MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

Wessex and Thames Valley Sickle Cell Haemoglobinopathy Coordinating Centre

Oxford University Hospitals NHS Foundation Trust

Visit date: 19th June 2024

Report date: 25th September 2024

Contents

Introduction

This report presents the findings of the review of the Oxford University Hospitals NHS Foundation Trust (OUH) that took place on 19th June 2024. The purpose of the visit was to review compliance with the Health Services for People with Haemoglobin Disorders Quality Standards Version 5.2, November 2023, which were developed by the UK Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit was organised by the Nursing and Urgent Care Team (NUCT) at the Midlands and Lancashire Commissioning Support Unit (MLCSU). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

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

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

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

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

- Oxford University Hospitals NHS Foundation Trust
- NHS England – South East
- NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board

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

About the UKFHD and NHSML

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.

NHS Midlands and Lancashire (NHSML) 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 NHSML are available at https://haemoglobin.org.uk/ and https://www.midlandsandlancashirecsu.nhs.uk/our-expertise/nursing-and-urgent-care/

Acknowledgements

The UKFHD and NHSML would like to thank the staff and service users and carers of the Oxford 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

Wessex and Thames Valley Sickle Cell Haemoglobinopathy Coordinating Centre

General Comments and Achievements

Oxford University Hospitals NHS Foundation Trust (OUH) was a large tertiary hospital providing a vast range of specialised services and acted as the Specialist Haemoglobinopathy Team (SHT) hub for Haemoglobinopathy tertiary referrals in the Thames Valley region.

In 2019, OUH was awarded the status of Wessex and Thames Valley Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell following a national procurement exercise. The HCC worked in collaboration with the Red Cell Network (TRCN), led by University College London Hospitals NHS Foundation Trust, as the responsible HCC for Thalassaemia and Rare Inherited Anaemias for their region.

The HCC supported two SHT teams - Oxford University Hospitals NHS Foundation Trust and University Hospitals Southampton NHS Foundation Trust and their Local Haemoglobinopathy Teams (LHTs).

Wessex and Thames Valley HCC was defined as a 'low' prevalence region; however, patient numbers were continually increasing and patient caseload in the individual LHTs varied between 2-230. Not all the LHTs had haemoglobinopathy specific clinics and haemoglobinopathy clinical and/or admin support. There had been a rapid change in population size, particularly driven by increased new patient referrals.

With the new Integrated Care Board (ICB) structure, funding streams were likely to become more complex as the network will fall across multiple ICBs.

The HCC had designated clinical leads all of whom had considerable expertise and provided representation at numerous boards and national groups. The HCC had the below leadership in place:

- Adult HCC Consultant Lead
- Paediatric HCC Consultant Lead
- Lead Nurse (also Education Lead)
- Research Lead
- Audit Lead
- Senior Specialist Nurses – Adult and Paediatric
- Service and Quality Manager (who was also service user engagement lead)
- TCD Lead
- Pain Management lead (post vacant)

Quality Management and Governance Framework

The HCC had a full-time Network Manager to coordinate the agreed Quality Management programme. Essential components of the programme included audit (NICE, national quality standards, SSQD, etc), assurance, and benchmarking, data quality, patient and service user feedback, research and clinical governance.

TCD Quality Assurance Programme

TCDs were performed at Oxford SHT, Milton Keynes and Southampton sites. The service was regulated to meet the national TCD Quality Assurance programme standards. There was an internal assurance framework in place

whereby all TCD operators attended 6-monthly meetings to ensure compliance with the national programme and all practitioners were approved by the UK Forum and part of the quality assurance programme.

HCC Education and Staff Training

The HCC had published an education strategy and ongoing work plan for the region, which included workforce resource development and education sessions. A YouTube channel provided recorded education sessions both staff/patient resources and an annual education event was held.

HCC Network Policies, Procedures and Guidelines

The HCC had prioritised the harmonisation of network protocols for the acute and chronic management of people living with Sickle Cell Disorder, Thalassaemia and Rare Inherited Anaemias. All clinical guidelines, protocols and patient information were centrally-held on the Oxford-managed Thames Valley Network Site Specific Group (NSSG) Haematology website, which is publicly available for all staff and patients. All new patient information developed by the HCC was disseminated to the network for sharing with patients with SCD, Thal and RIAs. Collaboration with the Wessex (Southampton) SHT and the TRCN HCC for Thal/RIA was ongoing to consolidate the harmonisation and development of all protocols and patient information at a national level.

HCC/SHT Multi-disciplinary Team Meetings

The OUH HCC/SHT coordinated the HCC-wide, twice-monthly virtual haemoglobinopathy MDT for paediatric and adult patients. All linked clinicians in the LHTs were invited to attend by submission of a standard referral proforma. The MDT discussion was documented and outcomes from the discussion returned to the presenting team and documented on the Patient Electronic record. Southampton SHT fed into these for HCC input as required.

More complex cases were referred to the NHP or the Specialist Thalassaemia and RIA MDT. There was a well-established process for advice and referral of acutely unwell patients across the region.

The OUH HCC adult haematology consultants also fed into the Wessex/ Southampton Obstetric Haematology monthly MDT meeting where all pregnant patients with inherited red cell disorders were discussed.

HCC Patient Involvement and Support

There were various support groups led by HCC members:

- Monthly patient and parent education and support meeting via teams. Some topics covered had been pregnancy in SCD, Iron overload, Novel therapies (Voxelotor).
- Bi-annual information transition event for parents and young people.
- Weekly (during covid), and monthly teenage wellbeing support meeting via teams – currently on hold due to staff capacity.
- Annual Congenital Anaemia Network (charity for inherited anaemias) summer party which was held for patients, carers and families every year.

