MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

University Hospital Southampton NHS Foundation Trust

Visit date: 4th July 2024

Report date 19th November 2024

Contents

Introduction

This report presents the findings of the review of University Hospital Southampton NHS Foundation Trust that took place on 4th July 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 NHS Midlands and Lancashire (ML). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

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

A comprehensive peer review 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 Southampton 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:

- University Hospital Southampton NHS Foundation Trust
- NHS South East Region
- NHS Hampshire and Isle of Wight Integrated Care System

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

About the UKFHD and NHS ML

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

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

Acknowledgements

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

Trust-wide General Comments

This review looked at the health services provided for children, young people, and adults with haemoglobin disorders at University Hospital Southampton NHS Foundation Trust. In total the Trust serves 258 patients with Haemoglobin Disorders, mostly sickle cell disease (SCD). During the visit, reviewers attended the Southampton General Hospital and visited the emergency departments, assessment units and wards and met with patients and carers, and with staff providing the local haemoglobinopathy services.

University Hospital Southampton served the population in and around Southampton, which was estimated to be 500,000 at around the time of the visit. Patients with complex haemoglobinopathy problems were managed with the support of the adult and paediatric specialist haemoglobinopathy teams.

Although the area was low prevalence for haemoglobin disorders, the prevalence of sickle cell and thalassaemia had significantly increased since the last visit from approximately 40-50 patients to 146 patients registered with a haemoglobinopathy with the adult service and 47 patients to 96 patients registered with the haemoglobinopathy paediatric service. Patient numbers fluctuated slightly depending on the number of students with haemoglobin disorders studying at the local university.

The SHT was linked to the Wessex and Thames Valley Sickle Cell Haemoglobinopathy Coordinating Centre (HCC) hosted by Oxford University Hospital NHS Foundation Trust or The Red Cell Network (TRCN) Thalassaemia and Rare Inherited Anaemias HCC, hosted by University College London Hospitals NHS Foundation Trust.

The adult and paediatric Specialist Haemoglobinopathy Team (SHT) provided a service to the Wessex region which covered Hampshire, Dorset, Wiltshire, and Somerset. Eight Local Haemoglobinopathy Teams (LHT) were based at trusts across the region; Dorset County Hospital NHS Foundation Trust, Hampshire Hospitals NHS Foundation Trust, Isle of Wight NHS Trust, Portsmouth Hospitals University NHS Trust, Salisbury NHS Foundation Trust, University Hospitals Sussex NHS Foundation Trust and University Hospitals Dorset NHS Foundation Trust. The paediatric SHT also provided care to patients residing in the Channel Islands.

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

Trust-wide Good Practice

1. Reviewers were impressed by the work of the Trust to implement the patient safety initiative of 'My voice is heard' to allow patients and families to seek an urgent review of care if they were concerned. The local initiative had been 'rolled out' across the Trust before the introduction of Martha's Rule in the NHS.
2. Reviewers were impressed that the trust were able to provide an in-house 24/7 apheresis service for elective and emergency red cell exchange blood transfusions.

Trust-wide concern – children and young people

1. Access to analgesia

An audit of compliance with the NICE Clinical Guideline on the management of acute pain showed that an audit of six children and young people only 25% had been given pain relief within 30 mins.

Trust-wide Further Considerations

1. One of the haemoglobinopathy CNSs had been able to access funding from the Roald Dahl Marvellous Children's Charity to complete the Kings College University Training in enhancing client centred care in haemoglobinopathies, but this opportunity had not been available to the other CNS in the team. Ensuring

appropriate development opportunities are available equitably will support development of the SHTs and as well as workforce retention.

Views of Service Users and Carers

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

Adults, children and young people and their families did have an open invitation to join the patient groups run by the Wessex and Thames Valley Haemoglobinopathy Coordinating Centre (HCC) but there was only a patient led WhatsApp group in operation for some patients, locally.

During the visit the visiting team met with six adults, four were living with a sickle cell disorder, one adult living with thalassaemia and one adult living with a rare inherited anaemia.

From the children's perspective we met one parent of four children with Hereditary Spherocytosis and one young person living with a Sickle Cell Disorder and their parent.

The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences. Their views are documented in the children's and adult specialist haemoglobinopathy team sections.

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Specialist l Haemoglobinopathy Team (Children and Young People Services)

General Comments and Achievements

Other than the Lead Clinician the team were new in post since 2021, this small hardworking team were flexible to the needs of their patients and families. Reviewers were impressed with the consistently positive feedback received for them from both patients, carers and staff in all the areas visited.

