psychology input would ensure a more consistent approach for young people. An MDT approach would also help young adults to access psychology and share any concerns they have about transitioning, focusing more on preventative work, for example, building confidence and recognising the importance of taking on responsibilities for their health care, rather than 'treatment'

2 The preparation and impact on clinical staff time and patients to prepare for transition to the new hospital should not be underestimated. Patients particularly expressed their pride and confidence in the SCAT centre and will need assurance and time to adjust to the changes.

Commissioning

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

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

Commissioning Immediate Risk

1. Antenatal and Paediatric Community Haemoglobinopathy Service[3]

Reviewers identified an immediate risk in the pathway for providing timely antenatal support, which is crucial for enabling informed decision making during pregnancy and ensuring affected babies receive appropriate follow-up and treatment. This risk could result in lack of parental choice, an increase in number of births of affected children, and delays in identifying and transitioning affected newborns into clinical care.

The provision of antenatal screening is a national mandate (Antenatal screening - GOV.UK (www.gov.uk). Likewise there are very clear measures for neonatal screening (Newborn screening - GOV.UK (www.gov.uk) which require prompt identification and counselling of affected newborn children so that appropriate treatment can be initiated.

Following the notice in March 2024 from Birmingham Community Healthcare NHS Trust (BCHC) to transfer the service, Sandwell and West Birmingham NHS Trust (SWBH) assumed responsibility in April 2024. The commissioned service aimed to provide antenatal screening, follow-up, and a community paediatric haemoglobinopathy service across Birmingham, a high-prevalence area for Sickle Cell Disease, Thalassaemia, and Rare Inherited Anaemias. Notably, there was no consultation with the clinical staff within the Specialist Haemoglobinopathy Team (SHT), who were expected to deliver these services.

At the time of the visit, the service comprised a 0.8 WTE nurse with administrative support, and reviewers were informed that the nurse was scheduled to leave the service the following week. The current SHT staff lacked the necessary training and competencies to provide this level of care. While they were undergoing relevant training for genetic risk assessment and counselling, they did not have the capacity to deliver a comprehensive antenatal or paediatric community service.

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

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

It was unclear how SWBH (who currently held the contract for delivering this service) has escalated and responded to the significant risk posed by the lack of provision of this mandated service.

Since April, SWBH had been unable to provide a paediatric community haemoglobinopathy service, which includes newborn referrals, home visits, development of care plans, patient annual reviews, GP or patient education (particularly around admission/readmission prevention), assistance with social challenges, and welfare support for children and young people.

Reviewers were unable to explore the antenatal service arrangements in place across the rest of Birmingham.

Discussions during the visit made it clear to reviewers that system-wide cooperation and support is required between the Trust management and the SHT, working with BCH and commissioners to collaboratively address the issues surrounding antenatal screening, follow-up, and the provision of a paediatric haemoglobinopathy community service.

Commissioning Concern

1 Collaborative working

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

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Appendix 1 - Membership of Visiting Team

Sandwell and West Birmingham Hospitals Trust & HCCs

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

Birmingham Women's and Children's NHS Foundation Trust & HCCs

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

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

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

Appendix 2 - Compliance with the Quality Standards

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

Percentage of Quality Standards met

Service	Number of Applicable QS	Number of QS Met	% Met
West Midlands Sickle Cell Haemoglobinopathy Coordinating Care Centre - All Ages	13	10	77%
Midlands Thalassaemia and Rare Inherited Anaemias Haemoglobinopathy Coordinating Care Centre - All Ages	11	9	82%
Specialist Haemoglobinopathy Team (SHT) Adults	45	26	59%

West Midlands Sickle Cell Haemoglobinopathy Coordinating Care Centre - All Ages

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-198S	**Network-wide Involvement of Children, Young People and Families (SCD)** The Sickle Cell Disorder HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702).	Y	Regular patient voice meetings had been held and the HCC were relaunching their patient engagement strategy to encourage wider representation at HCC meetings.
H-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	Y	Lead consultants had been designated for both adults and paediatrics
H-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	Lead Nurses had been designated for both adults and paediatrics but these posts were not funded.
H-202A	**Lead Manager** A lead manager should be available with: a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs	Y	

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

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

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

Midlands Thalassaemia & RIA Haemoglobinopathy Coordinating Care Centre - All Ages

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-198T	**Network-wide Involvement of Children, Young People and Families (Th)** The Thalassaemia HCC should have mechanisms for involving patients and carers of all ages, including representation at HCC Business Meetings (QS H-702).	Y	Regular patient voice meetings had been held and the HCC were relaunching their patient engagement strategy to encourage wider representation at HCC meetings.
H-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	Y	Lead consultants had been designated for both adults and paediatrics
H-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	Lead Nurses had been designated for both adults and paediatrics. The SHT lead nurse had the joint role of co-leading the HCC with the paediatric Lead nurse. Though both staff were not funded for role.