Good Practice

1. The HCC had a positive relationship with NHSE South East and the ICB commissioning team. The commissioners were fully aware of the challenges that both the HCC and linked LHTs faced.
2. Overall, the network was well established with good engagement from LHTs. All LHTs spoken with on the visit reported feeling supported and that regular communication and training was received.
3. The HCC TCD lead had supported Southampton in training practitioners supporting the provision of a skilled and sustainable TCD service.
4. There was an acute outreach Pathway for Emergency Red Cell Apheresis, through a 24/7, 365-day service provided by NHSBT covering the whole HCC region

5. Formal SLAs were in place across the network and LHTs had clarity on service provision, support and requirements

6. The was a bespoke website (NSSG) for HCC network, hosting all HCC, SHT and LHT protocols, centrally managed by HCC Network Manager. All Education and Training and Patient information was publicly available within separate links for Adult and Paediatric services

7. A congenital anaemia network was well established. As one of the 4 centres in England which carried out next-generation sequencing for rare inherited anaemias, a weekly genetic MDT for the Wessex, West Midlands, and South West patient population was held. Referring clinicians were invited to attend the MDT which alongside benefits of collective expertise also provided a teaching opportunity for clinicians who have less familiarity with genomic medicine to better understand the process of determining the pathogenicity of genetic variants.

8. There was a strong commitment to patient engagement with patients involved in the type and format of information developed. The 'Young Persons Forum' collaborated with the red cell team on the development of an educational video on transition and a parent did a video on hydroxycarbamide after the team listened to feedback about what was needed. These were posted on a dedicated YouTube channel.

Immediate Risks: None were identified during the visit.

Concerns

1. Support available to Milton Keynes University Hospital NHS Trust

a) Although designated as an LHT the patient numbers were significantly higher in the Milton Keynes population than the Oxford population. Although the OUH SHT team provided excellent support on an outreach basis the review team felt that the team in Milton Keynes would benefit from additional resource on site, specifically specialist nursing and administration that would enable the clinical team to better complete audits, attend network meetings, and provide wider trust education. Additional regional NHSE funding may be available and appropriate to support increased resource for this team if an application was made for SHT designation.

b) The Milton Keynes LHT does not fall under the remit of NHSE South East and there was concern from the review team that this may disadvantage the Trust in terms of full commissioning oversight.

Further Considerations

1. The HCC and SHTs were very proactive with the communication and engagement of the LHTs which was appreciated however the LHT clinical teams felt that at times the email traffic could be overwhelming, and they had difficulty in knowing what to prioritise. The team should consider if they are able to flag communications and meetings such as red, amber and green so to enable the LHTs to prioritise their resource and focus.

2. Most LHTs did not have any CNS or administrative time allocated for the care of patients with haemoglobin disorders.

3. Audits are important for service development and the LHTs struggled to complete these due to limited resource. More LHT support especially administration support for data and audits would be greatly beneficial and the HCC should explore if the additional funding could be used to address this.

Review Visit Findings

Oxford University Hospitals NHS Foundation Trust

Trust-wide General Comments

Oxford University Hospitals NHS Foundation Trust was designated as an SHT in 2019 and was led by a Lead and Deputy-Lead clinicians and specialist haemoglobinopathy nurse specialists for both adult and paediatric services. The adult services were provided at the Churchill Hospital and Paediatric service at the John Radcliffe Hospital.

The SHT team was composed by the HCC Team as previously described and the below additional team members:

- Senior Clinical Nurse Specialist for adult service and Nursing Lead for Thames Valley region.
- Haematologist Deputy Lead for paediatric haemoglobinopathies.
- Clinical Nurse Specialist for adult and paediatric service for Thames Valley region (currently on Maternity Leave).
- Specialty coordinator/data manager for the adult service.
- Specialty coordinator/data manager for the paediatric service.
- Clinical Psychologist

The specialty coordinators supported the clinical team with OUH management of patient lists and clinics, outreach Annual Review appointments, liaison with administrative teams in local hospitals, network MDT and quality meetings administrative support, NHR data input.

Access to 24-hour automated red cell exchange, provided by NHS Blood and Transplant (NHSBT), was in place and the NHSBT team undertook red cell exchange transfusions for patients requiring emergency apheresis across the region.

Transition

The service had a well-established transition programme, using the 'Ready, Steady, Go, Hello' model. The programme was introduced to children at 13-14 years of age as a tool to develop knowledge; self-advocacy; health and lifestyle, in a nurse-led clinic. Parents and young people new to the transition pathway were invited to attend an information meeting at the beginning of their journey. Joint clinics with the adult service were part of the final stages of the pathway.

Trust-wide Serious Concern

1. **HCC and SHT Allocated Funding**

   Reviewers were seriously concerned that Trust management arrangements had not ensured that specialised commissioning funding had been fully allocated to address the staffing issues (see below). This would have been considered an immediate risk but consultant medical staff were working far beyond their expected hours and workload to ensure that patients were not at risk. This situation is unsustainable in anything other than the very short-term. Contracting arrangements should be reviewed to ensure that HCC and SHT funding is utilised for the purpose for which it was allocated.