The two CNSs covered the paediatric and adult services. They had commenced a range of training for different staff groups and were planning to implement a more formal competence framework. Both CNSs led on the development of school care plans and provided support to community paediatric teams.

The SHT participated in the twice monthly haemoglobinopathy HCC wide MDT meetings for paediatric patients whereby the LHTs were also invited to present cases for discussion and HCC advice provided as required.

Annual reviews were undertaken by the Lead clinician with support from the CNSs. The process for annual reviews had been restructured so that patients attending would also be able to have TCD scanning and monitoring, if on hydroxycarbamide, on the same day.

Psychology provision for children and young people had recently been extended to those with all haemoglobin disorders rather than just those with a sickle cell disorder, despite the funding only covering those with SCD. This support was located in the child psychology department which reviewers were told worked well and families liked having the option to attend more face to face appointments than virtual. The area was welcoming and child friendly.

The team had support from the database and service coordinator (0.5WTE) whose time was divided between the adult and paediatric SHTs. The introduction of the data manager had resulted in more accurate NHR recording, including data for annual reviews conducted.

All staff had access to the Wessex and Thames Valley HCC virtual learning platform for sickle cell disorders and staff had attended the region wide Sickle Cell Disorder Study Day that had been held in March 2024. Education on the care of patients with thalassaemia was not covered.

A range of surveys to ascertain feedback from patients and their families had been completed, covering, for example blood transfusion, transition to the adult service and PED attendance.

The reviewing team were told that a regular hospital wide newsletter 'NERD' was produced, this promoted staff engagement and provided useful information, sickle cell disorders had recently been a feature in this newsletter.

The SHT were clear about the challenges and areas for development for the next few years, which included developing nurse led clinics, adapting the SCD HCC guidelines for use locally, building networks with their constituent LHTs for education and support and more focus on education and engagement for patients and their families around haemoglobinopathy disorders and, for young people transition to adult services.

Feedback from the LHTs

The paediatric representatives from the LHTs who met with the visiting team were positive about the support from the SHT, but did comment that they had limited access to psychology.

SPECIALIST HAEMOGLOBINOPATHY TEAM - CHILDREN AND YOUNG PEOPLE[1]			
University Hospitals Southampton – Southampton General Hospital	Linked Haemoglobinopathy Coordinating Centres (HCC)		
	Wessex and Thames Valley Sickle Cell HCC – *hosted by Oxford University Hospitals NHS Foundation Trust* The Red Cell Network (TRCN) Thalassaemia and Rare Inherited Anaemias HCC - *hosted by University College London Hospitals NHS Foundation Trust*		
	Linked Local Haemoglobinopathy Teams (LHT)	Patient Distribution	
		SCD	Thal.
	Dorset County Hospital NHS Foundation Trust	<=5	0
	Hampshire Hospitals NHS Foundation Trust • Basingstoke and North Hampshire Hospital • Royal Hampshire County Hospital	14	<=5
	Isle of Wight NHS Trust -St Mary's Hospital	<=5	<=5
	Portsmouth Hospitals University NHS Trust	24	20
	Salisbury NHS Foundation Trust	7	<=5
	University Hospitals Sussex NHS Foundation Trust	5	<=5
	University Hospitals Dorset NHS Foundation Trust	14	0
	Channel Islands	<=5	<=5

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 Disorder	Children and Young People	84	84	76	0	58	22
Thalassaemia	Children and Young People	12	12	6	<=5	<=5	<=5

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual WTE (at time of visit)
Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies	96	Two consultants had 2 PAs each for all red cell work.
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with haemoglobinopathies	96	For paediatrics and adults - 1.6WTE comprising of:- 1 CNS 0.8 WTE with 0.2 WTE in the apheresis unit 1 CNS 0.8WTE
Clinical Psychologist for paediatric patients dedicated to work with patients with hemoglobinopathies	96	0.2 WTE

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

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

Urgent and Emergency Care

The University Hospital Southampton had a dedicated Paediatric Emergency Department (PED) which all paediatric patients had emergency access to and was staffed by Paediatric Emergency Medicine doctors and specialist nurses. It had 11 cubicles, a play area, an 8 bedded short stay unit and a dedicated children's triage and waiting room. All paediatric patients from the LHTs had open access to paediatric services at their local hospital.