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
H-202A	**Lead Manager** A lead manager should be available with: a. Responsibility, with the lead consultant and lead nurse, for management of the network and achievement of relevant QSs b. Responsibility for liaison with other services within the network c. The lead manager should have appropriate time for their role.	Y	
H-203	**Lead for Transcranial Doppler Ultrasound** The HCC should have a nominated lead for Transcranial Doppler Ultrasound screening.	N/A	This QS is not applicable to Thalassaemia & RIA HCCs
H-602T	**HCC Service Organisation (Th)** A Thalassaemia HCC service organisation policy should be in use covering arrangements for provision of advice to all linked SHTs and LHTs including: a. Telephone or email advice for outpatient and inpatient care b. Advice on emergencies outside of normal working hours	N	For adults there was no formal arrangement to provide advice out of normal working hours. In practice the adult consultants at SWBH would be contacted. A service operational policy was in place. There were arrangements in place to provide advice from the paediatric team at BWCH.
H-605T	**HCC Multidisciplinary Discussion (Th)** MDT meetings for the discussion of more complex patients with thalassaemia should take place at least monthly. SHT and LHT representatives should have the opportunity to participate in discussion of patients with whose care they are involved. Guidelines on referral to the National Haemoglobinopathy Panel of rare or very complex cases, or for consideration of novel therapies, should be in use.	Y	Four HCC MDTs had taken place.
H-609	**NHS Blood and Transplant Liaison** The HCC should meet at least annually with NHS Blood and Transplant to review the adequacy of supplies of blood with special requirements and agree any actions required to improve supplies.	Y	

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

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

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Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-102	**Information about Haemoglobin Disorders** Patients and their carers should be offered written information, or written guidance on where to access information, covering at least: a. A description of their condition (SCD or Th), how it might affect them and treatment available b. Inheritance of the condition and implications for fertility c. Problems, symptoms and signs for which emergency advice should be sought d. How to manage pain at home (SCD only) e. Transfusion and iron chelation f. Possible complications g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	Y	The SHT had also developed some very good educational videos.
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	Y	Sickle Cell Emergency Care plan and NTDT and TDT annual review letter examples were seen. However, one example letter was not clear about follow up when the patient appeared to have multiple issues. Patients living with thalassaemia felt there annual review letters were very brief and would value more detailed information. SCD patients reported that when required they had clear shared care plans with LHTs.
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	Y	Included in information for patients, care plans and annual review letters

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents (SCD and Th) c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	Adult Patient Management in Primary Care Sickle Cell Disease (SCD) Information for GPs and Thalassaemia Information for GPs: Adult Patient Management in Primary Care Sickle Cell Disease (SCD) Information for GPs seen. Each letter included a link to the relevant information guide for GPs
HA-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	**Y**	Although at the time of the visit a number of patients were being cared for on outlying wards

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	**N**	Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care was not seen or information that covered 'f'. The transition information and process was based on 'The Ready Steady Go transition programme'. The service held quarterly transition evenings for patients and families to come and look around the service and meet some of the staff. Pre transition reviews were held with the young person and nursing staff and transition meetings were also offered in the in school holidays after young people had completed their exams. Nurses from the service also delivered regular presentations outlining the key stages in the transition process. The transition leaflet for those with thalassaemia was very well written and informative.
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	N	Sickle Cell survey completed in 2023 - 23/624 responses Thalassaemia & RIA survey completed in 2023 - 4/168 responses Analysis of results and feedback themes had been collated Neither surveys met the expected 10% response rate. Regular patient voice meeting were scheduled.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback b. Mechanisms for involving patients and their carers in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HA-797) c. Examples of changes made as a result of feedback and involvement	Y	Patient voice meetings were held and there was evidence of changes made in response of patient feedback
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	Lead and deputy had a total of 11PAs for 792 pts. They did not have any haemoglobin related CPD time allocated. and there was little time allocated for SHT leadership across the region.
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The SHT had a 1wte Lead Nurse but they did not have time available for leadership and HCC role. The lead was also covering the antenatal screening follow up.
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	There was only 11PAs in total for the care of 792 patients with haemoglobin disorders for clinics and regular reviews.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	On call was covered by lead and deputy and other haematology /oncology consultants
HA-206	**Doctors in Training** If doctors in training are part of achieving QSs HA-204 or HA-205 then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	Team commented that doctors in training had the opportunity to be involved in all aspects of HBO. There was a good training plan for junior staff
HA-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	At the time of the visit there was 1.3 WTE CNS which was insufficient to provide the appropriate level of support across the acute service and community. A competence framework was in place but it was unclear how competences were assessed and the process for ongoing monitoring.
HA-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	**N**	The SHT had 0.8WTE 8a and 1.0 WTE B4 in post for 792 patients which did not meet the *British* Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE. for 300 patients. At the time of the visit the psychologist was not involved in annual reviews and transition meetings. There was limited access to virtual and online information and support which may be helpful for patients and families