Views of Service Users and Carers

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

During the visit the visiting team met with 5 adults, 4 had sickle cell disease, and 1 adult with thalassaemia. From the children's perspective the review team met with one family (two parents) of a child with rare anaemia, 2 parents of with a child with sickle cell disorder, and one parent of a child with B thalassaemia major.

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

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

Specialist Haemoglobinopathy Team (Children and Young People Services)

General Comments and Achievements

The Children's Hospital was based at the John Radcliffe site. The Paediatric SHT worked closely with the adult haemoglobinopathy service to provide a whole life service. The Paediatric SHT were part of a large Division within the Trust however management were familiar with the service and aware of the challenges the SHT faced.

The SHT team supported six LHT teams, the largest being based at Milton Keynes University Hospital NHS foundation Trust who had a significantly larger patient number than Oxford itself as an LHT. All LHTs had a linked consultant and the SHT team provided annual reviews at the LHT sites. Training was offered to LHTs both virtually and face to face by both the consultant and nurse lead which the LHTs described as accessible and good. The face-to-face teaching enabled visibility of the SHT team across the local teams which was valued.

The support provided by the CNS and consultant was positively commented on across all LHTs and by the patients spoken to during the review; the review team felt this should be applauded.

This was a relatively small team covering many roles. The psychologist was allocated half a day a week to support the service and wait times for neuro cognitive assessment by the general psychology team could be up to one year. The team had developed plans to address workforce gaps such increased nursing, medical, data management, psychology and specialist pharmacy support however there was uncertainty in the team about where the uplift and additional NHSE monies had been allocated for them to progress plans. A freeze of appointments within the Trust was also a concern for the team in terms of service development even with external funding.

A new pain protocol was being rolled out in the Trust using intranasal diamorphine with the training progressing at the time of the visit prior to implementation. The ACT NOW Sickle Cell programme to improve patient experience and clinical outcomes for adults and children experiencing a sickle cell crisis was also in the process of being rolled out across the Trust.

Transition

A structured approach to transition was in place which commenced at the age of 13 years of age in the annual review clinics. The ready, steady, go framework was used and facilitated by nurse led transition appointments held virtually to minimise travel and held outside of school hours. Joint clinics with the adult service were part of the final stages of the pathway.

The team were particularly proud of the below innovations:

- Flag on Electronic Patient Record for Sickle Cell crisis management.
- Paediatric annual outreach review clinics for Thames Valley LHTs, where all patients were seen once a year.
- Annual review standardised letter.
- Structured transition pathway for patients across the network; nurse-led clinics using Ready, Steady, Go framework; comprehensive patient information resources.
- Robust MDT meeting structure across Thames Valley region, with good attendance and allocated slots for each of the local teams.
- Fully integrated and collaborative whole of life care service structure.
- Clinical Nurse Specialist Education sessions regularly delivered at University of West London and Oxford Brookes University and Buckinghamshire on numerous topics regarding haemoglobin disorders.

- Development of parent story video on their child's hydroxycarbamide experience for the purposes of patient and staff education.

SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE							
Oxford University Hospitals NHS Foundation Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)						
	Wessex and Thames valley Sickle Cell HCC *(hosted by Oxford University Hospitals NHS Foundation Trust)* The Red Cell Network - Thalassaemia and Rare Inherited Anaemias HCC						
	Linked Local Haemoglobinopathy Teams (LHT)				Patient Distribution		
					SCD	Thalassaemia.	
	Buckinghamshire Healthcare NHS Trust				15	8	
	Frimley Health NHS Foundation Trust				27	3	
	Great Western Hospital NHS Foundation Trust				25	4	
	Milton Keynes University Hospital NHS Foundation Trust				83	1	
	Royal Berkshire NHS Foundation Trust				34	6	

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[1]	Annual review **	Long-term transfusion	Eligible patients – hydroxycarbamide	In-patient admissions in the last yr.
Sickle Cell Disease	CYP	215 (31 OUH)	215	215	All patients were transfused locally	93/143	29 – OUH only
Thalassaemia	CYP	24 (3 OUH)	24	24		None	Not known

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual WTE/PA (at time of visit)
Consultant Haematologist/Paediatrician dedicated to work with patients with haemoglobinopathies	35 (OUH pts only)	0.5 WTE Lead 0.1 WTE Deputy
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with haemoglobinopathies	35 (OUH pts only)	1.2 (inc 0.2 Band 6) Post also covered community services
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with hemoglobinopathies in the community	35 (OUH pts only)	
Clinical Psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies	35 (OUH pts only)	0.1 Thames Valley/ OUH psychologist

Urgent and Emergency Care

All OUH haemoglobinopathy patients had direct access to Kamran's ward for assessment and treatment, when presenting with acute problems. Patients could also call for advice 24/7 and a haematology consultant was always available if required. Very few patients presented to the Children's ED however all known children with

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

SCD had a flag on their EPR record to highlight the need for timely review and analgesia, which included a link to the acute protocol. This information was included in their annual review letter, which was available on EPR, and the patients were encouraged to have their care plans on their phones. The addition of a patient card was being rolled out at the time of the visit.

In-patient and Day Care

OUH patients were admitted to Kamran's ward which was a mixed haematology/oncology ward. If no bed was available, teenagers would be cared for on Melanie's ward next door (YP facility) and younger children in outlying children's wards. For planned surgery, patients would go to Tom's ward. Acute red cell exchange was performed in PHDU/PITU. The haematology team would review patients in outlying wards as part of the ward round.