The PED was a positive and well-maintained environment, tailored to meet the needs of children and young patients. A 'Tannoy' system was in use which supported effective resource and capacity management, in turn improving the patient experience and department flow.

There was no flag system in place on reception to alert triage or the specialist team of attendance of any known haemoglobinopathy patient. This relied on communication from the receptionist to triage, located opposite, should they be made aware by the family when the patient was booked in at reception.

Staff had a good base knowledge of haemoglobinopathy and described the verbal notification system as working well, with triage normally expediting patients in order to administer nasal pain relief prior to any further analgesia via canulation.

In-patient Care

There were five main paediatric wards where patients with haemoglobin disorders could be admitted and all wards had staff training in the use of patient controlled analgesia and access to the paediatric acute pain management team. All the wards had dedicated playworkers.

Day care

The John Atwell (JAW) children's day ward was part of the paediatric department, based on G level of Southampton Children's Hospital. It was equipped with eight beds or cots and cared for children undergoing a wide variety of medical and surgical procedures.

Children who required regular blood transfusion support visited JAW for their transfusions. This was organised jointly by paediatric consultant, clinical nurse specialists and ward senior sisters. Wherever possible blood transfusions were planned for Saturday mornings to optimise a calm environment and not to disrupt the school day.

Children were encouraged to use the play area, which was well resourced with toys and books for all ages from one month to 16 years. There was also a television, videos and electronic games.

Outpatients

Children's outpatient unit was situated on level C of the children's outpatient department at University Hospital Southampton. The paediatric consultant and clinical nurse specialists saw children face to face at a clinic held every 2nd Monday of the month. Other clinics for example annual reviews of children living with thalassaemia and rare inherited anaemias, and routine reviews of patient residing in Southampton were seen on Tuesday mornings or Tuesday afternoons. There was good capacity in the clinics with new patients being seen within 6 weeks. Some telephone appointments with parents of children had taken place as required. It was explained that, should a child require a blood test, the unit had a facility for children's blood tests, situated in the same area and undertaken by specially trained children's nurses.

It was described that new patient appointments take approximately 30 minutes and routine appointments 20 minutes. Annual review appointments for children with SCD could take up to 2 hours as they usually involved transcranial doppler scanning, review by the paediatric team and blood tests.

Community-based Care

The Specialist Nurses linked into schools as required to support, amend or feedback on care plans.

Community Children's Nurses, worked closely with the Specialist Nurses who liaised with the team when blood tests were to be carried out for those children who need Hydroxycarbamide monitoring. Community Nurses would send through the blood results so that dosages could be amended, according to those results.

Community nurses will also let the Haemoglobinopathy team know if any of the Haemoglobinopathy patients have been admitted to the wards or if a parent has contacted them to let them know that their child is unwell in the community.

Views of Service Users and Carers

Service user Feedback

The review team met with 1 child living with a Sickle Cell Disorder and their parent, and the parent of four children living with Hereditary Spherocytosis.

The patient with SCD and parent were both happy with the care received at the hospital, they were especially happy with the consultant and the specialist nurses, expressing they felt well looked after and supported. They were able to confirm that medication is received promptly on attendance at the Paediatric Emergency Department (PED) and there has always been a clear understanding of the emergency. They had previously been able to call the ward directly if needed but now must access acute care via the PED, this has since worked well. The parent confirmed that school is aware and supportive of the disorder, a care plan is in place and did not convey any problems.

The parent of the four children with Hereditary Spherocytosis was very complimentary about the service from both the consultant and nurse specialists, however they described a less positive experience of the PED. It was explained that on the two most recent experiences triage was effective but resulted in 9 and 12 hour waits for blood, which was the main treatment for the children. On one of these occasions, they were required to re attend on two consecutive days with the same waiting period for blood on each day.

They also explained that the children did not have care plans and literature had been provided based only on personal research and knowledge of the condition.

Good Practice

1. The day unit was operational six days a week, Monday to Saturday from 8am – 8pm which meant that children and young people could attend for elective blood transfusions at the weekend
2. The screening pathway and genetic counselling was very robust. The nurse led service provided carrier information and counselling throughout the lifespan from newborn screening to new carriers identified in later years alongside local delivery of the National Sickle Cell and Thalassaemia Antenatal and Newborn Screening Programmes.
3. Both within the Paediatric Emergency Department and patient areas visited, the facilities for children and young people were child friendly and provided a calm, positive and patient centred environment,
4. The SHT had developed an hydroxycarbamide blood result database which meant that results from children and young people receiving hydroxycarbamide from the LHTs could be reviewed in a timelier manner and any changes to treatment plans initiated.
5. The SHT had a proactive and effective approach to prioritising and managing the available TCD scanning capacity.
6. The SHT had links with a GP who had a specialist interest in the management of pain in children and young people.