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	**N**	The SHT had some support from the 0.8WTE B6 Network Coordinator along with funding for an additional B3 data administrator 0.6WT. At the time of the visit the B3 post was vacant and covered by long-term bank.
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	**Y**	
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	Y	Access to manual exchange transfusion (24/7) was not applicable as NHSBT provided a comprehensive apheresis service
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	N	A training programme was offered and some sessions delivered but process for assessing competence following training was not in place. The audit of NICE guidance first dose analgesia within 30 mins compliance in the ED was 38% .

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	N	For SCD there were three separate guidelines and one for apheresis. The guidance seen did not cover recommendation around the number of cannulation attempts 'd' and patient pathway timescales 'e'. There was also a HHC Thalassaemia guideline in use. Consolidation into a single guideline would avoid duplication.
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	Y	The guidance was comprehensive.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring of complications e. Indications for discontinuation	N	Guidance on the use of disease modifying therapies was included in the Trust SCD guidelines and HCC guidance. However, reviewers noted that the guidance was not fully consistent with the national BSH guidance, in particular in relation to ensuring that patients are escalated to maximum tolerated dose hydroxycarbamide as a default treatment plan.
HA-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	
HA-509	**Clinical Guidelines: Acute Complications** Guidelines on the management of the acute complications listed below should be in use covering at least: i. Local management ii. Indications for seeking advice from the HCC / SHT iii. Indications for seeking advice from and referral to other services, including details of the service to which patients should be referred i. For patients with sickle cell disorder: a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision ii. For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine	**Y**	The guidance was comprehensive

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

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	N	It was not clear from the operational policy for SCAT and West/Midlands Haemoglobinopathy Coordinating Centre for Sickle Cell, Thalassaemia & RIA guidance the arrangements for transfer of patients (d) and those admitted to other hospital sites (e). Guidance was in place for lone workers and telephone triage but not other consultation modalities (f)
HA-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HA-503) d. National Haemoglobinopathy Registry data collection (QS HA-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HA-607) (if applicable) g. Participation in HCC-agreed audits (HA-706)	N	Shared care arrangements were in place with University Hospitals Coventry & Warwickshire (UHCW) but not other LHTs across the region.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when requested, representatives of support services (QS HA-301).	Y	Local MDTS were well organised and arrangements in place for LHTS to participate.
HA-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services	N/A	Integrated acute and community trust
HA-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each Sickle Cell Disorder HCC Business Meeting (QS HA-702).	Y	Attendance seen for the network nurses meeting and QIHD monthly meetings
HA-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HA-702).	Y	Attendance seen for the network nurses meeting and QIHD monthly meetings
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	N	Data seen for all but pregnancy. No patients had requested anonymisation.
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	N	An audit covering acute admissions to inappropriate settings, including patient and clinical feedback on these admissions had not been undertaken in the last two years.
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	
HA-797	**Review of Patient Experience and Clinical Outcomes** The service's multidisciplinary team, with patient and carer representatives, should review at least annually: a. Achievement of Quality Dashboard metrics compared with other services b. Achievement of Patient Survey results (QS HA-197) compared with other services c. Results of audits (QS HA-705): i. Timescales and pathway for regular transfusions ii. Patients admitted to inappropriate settings Where necessary, actions to improve access, patient experience and clinical outcomes should be agreed. Implementation of these actions should be monitored.	N	Reviewers did not seen any evidence that the MDT with patient and carer representatives had reviewed patient experience and outcomes. The 22-23 service survey undertaken was not the SCS / UKTS surveys, but one designed for whole service including all patients. Responses and numbers were provided. a and b were not seen i.e. comparisons to other services, and since for b there was a service-specific questionnaire this meant that comparison was more challenging. c. results of audits were not seen
HA-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	Y	
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	The Trust governance of polices had required the SHT to develop SWBH versions of the SHT and HCC guidance that was available to stakeholders across the region.

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