Kamran's ward had five cubicles and a four bedded bay. At the end of the ward was a four bedded day unit. There was a playroom and teenage room accessible, and the ward and day ward were supported by two play specialists. The Trust lead play specialist supported the team for children needing more intensive play support if requested.

Kamrans daycare was open Monday to Friday 8am-8pm for phlebotomy, blood transfusion, other infusions and review/assessment. The clinical team described that the day care and ward space was limited as it catered for a range of children with a range of health care conditions, collectively with oncology patients, the team felt that the demand had outgrown its original base.

New nurses to Kamran's ward completed dedicated haemoglobinopathy competencies and received regular teaching sessions which were also recorded and shared across the network.

There was a paediatric haematology/oncology consultant on call rota every night and at weekends (non-resident) with a paediatric registrar team on site. If the on-call consultant was an oncologist there was on informal arrangement to contact the haematology consultants who the service reported were always responsive. The Lead or Deputy lead Consultant was available on site every day of the week in normal working hours.

Outpatients

Children were seen in the colourful outpatient department on level LG1 of the children's hospital. The displays observed on the wall provided information about both Sickle Cell and Thalassaemia alongside QR codes that linked to patient information. Annual review clinics took place on a Tuesday afternoon and TCDs in the nearby radiology department. A general review clinic took place on a Thursday afternoon. There was a phlebotomy room within the outpatient department supported by a play specialist.

Annual review clinics were held by the SHT at the LHTs. (Royal Berkshire-3 times per year, Milton Keyne - 4 times per year, Swindon-2 per year, Buckinghamshire-1 per year, Frimley (Wexham Park Hospital) -2 per year).

Community-based Care

There was 1.2 WTE nurses to cover the whole network. The CNS supported with community care for newborn visits providing a home visit for all newborn diagnosis, new patient visits, school plans and education, housing/DLA support, and other individual needs. Alongside the OUH patients the lead nurse also supported 130 LHT patients often post discharge.

The CNS had good links with the Health Visiting Team and referred to the District Nursing service as appropriate such as for line care etc.

School care plans were not routinely done every year but completed at key points of the child's life and on request. There was a focus on the delivery of education sessions into schools and across the wider network.

Views of Service Users and Carers

During the visit the visiting team met with one family (two parents) of a child with rare anaemia, 2 parents of with a child with sickle cell disorder, and one parent of a child with B thalassaemia major.

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

Service user Feedback

General

- All parents commended the entire haemoglobinopathy team. They praised the lead CNS for being the glue of the service and felt that her role changed how the service was run. They all felt well supported by the team and commented that they trusted them with their children's lives. Most commented that the CAN family day in the summer was a joyful and lovely event and they were looking forward to it.

Sickle Cell

- The families felt that they could always contact the team no matter the issue and it would be sorted. They felt they were given enough information about medication; they were listened to and knew what emergency markers to look out for.
- The children of the family spoken to during the review fortunately hadn't been admitted to hospital for some time, but they described that the process worked well. They would call in and be triaged and then told to come in. They felt that the nurses on the inpatient ward knew a lot about sickle cell and knew how to treat their children.
- They felt the team went above and beyond to support them with schooling, letters etc and they were very happy about the service they received. They felt all the necessary scans and tests they knew about were in place and the children were being managed and monitored well.
- Transition – described that the young person was involved and happy with the process. They felt it was explained well.

Rare Inherited Anaemia

- The parents were generally happy and felt they were supported well. They expressed a preference for receiving information including condition specific information in their first language and had lots of questions about a variety of topics. They felt the staff were attentive and took great care of their child.

Thalassaemia

- The parent the review team met was extremely happy with the service and praised the clinical lead and lead CNS for their advice and support. The parent felt they knew what emergency signs to look out for and trusted that if anything serious happened, they could contact the lead nurse or the ward.
- They expressed a need for more information about thalassaemia and possibly to be linked to patient groups/ families with thalassaemia.
- They felt all the necessary scans and tests they knew about were in place and they were happy with the unit/ hospital.

Good Practice

1. The feedback from Southampton and the LHTs was highly positive in terms of both the training and the support available. The LHTs all commented that they were easily able to access the consultants or lead nurse for advice who were responsive.
2. The lead CNS provided undergraduate nurse education through attendance at the local universities to deliver specific haemoglobinopathy training.
3. There was a successful direct access pathway to Kamran's ward resulting in very few admissions through ED.
4. A shared care protocol was in place with GPs who could prescribe Hydroxycarbamide closer to the patients home and prevent travel to hospital for prescriptions.
5. There was a strong commitment to patient engagement with patients involved in the type and format of information developed. One patient made an animated video on transition, and a parent did a video on hydroxycarbamide after the team listened to feedback about what was needed. These were posted on a dedicated YouTube channel.

Immediate Risk

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

Serious Concern

See Trust-wide section of this report.

Concerns

1. Consultant Staffing

The lead consultant only had 4.5 PAs for direct clinical care which was insufficient for the number of patients locally and across the LHTs**.** There was insufficient medical staffing to provide clinics and annual reviews for the 237 patients of the SHT.

2. CNS Workload

The lead nurse had insufficient time for leadership of the SHT and clinical work with the number of patients. The reviewers noted the additional work the lead nurse had done to upskill the team to enable more time for leadership.

3. Glucose Tolerance Testing

The review team were concerned that glucose tolerance tests were not performed routinely as part of the annual review once the child had reached the age of 10 for all children on regular transfusions. Glucose Tolerance Testing should be implemented as part of the annual review process.