Immediate Risk: None were identified during the visit.

Concerns

1. Consultant workload

At the time of the visit reviewers were concerned that the Lead Clinician had insufficient time for the care of children and young people with haemoglobin disorders. The Lead Clinician had 2 PAs leadership of the SHT which includes supporting a number of LHTs and for direct clinical care. Reviewers were concerned that allocated PAs for both consultants for red cell work did not reflect the clinicians existing workload and there was no consultant cover to provide clinics and regular reviews for all red cell conditions. This resulted in a vulnerability of the service should the lead clinician be absent.

Due to clinical commitments the lead clinician was unable to attend the Wessex and Thames Valley Sickle Cell HCC or the TRCN Thalassaemia and RIA HCC.

The named deputy for the Lead Clinician had 2 PAs for the management of most of the paediatric patients with thalassaemia and other rare inherited anaemias, but did not have allocated time to cover all red cell work.

2. Access to analgesia and training for Emergency Department staff

The most recent service audit of compliance with the NICE clinical guideline on the management of acute pain (six patients) showed that only 25% of patients had received analgesia within 30 minutes of arrival to the Emergency Department.

There was no dedicated teaching programme for ED staff with relevance to haemoglobinopathy emergency presentations.

3. Access to Psychology

The SHT had 0.2WTE psychologist to provide support for approximately 96 children, young people and their families and cover was only available for outpatients. Psychology provision for children and young people had recently been extended to those with all haemoglobin disorders, although funding for the service was only for those with a sickle cell disorder, which reviewers were concerned that the service was vulnerable. In addition, LHT representatives who met with the visiting team commented that they had very limited access to psychology. The available time did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE for 300 patients. Reviewers were concerned that children and young people affected by these disorders who do not have access to specialised psychological input, have the potential for increased stress, anxiety, depression, or difficulties in coping with challenges associated with their condition. Psychologist staffing for the future will also need to take account of increasing patient numbers and their complexity.

4. Competence framework and training

A formal competence framework and process for ongoing monitoring of staff competences in the care of children and young people with haemoglobin disorders was not yet in place. Nursing staff both on the wards visited and the day unit had competences in transfusion and cannulation but had no specific training in haemoglobin disorders and were not aware of formal processes and optimum pathways.

5. Standard Operating Procedure and Lack of standardisation

Governance processes did not appear to be robust. The SHT did not have a service operational policy or standard operating procedures which meant that there was a dependency on both the lead clinician and specialist nurses to inform process and practice.

The SHT had adopted some Wessex and Thames Valley HCC guidance but other documentation was not in place or ratified. Reviewers were concerned that agreed of written guidelines and/ or protocols are important to guide new staff to the service, reduce the potential for variation in practice and enable auditing.

6. Engagement with LTHs

The SHT covered a wide region with LHTs crossing multiple ICB boundaries. At the time of the visit the service level agreements (SLA) between the SHTs and LHTs had not been agreed. Reviewers considered having approved SLAs with the LHTs could have the potential to clarify clinical responsibilities between teams, improve engagement and ease the commissioning transition planned for 2025.

Further Considerations

1. TCD provision was being actively managed due to the restricted capacity and unlikely to be sustainable in the near future given the increasing numbers of children with Haemoglobinopathies. Reviewers were told that they only had 55 TCD slots, although this would increase when a second member of staff had completed their training. Should capacity not increase then it could have serious impact on the health of children and young people who are at risk of 'silent' strokes if not identified.
2. Confirmatory Haemoglobin High-Performance Liquid Chromatography (HPLC) was done at six months and the routine 2 months which reviewers considered should be completed earlier as this could delay patient care.
3. Reviewers were told of plans to extend the apheresis service for paediatric patients with early discussions being had with in house teams, namely the dialysis team to see if there was the potential for a joint service, as numbers of patients with haemoglobin disorders would be low. As the CNSs work across adults and paediatrics and the lead CNS was an apheresis specialist nurse, reviewers considered that it would be easier to extend the service to the paediatric population once other aspects for running a service were in place. Extending the provision would provide an equitable service for adults and paediatric patients with haemoglobinopathy disorders.
4. The process for transitioning young people to adult care was on an ad hoc basis. Reviewers were told that this was because of the low numbers of young people transitioning at any one time. However, reviewers considered that formalising the process and wider MDT involvement would ensure there was a robust pathway and support for young people transitioning to the adult services.
5. The CNS team were relatively new in post in the last 12 months. Reviewers considered that it was important that the team have sufficient and dedicated time for training and development of their CNS roles so that they can develop key areas including transition and liaison, support and to the paediatric LHTs within their region.
6. The SHT had limited engagement with the Wessex and Thames Valley HCC. Increasing liaison would provide additional support for training and education.
7. The paediatric wards did not have link nurses, development of this model in the way it has been introduced for adult areas may help with improving the knowledge, skills and confidence of staff working in these areas. Implementing a similar approach with the LHTs may also be helpful.
8. From discussions with staff who met with the reviewers during the visit, a refresh of skills, knowledge and clinical guidelines in relation to acute complications, particularly priapism and splenic sequestration would ensure that staff competences were adequate to meet the needs of patients when experiencing these complications.
9. Reviewers did not see any signage or information displayed for red cell services in any of the child and young people areas visited, which has the potential to make children young people and their families with haemoglobin disorders feel less important than patients with other conditions.
10. The 'WhatsApp' group was not widely known about and reviewers considered that the development of a support group in addition to the informal group, would provide a more structured and governed forum for information, support, discussion and education and that the CNS team may need to provide support and guidance in facilitating the group until established.

Specialist Haemoglobinopathy Team (Adult Services)

General Comments and Achievements

This was a hardworking small team who were flexible to the needs of their patients and families. Reviewers were impressed with the progress made towards the delivery of the NHSE service specification for SHTs. Since the last visit in 2019 the number of patients with haemoglobin disorders had trebled, the SHT had established a network with their constituent LHTs and there had been considerable changes in SHT staffing with all but the lead clinician, new in post since 2023.

The CNSs covered the paediatric and adult services and were clear about what they needed to achieve in the next 12 months. They had commenced a range of training for different staff groups and were planning to implement a more formal competence framework. One of CNSs also spent a day a week on the apheresis unit. Both CNSs provided inpatient and outreach support to adult and paediatric patients in the community as well as being available for advice and support to the LHTs.

The haematology department had created a role of 'red cell SpR' which had been instrumental for continuity of care for patients with haemoglobin disorders. The SpR attended clinics, looked after patients haemoglobin disorder inpatients and also had an important role in the blood transfusion service.

The psychologist had joined the team in January 2024 and had one clinical day with the team which they spread across the week to be flexible to cover meetings and consultations. The psychologist was located with the general psychology team but had regular meetings with the SHT. Consultations were offered face to face though most patients were requesting telephone consultations. Reviewers were told that should more patients require a face to face consultation in the future then appropriate space to see patients would be challenging. Due to capacity the psychologist was not able to be involved on a regular basis in transition or attend the haemoglobinopathy clinics. Some referrals were received for psychology support from the LHTs and representatives from the LHTs who met with visiting team commented that patients had spoken highly of the support they had received.

An in house 24/7 apheresis service was in operation and monthly business meetings were held to discuss any issues. There appeared to be adequate capacity for the local/regional need because of the presence of one of the CNS in apheresis, red cell targets were reviewed 'live' and apheresis plans adjusted accordingly as required.

The lead clinician undertook all annual reviews during the hemoglobinopathy clinic at UHS. At the time of the visit 2/3rds of annual reviews across the region had been completed. The annual review completion rate of the LHT within the network was significantly lower. Reviewers considered this may be due to a number of issues; partly a registration issue; it was not entirely clear whether certain LHT patients could have been counted twice and also because of the traditional distribution of the network and the overlap with TRCN, some LHT patients may have had their annual review performed elsewhere.

A process of sending patients reminders of their clinic appointments had seen a significant reduction in the level of patients who did not attend.

The SHT worked closely with the pain team, and a link practitioner was actively involved supporting patients with acute and complex pain needs and development of their analgesia plans. Patients admitted to the AOS did have access to patient controlled analgesia devices (PCA) but not on the main haematology wards.

Due to low numbers of patients an adult MDT was held twice a monthly with the Wessex and Thames Valley HCC MDT to which LHTs were invited to attend. The HCC and SHT also held quarterly quality and governance meetings.