4. Psychology support

Psychology support was resourced for only 0.5 days per week which was required to support the whole network, additionally there were long waits to neuro cognitive assessments (around 1 year). The review team noted that a business case had been submitted internally for additional psychology resource and if not progressed, consideration should be given to using the additional HCC funding to support.

Further Considerations

1. LHTs should be involved in the allocation of additional funding and SHT workplan and reported that they had not been. Reviewers noted that a communication and survey was sent out however this may not have been fully understood. Prioritising of requests as per the further consideration one above may support this.
2. Audits are important for service development across the LHTs who struggled to complete due to limited resource. More LHT support especially administration support for data and audits would be greatly beneficial.
3. Time to analgesia can be impacted by delays to prescribing out of hours. Consideration should be given to what options are available to support faster out of hours prescribing such as the adoption of nurse prescribers, education of on-call registrars, or attendance via ED.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

This was a well organised and hardworking team who were flexible to the needs of their patients and families and there were good working relationships across the multidisciplinary team. The clinical leads had considerable expertise and provided representation at numerous boards and national groups.

The SHT provided considerable support and promoted high quality patient care across the LHTs in Thames Valley area through joint Annual Review Outreach Clinics in conjunction with local clinical teams (Consultant Haematologists and Clinical Nurse Specialists, where available).

Members of the SHT were active in promoting patient involvement and feedback and had undertaken a wide range of surveys across a number of patient focused topics.

Working with their client group a number of patient stories had been authored and published on the network website (NSSG) as well as videos for training about sickle cell disorders for Ambulance staff. The CNS delivered education sessions regularly for the University of West London and Oxford Brookes University on numerous topics regarding haemoglobin disorders.

The SHT had developed a specific pathway for SCD painful acute admissions which enabled patients with a vaso occlusive crisis to bypass the Emergency Department by directly contacting and attending the Triage Unit so that timely analgesia could be given.

The transfusion service was provided at Day Treatment Unit at Churchill site and patients could attend at weekends which had increased patient attendance and minimised life-disruption. Patients who spoke to the reviewers were highly appreciative of this option. The acute pain pathway was also published on the Trust 'Microguide' application.

A joint quarterly MDT for Haemoglobinopathies was held between the NHSBT and OUH haemoglobinopathy team, for discussion and individual case management of those requiring transfusions.

SPECIASLIST HAEMOGLOBINOAPTHY TEAM – ADULTS			
Oxford University Hospitals NHS Foundation Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)		
	Wessex and Thames valley Sickle Cell HCC *(hosted by Oxford University Hospitals NHS Foundation Trust)* The Red Cell Network - Thalassaemia and Rare Inherited Anaemias HCC		
	Linked Local Haemoglobinopathy Teams (LHT)	Patient Distribution	
		SCD	Thal.
	Buckingham Healthcare NHS Trust	23	14
	Frimley Health NHS Foundation Trust	42	19
	Great Western Hospital NHS Foundation Trust	22	3
	Milton Keynes University Hospital NHS Foundation Trust	146	10
	Royal Berkshire NHS Foundation Trust	43	13

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	333 (57 OUH)	333	289	All patients were transfused locally	191/201	56 – OUH only
Thalassaemia	Adults	94 (35 OUH)	94	71		None	1

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant Haematologist dedicated to work with patients with haemoglobinopathies	92	0.45 0.45 (deputy)
Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies	92	1.2 (inc 0.2 Band 6)
Clinical Nurse Specialist for adult patients dedicated to work with patients with hemoglobinopathies in the community	92	
Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies	92	0.3 Thames Valley/ OUH psychologist

Emergency Care

All OUH patients had 24/7 direct access to the haematology centre. Patients could contact the triage unit which was open 08:00-20:00, 7 days a week; outside of these hours patients would call the haematology ward directly. Patients were initially assessed over the telephone, then seen face to face, if the assessing practitioner deems it necessary for the patient to be admitted. When patients attended the triage unit there were seen by the haematology registrar on call, who would assess whether treatment could be provided on the unit or if an inpatient admission was required. If the patient required in patient admission they would be transferred to the appropriate ward areas which, on most occasions, was the clinical haematology ward.

Access for patients in the Thames Valley LHTs was via their local pathway, usually the Emergency Department. Once assessed by the medical team, if they required an admission, as a general principle, they would be admitted direct to the haematology ward or medical ward and seen by the local haematology team. The local haematology team would liaise with the SHT for further advice as required.

Inpatient Care

For OUH, patients tended to be admitted to the clinical haematology ward (25-bedded ward), either directly or via the triage unit. If there was no bed availability, patients were admitted into one of the other medical wards with daily review by the haematology team.

For planned surgery (OUH and LHTs), patients would be admitted to the appropriate specialist ward. The haematology team (for OUH and LHTs) would review patients in outlying wards as part of the daily ward round.

[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 .

Day Unit

There was a dedicated haematology outpatient clinic at the Churchill hospital with a phlebotomy service from 08:00 until 1600 from Monday to Friday.

The haematology day unit was open between 08:00-20:00 and co-located with the outpatient area, where patients could attend for regular blood transfusions and top-up transfusions. Patients with difficult venous access requiring a femoral line, also attend the day unit for red cell exchanges undertaken by the apheresis team. All other red cell exchanges took place at the NHSBT unit, onsite at the John Radcliffe hospital.

Automated apheresis was available 24/7 and there was an arrangement with NHSBT to provide out of hours automated exchanges for inpatients for all LHTs across the region when required.