All staff had access to the HCC virtual learning platform for sickle cell disorders and staff had attended the region wide Sickle Cell Disorder Study Day that had been held in March 2024. Education on the care of patients with thalassaemia was not so evident.

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

The SHT had developed a specific pathway for SCD painful acute admissions which enabled patients with a vaso occlusive crisis to be seen more quickly in the Emergency Department so that timely analgesia could be given and then referred to the Acute Oncology Service (AOS) for further specialist management.

The team had support from the database and service coordinator (0.5WTE) whose time was divided between adults and paediatrics . The introduction of the data manager had resulted in more accurate NHR recording, including data for annual reviews conducted.

LHT Meeting

The visiting team met with representatives from the LHTs. None of those who met with the visiting team were able to attend the MDT meetings but would contact the SHT for advice when required. They commented about being under resourced to be able to deliver a red cell service and had little time for data collection and completion of key audits such as compliance with the NICE guidance on timeliness of analgesia for patients attending with a vaso occlusive crisis. They raised concerns for the future in being able to develop red cell expertise as a low prevalence areas and that succession planning for their services was challenging. Some commented that they would like more support from the SHT CNS team.

Some of the representative Representatives commented that there was no reliable route for Ferriscans and patients were referred to London and that this was challenging to arrange and wondered if it could be undertaken at UHS as the SHT managed their patients iron chelation.

Patients who required automated red cell exchange transfusions had to travel to the unit at UHS. Annual reviews were undertaken face to face by the SHT at UHS. The LHT representatives had not been able to attend the educational days but would attend if more notice.

SPECIALIST HAEMOGLOBINOPATHY TEAM - ADULTS[3]			
University Hospitals Southampton – Southampton General Hospital	Linked Haemoglobinopathy Coordinating Centres (HCC)		
	Wessex and Thames Valley Sickle Cell HCC – *hosted by Oxford University Hospitals NHS Foundation Trust* The Red Cell Network (TRCN) Thalassaemia and Rare Inherited Anaemias HCC - *hosted by University College London Hospitals NHS Foundation Trust*		
	Linked Local Haemoglobinopathy Teams (LHT)	Patient Distribution	
		SCD	Thal.
	Dorset County Hospital NHS Foundation Trust	0	0
	Hampshire Hospitals NHS Foundation Trust - Basingstoke and North Hampshire Hospital	17	<=5
	Isle of Wight NHS Trust -St Mary's Hospital	0	0
	Portsmouth Hospitals University NHS Trust	33	13
	Salisbury NHS Foundation Trust	6	<=5
	University Hospitals Sussex NHS Foundation Trust – St Richards and Worthing Hospital	<=5	0
	University Hospitals Dorset NHS Foundation Trust - Bournemouth hospital and Poole	25	<=5

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

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *4	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disorder	Adults	118	101	67	13	24	59 (2 high intensity uses at Portsmouth and S'ton)
Thalassaemia & RIA	Adults	28	17	9	12	0	<=5

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual PA/WTE (at time of visit)
Consultant haematologist dedicated to work with adult patients with haemoglobinopathies	146	3PAs
Clinical Nurse Specialist for adult patients dedicated to work with patients with haemoglobinopathies	146	For paediatrics and adults - 1.6WTE comprising of:- 1 CNS 0.8 WTE with 0.2 WTE in the apheresis unit 1 CNS 0.8WTE
Clinical Psychologist for adult patients dedicated to work with patients with haemoglobinopathies	146	0.2WTE

Emergency Care

Patients with acute presentations including painful vaso occlusive crisis attended the emergency department and were triaged and were seen in the majors area of the department. Patients generally had emergency care plans which were also accessible to staff in the ED. However, the care plans did not have a dedicated place in the electronic patient record and it requires browsing through notes to find individual plans. The A&E had developed a sickle cell alert that linked in with the Trust guideline for acute management of a sickle cell patient and contained individual notes. This was incorporated into a separate computer system from the electronic patient record only used in A&E. The SHT ha also commenced sharing of patient emergency care plans with the South Central Ambulance Service (SCAS) which had enabled ambulance staff to commence treatment on arrival to the patients home.

The Trust had very recently introduced a new pathway for sickle cell patients (< 4 weeks before the peer review visit) not yet reflected in the background report. This involved rapid transfer from A&E to the Macmillan Acute Oncology Service - AOS, for further management, bypassing admission to the acute medical units. On AOS there was the provision to provide patient controlled analgesia devices (PCA) which had not been possible with the previous pathway when patients were admitted from the ED to the acute medical unit. In addition, AOS was manned by a dedicated group of nurses and doctors in training who were much more aware of the needs of patients with a sickle cell disorder.

The AOS was for oncology and haematology patients who needed to be admitted urgently due to their cancer or haematology treatment. Patients could contact the emergency phone line which was staffed 24 hours a day and the unit could take admissions seven days a week. The unit was located next to the ED consisted of two bays with six and four beds and two side rooms.

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

If patients were likely to require admission for more than 24hrs then the on call haematology team would take over the patients care, the SHT notified and the patients were transferred to ward C2.

Inpatient Care

Patients with haemoglobin disorders tended to be admitted to Ward C2 the haematology/ oncology ward (a 27 bedded ward) either directly or via the AOS. The ward staff were trained in the administration PCA and regular training sessions on management of patients living with a haemoglobin disorder were delivered by members of the SHT.

Young patients with a sickle cell disorder, thalassaemia and rare inherited anaemias who required blood transfusions and other treatments on regular basis could be accommodated , if capacity on the Teenage and Young Adolescent Unit (TYA)

Day Unit

There was a dedicated Haematology – Oncology /Apheresis Day Unit (C7) comprising of 12 treatment spaces and phlebotomy. The unit was open 7 days a week, 8am to 8pm on weekdays and 8am to 4pm on Saturdays and Sundays. Patient with haemoglobin disorders could attend for transfusion, blood tests and more recently a red cell exchange programme for patients with a sickle cell disorder. The apheresis team had recently developed an on-call service for patients requiring emergency apheresis procedures. This 24/7 on call service for emergency apheresis procedures had enabled patient to be treated closer to home rather than being diverted to other regional centres.

Young people with thalassaemia or RIA who required blood transfusions could also be admitted to the TYA unit if capacity.

Outpatient Care

A specialist haemoglobinopathy outpatient clinic was held every Tuesday afternoon and was led by the lead clinician, CNS and psychologist with support from a specialist registrar. Patients could attend or have a telephone appointment. GP's and patients were sent a copy of any discharge summary and clinic letters following admission and clinic visits.

Community-Based Care

There was no community service for adult patients living with a haemoglobin disorder. The SHT did however have good links with one of the community CNS's who previously was the CNS with the adult and paediatric SHTs.

Guidelines

There was only one Trust-wide guideline available on the acute management of sickle cell disease, written by the A&E team. The haemoglobinopathy team at UHS used the excellent network guidelines from the Wessex and Thames Valley Sickle Cell HCC otherwise. The HCC guidelines were available via their external website. Most doctors in training who met with the visiting team were aware of how to find the HCC guidelines, however without induction on the topic it would not be possible to find these guidelines via the UHS intranet or document management system; one had to 'know' of the HCC website.

Views of Service Users and Carers

During the visit the visiting team met with six adults, four were living with a sickle cell disorder, one adult living with thalassaemia and one adult living with a rare inherited anaemia (RIA). The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences.

The HCC did offer patients an open invitation to join the monthly support groups but in practice the patients and the psychologist who met with the visiting team were not aware that the group was active.

All those who spoke to the visiting team commented about the 'great' care and support they received from the specialist haemoglobinopathy team.

Feedback from patients with a sickle cell disorder

- Emergency Care pathway: One patient had never had to attend the ED. Three other patients had attended during a vaso -occlusive episode and two commented that their care was excellent and they were assessed and received analgesia within 30 mins. One patient said that they were admitted to a 'holding' ward and did not receive timely analgesia and had to contact the CNS to ask for support. All the patients commented that care in the ED tended to be less efficient at weekends. Patients felt that some staff in the ED lacked knowledge about their condition.
- Patients were aware of their care plans, but commented that they were not always followed when they attended the ED.
- Two patients had received support from the psychologist and had found this valuable, one patient was not aware that this service was available.
- Patients who were at risk of a priapism had not been offered or received any information about this aspect of their condition.
- Patients who attended the ward for cross matching prior to their transfusion commented that in general the process was efficient but depending on how busy the ward was they could wait several hours.
- Those patients who required exchange transfusions said that the process was well managed and there was flexibility in the time and days that they could attend for this procedure.
- All the patients commented that they would like more support and information. On the visit day not all those who spoke to the visiting team were aware of the patient WhatsApp group but joined at the meeting.
- One young person commented that they had found it uncomfortable to be cared for in the same area as patients living with cancer and it was 'depressing as they look so ill '