Outpatient

Adults were seen in the outpatient department based in level 0 at the Churchill hospital on the 1st and 3rd Fridays of the month (am) for annual review and general review clinics. Outpatient clinics were attended by three Consultant haematologists.

Monthly outreach clinics were jointly held with the LHT clinical teams in Royal Berkshire NHS Foundation Trust (RBH), Milton Keynes University Hospital NHS Foundation Trust (MK) and Frimley Health NHS Foundation Trust. Outreach clinics in Great Western Hospital NHS Foundation Trust Swindon and Buckinghamshire Healthcare NHS Trust were held on alternate months.

Community-Based Care

Community care was provided by the SHT but was very limited due to workload pressure on staff.

Views of Service Users and Carers

During the visit the visiting team met with five adults, four were living with a sickle cell disorder and one patient living with thalassaemia. The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences.

All the patients who met with the visiting team were generally very happy with the care they received.

- The spoke highly of the CNSs both past and present who were ‘amazing’
- Patients commented that if they could not be admitted to a ward at the Churchill hospital and were admitted onto the general wards at the John Radcliffe hospital, staff had little knowledge about their condition
- Comments were received that staff in the ED had no knowledge about thalassaemia.
- Patients had mixed views about whether they had a care plan or knew of their care plan.
- All had high praise for the triage unit in terms of advice received and treatment if they had to attend.
- Patients were also happy with the care on the day unit. They commented that staff had ‘good cannulation skills’ and that staff seemed to have a good understating about sickle cell disorders but basic knowledge about thalassaemia and long term transfusion issues for this group of patients.
- All knew how to contact their consultants and the CNSs and commented that staff were quick to respond to any queries.
- Those who were on disease modifying therapies talked about the shared decision making that took place with them and the team.
- For those living with thalassaemia they considered that they had appropriate iron overload monitoring, and their annual reviews were completed including reviews by endocrinologists. The transfusion process was also working well, with no delay between each transfused unit of blood.

- The patients were pleased with the referral to other monitoring services such as ophthalmology. The referrals were timely, and they did not have to wait too long for an appointment

Good Practice

1. When problems with staff stereotyping patients with haemoglobin disorders had been identified, the team had completed an incident form and undertaken targeted training. Simulation training covering care of patients with haemoglobin disorders had also been delivered on the haematology ward.
2. The NSSG website was used very well. Guidance and documentation were easily accessible and Trust staff knew how to find what they needed. The website also had a wealth of patient information and other useful resources.
3. The SHT held monthly meetings with patient representatives with the agenda set by the patients. Between 12 and 20 patients attended regularly.
4. The SHT had developed and agreed a formal Service Level Agreement with all their linked LHTs.
5. The triage pathway was working well. Patients rang and were assessed by phone. This assessment was then reviewed by a member of the medical team, a treatment plan agreed and drugs prescribed. Patients were very satisfied with this service and times to analgesia had improved. Out of hours, the triage service was provided by staff on the haematology ward.
6. The team had undertaken innovative projects relating to pain and fatigue. The pain project used patient co-design to help train nurses in improving their approach to dealing with sickle cell patients who were having a painful crisis. Using professional role-play and patient-designed scenarios, ward nurses were engaged in a moderated discussion about language and small changes in attitude can alter a patient's experience of pain. The fatigue project was also patient co-designed and was informed by evidence-based research on fatigue in sickle cell disease. An educational session for sickle cell patients on understanding fatigue and developing strategies to diminish the impact of fatigue on their lives and improving their quality of life had taken place.

Immediate Risk

No immediate risks were identified.

Serious Concern

See Trust-wide section of this report.

Concern

1. Consultant Staffing

The service had insufficient consultant medical staff with appropriate competence in the care of people with haemoglobin disorders to provide regular reviews, clinics and outreach support to patients in the linked LHTs:

- The SHT had seen an 34.6% Increase in patients with haemoglobin disorders across the OUH and Thames Valley region (including repatriation from the London Haemaglobinopathy networks) since 2021/22. The increase in patient numbers, requiring annual reviews, emergency and ongoing care, and associated workload, was creating considerable pressure on an already understaffed and overstretched team. Total number of patients being cared for by the team was 427 at the time of the visit:

	SHT	LHT	Total
Sickle Cell Disorder	57	276	333
Thalassaemia	35	59	94
Total	92	335	427

- At the time of the visit the lead consultant and deputy had nine programmed activities (PA) for the care of 92 patients with haemoglobin disorders residing in the Oxford catchment and were undertaking monthly clinics to three LHTs and bi-monthly support to a further two, involving 335 patients. If one consultant was on leave for any reason, there was no specialist haemoglobinopathy cover at OUH while the other was undertaking outreach clinics. The on-call haematology consultant who was then contacted did not always have appropriate expertise in the care of people with haemoglobin disorders. The lead clinician and deputy were therefore sometimes contacted for advice when not on call.
- Patient numbers across the SHT and linked LHTs were predicted to increase further in the near future and patient longevity and complexity were also increasing. Although there were plans for an additional consultant or clinical fellow with time allocated for red cell work, recruitment to this post may be difficult. Alternative strategies may be needed to relieve the unsustainable pressure on the lead consultant and deputy.

2. CNS Workload

CNS staffing (1.2 wte) was insufficient for the number of patients. CNSs were undertaking outreach and wellbeing work and the lead nurse had a large remit as nurse lead for the Thames Valley SHT. The CNSs were expected to provide community as well as acute support for patient. They were also spending time on non-clinical activities due to a lack of administrative support. In practice, therefore, very limited community support was available with a resulting impact on the acute service. Support for young people transitioning from children's service was also limited. CNS staffing for the future also needs to take account of increasing patient numbers, longevity and complexity.

3. Access to Psychology

The SHT had 0.3 WTE psychologist to provide support for approximately 430 adult patients across the region which did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE for 300 patients. The waiting list for patients with a haemoglobin disorder to access psychological and mental health support had increased exponentially. Reviewers were concerned that individuals affected by these disorders had limited specialised psychological input, which may result in increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition. Psychologist staffing for the future also needs to take account of increasing patient numbers, longevity and complexity.

4. Access to Specialist Haemoglobinopathy Team care

The SHT undertook outreach to five hospitals. The Trusts in the SHT area had multiple hospital sites and clinical staff were not confident that all patients with haemoglobin disorders at the 24 possible sites were being referred for MDT discussion and SHT care. Clinical staff at some hospital sites were not in regular communication with the SHT and the workload pressure on the lead consultant and deputy meant that they did not have time to address this issue.

Further Considerations

1. Relatively few patients with thalassaemia were seen in OUH and staff were therefore less confident in the care of these patients. Guidelines were in place and the ED consultant had recognised that further work on ensuring appropriate competence and confidence may be needed.
2. The SHT had no support for entering patients into research and clinical trials which had created challenges with patient recruitment and with the development and implementation of a Research Strategy.
3. Patients had consultants' individual email addresses. Consultants should ensure robust arrangements are in place in the event of absences, including unexpected absences, to ensure patient care is not delayed.
4. The care pathway for new university students the care pathway for university students had challenges due to the local and specialist haemoglobinopathy teams not always being notified of their move to University in Oxford, leading to their attendance at ED instead of the Triage admission unit. More awareness work could improve this pathway but, due to limited staffing (see above), this was not realistic at the time of the visit.
5. Limited administrative and data collection support was available. As a result, clinicians were entering patient data on the NHR and SSQD. This was adding to their workload pressure.
6. Some patients who met the visiting team said that they did not know how to access information on the NSSG website and would welcome help. Some patients also commented that they would like written information given on disease modifying medication such as Hydroxycarbamide and the potential side effects. Reviewers suggested this could be addressed in the Patient Forum meetings.
7. Although the CNS lead was undertaking good training in the ED and wards, her time was insufficient to maintain the ongoing programme to address the culture and attitudes of staff in all relevant areas. A competence framework had been developed but not yet fully implemented due also to insufficient CNS time.
8. Clinical staff were concerned that planned changes to general haematology clinics could result in routine haematology patients being referred to the red cell clinic. These clinics did not have capacity to accommodate additional patients.

Commissioning

The review team had discussions with the regional NHS specialist commissioner from NHS England South East and the local commissioner from NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board. Several of the issues in this report will require the active involvement of the Trust leadership team and commissioners to ensure that timely progress is made.

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Appendix 1 - Membership of Visiting Team

Visiting Team		
Dr Lovina Thomas	Adult Consultant Haematologist	Mid and South Essex NHS Trust
Paula Lindo	CNS Sickle Cell & Thalassaemia	Croydon Health Services NHS Trust
Maureen Scarlett	Community Nurse Specialist - Haemoglobinopathies	Cambridgeshire Community Services NHS Trust
Leah Denver	HCC Network Manager	Birmingham Women's & Childrens Hospital NHS Trust
Dr Claire Weights	Paediatric Consultant with a special interest in Haematology	University Hospitals of Derby and Burton
Hazel Marriott	Sickle Cell and Thalassaemia Nurse Specialist	Nottingham University Hospitals NHS Trust
Isabel Adams	Haemoglobinopathy Liaison Sister	Birmingham Women's & Childrens Hospital NHS Trust
Zoe Hamilton	National Programme of Care Senior Manager – Blood and Infection, Specialised Commissioning	NHS England
Roanna Maharaj	User representative	UK Thalassaemia Society
Elizabeth Naamorkor Caulley	User representative	Manchester Sickle Cell Society

Clinical Leads		
Dr Mark Velangi	Consultant Paediatric Haematologist	Birmingham Women & Children's Hospital NHS Trust
Dr Rachel Kasse-Adu	Consultant Haematologist	Guy's and St Thomas NHS Trust

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

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Appendix 2 - Compliance with the Quality Standards

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

Percentage of Quality Standards met

Service	Number of Applicable QS	Number of QS Met	% Met
Wessex and Thames Valley Sickle Cell Haemoglobinopathy Coordinating Centre (HCC)– All Ages	13	11	85%
Specialist Haemoglobinopathy Team (SHT) Children and Young People	49	41	85%
Specialist Haemoglobinopathy Team (SHT) Adults	45	36	82%

Wessex and Thames Valley 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).	N	The HCC did not have patient representation at the HCC business meetings or a mechanism for two way sharing of information between patient representatives and the HCC. The HCC did have other mechanisms in place for sharing information with patients and patients could access a range of online resources.
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.	Y	
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 The lead manager should have appropriate time for their role.	Y	

Ref.	Quality Standards	Met? Y/ N	Reviewer Comment
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	Y	A service operational policy was in place and arrangements to provide advice to all linked SHTs and LHTs .
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 MDT meetings were held every two months and the responsibilities agreed within the SLAs with the SHT and LHTs. Terms of reference for the HCC MDT was in place including the criteria for escalation to the NHP.
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	N	Commissioners had not seen the 24/25 workplan

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	Y	
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	

Specialist Haemoglobinopathy Team for Children and Young People with Haemoglobin Disorders

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

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-105	**Information for Primary Health Care Team** Written information, or written guidance on where to access information, should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SCD and splenectomised Th) and analgesia (SCD) b. Side effects of medication, including chelator agents [SCD and Th] c. Guidance for GPs on: i. Immunisations ii. Contraception and sexual health (if appropriate) d. What to do in an emergency e. Indications and arrangements for seeking advice from the specialist service	Y	
HC-106	**Information about Transcranial Doppler Ultrasound** Written information should be offered to children, young people and their families covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	Y	
HC-107	**School or College Care Plan** A School or College Care Plan should be agreed for each child or young person covering at least: a. School or college attended b. Medication, including arrangements for giving / supervising medication by school or college staff c. What to do in an emergency whilst in school or college d. Arrangements for liaison with the school or college e. Specific health or education need (if any)	N	Care plans were agreed at key points of a child's life or on request but not routinely done for all children

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	Y	
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The lead consultant only had 4.5 PAs for direct clinical care which was insufficient for the number of patients locally and across the LHTs
HC-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The lead nurse had insufficient time for leadership of the SHT and clinical work with the number of patients. The reviewers noted the additional work the lead nurse had done to upskill the team to enable more time for leadership It was noted that there was an intention to use additional funding for nursing support.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	There was insufficient medical staffing to provide clinics and annual reviews for the 237 patients.
HC-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of children and young people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	
HC-206	**Doctors in Training** If doctors in training are part of achieving QSs HC-204 or HC-205 then they should have the opportunity to gain competences in all aspects of the care of children and young people with haemoglobin disorders.	Y	Reviewers noted that trainees would benefit from additional time if they wanted to be a haemoglobinopathy consultant but exposure was achieved for general haematology training.
HC-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses or other staff with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	Reviewers were concerned that there was not enough CNS time/team to support achievement of the standard as a whole.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-208	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multidisciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuropsychology Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The SHT had 0.1 WTE Psychology support which was insufficient for the numbers of patients cared for by the SHT.
HC-209	**Transcranial Doppler Ultrasound Competences** Sufficient staff with appropriate competences for Transcranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	Y	
HC-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	There was a plan in place to increase data support to the LHTs.
HC-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required: a. Social worker / benefits adviser b. Play specialist / youth worker c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Child and adolescent mental health services	Y	

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

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

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

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

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

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

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

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

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

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Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

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

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**	
HA-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Planned acute and long-term management of their condition, including medication iii. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed c. The care plan and details of any changes should be copied to the patient's GP and their local team consultant (if applicable).	**Y**	
HA-104	**What to Do in an Emergency?** All patients should be offered information about what to do in an emergency covering at least: a. Where to go in an emergency b. Pain relief and usual baseline oxygen level, if abnormal (SCD only)	**Y**	

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	
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	
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-197	**Gathering Patients' and Carers' Views** The service should gather patients' and carers' views at least every three years using: a. 'Patient Survey for Adults with a Sickle Cell Disorder' b. UKTS Survey for Adults living with Thalassaemia	N	The UKTS survey for Adults living with thalassaemia had not been undertaken. However, a range of other surveys had been undertaken to gather patient and carer views.
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	
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.	Y	The designated clinical lead had 4.5PA allocated for leadership of the HCC, SHT and direct clinical care. The named deputy also had 4.5 PAs for leadership and direct clinical care.
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The lead and deputy had only 9 PAs for leadership of the HCC, SHT and provide clinical care for patients locally and provide outreach (clinics and annual reviews) across the LHTs. The SHT cared for 430 patients across their catchment area.
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	N	On call cover was not always a haematologist with an interest in haemoglobinopathies therefore the Leads were phoned for advice when not on call.
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	
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	CNSs did provide training in haemoglobinopathies but, due to changes in staffing only new staff had completed the training competences. The team had plans to fully implement the competence framework including ongoing monitoring of staff competences every three years.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
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 0.3 WTE psychologist for 430 adult 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. Some of the patients did not know they could have access to a psychologist
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	Limited Administrative support was available as the role was shared across the whole of haematology/ oncology
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	N	Patients did not have timely access to Social worker / benefits adviser or to mental health services.
HA-302	**Specialist Support** Access to the following specialist staff and services should be easily available: a. DNA studies b. Genetic counselling c. Sleep studies d. Diagnostic radiology e. Manual exchange transfusion (24/7) f. Automated red cell exchange transfusion (24/7) g. Pain team including specialist monitoring of patients with complex analgesia needs h. Level 2 and 3 critical care	Y	

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
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	Staff did have some training in the use of the UK oncology guidance for urgent care (UKON) but not specific training and competences in the urgent care of patients with haemoglobin disorders
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	Y	
HA-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Self-administration of medications and infusions and encouraging patient and carer involvement in monitoring wherever possible	Y	

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

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	Y	
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	Y	
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)	Y	Reviewers were impressed that the SHT had SLAs with all the LHTs

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	
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 service
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	
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	
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	Y	
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	Y	'a' was in progress and 'b' had been presented at a business meeting.
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	'b' achievement of patient survey results for those with thalassaemia (QS HA- 197) had not been had not been undertaken so a comparison could not be made with other services. There were other mechanisms in place to liaise with patients and gain feedback.
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	

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