Feedback from patients living with thalassaemia or a RIA

- Those who spoke to reviewers had not been offered or received information about their condition, when asked they did not seem to be aware of any side effects of the medication they were taking and the need to report any issues with their vision or hearing.
- They were not aware of the support available from the psychology service.
- They knew to access emergency care via the ED if acutely unwell. Although one patient had attended a walk in centre rather than the ED but were quickly referred by the centre to the ED.
- Reviewers were told that they were reviewed by a member of the See SHT team every three months
- They could contact the CNSs but they tend to deal with children. If it is an emergency it is difficult to get hold of anyone. Easy to obtain prescriptions and Exjade was delivered. The CNSs had also helped with PIP application.
- Those who required regular transfusions considered that the process worked well. Patients commented that they had transfusion plans. They had confidence in the staff on C7 who were competent in accessing their ports and in venepuncture. Less positive were the easy chairs they used when being transfused which were not that comfortable for long periods of time.
- Those who met with the visiting team had shared care arrangements in place with the University College Hospital NHS Foundation Trust/ Whittington HealthCare NHS Trust and they had the following comments about these arrangements:-

- They did not have a care plan that was accessible if they attended the ED locally. When they had attended the ED they had not been followed up by the local SHT.
- Endocrine and scans were all completed in London on an annual basis but they were not aware of some aspects of their care including monitoring for diabetes and the need for a cardiology review.
- Communication between the London teams was poor and GPs were not always aware of their latest treatments and care plans.
- When attending UCLH they had access to alternative therapies which were not available at UHS.

Other comments

- Those who met with the reviewing team had completed the trust friends and family surveys but had not any experience in providing feedback about their local service.
- One family member had concerns about an expected grandchild who potentially may be affected with a haemoglobin disorder. They were concerned about the screening process and potential delay in a newborn diagnosis having experienced this with their own child.

Good Practice

1. Reviewers were impressed with the work undertaken by the ED consultant and SHT to develop the AOS pathway. At the time of the visit the new pathway had been in operation for a month and enabled patients to be seen more quickly in the ED, given analgesia if appropriate and then transferred to the AOS so that specialist treatment could be commenced.
2. Commendable was that despite relatively small numbers of patients with haemoglobin disorders, the trust had managed to change the pathway to ensure patients were admitted to a haematology ward rather than to a general medical ward, and with the pathway being more streamlined, the SHT had been able to provide more targeted training for staff covering the urgent care needs of patients with a haemoglobin disorder.
3. The latest audit on compliance with the NICE guidance on the timeliness of analgesia audit had shown a significant improvement in compliance with 60% of patients receiving their analgesia administered within 30 mins of presentation from 20% in 2022-3. Reviewers were also told that it was hoped that the new AOS pathway would see a further improvement with compliance with this standard.
4. When adult patients with a haemoglobin disorder attended the ED a pop up alert would be triggered on the patient record on the symphony system to notify staff of their condition.
5. The SHT had been successful in gaining a dedicated clinical registrar post for the red cell service which would improve capacity and resilience within the specialist team as well as improve regional haemoglobinopathy training and increase the likelihood that trainees consider this underrepresented subspecialty as a future career or special interest option.
6. The SHT had a good relationship with the pain team. The lead practitioner in the team had a special interest in the care of sickle cell disease pain management and was aware of patients who were likely to attend the ED in a vaso occlusive crisis. The lead practitioner in the pain team was proactive in working with patients to ensure they had information and up to date emergence care pain plans. The practitioner also supported ward staff in PCA training and management.
7. The joint obstetric and sickle cell disorder pathway was very good and had been developed across the network by a haematologist with a special interest in obstetrics. As part of the network pathway a regional monthly MDT was held where all pregnant patients with inherited red cell disorders were discussed and to which any LHT/obstetric service could refer and attend.
8. The CNS team had been active in developing the link nurse model in key areas to improve the knowledge, skills and confidence of staff in the care of patients living with a haemoglobin disorder. Link nurses were in place in the ED, AOS and ward C7.

9. The SHT had been proactive at accessing novel therapies and had assured the LHTs that their patients would also have equitable access to novel therapies.

Immediate Risk

No immediate risks were identified during the visit.

Serious Concern

1. **Consultant staffing**

   At the time of the visit the Lead clinician had insufficient time for the care of people with haemoglobin disorders.

   a. The Lead Clinician had three PAs for SHT leadership and for direct clinical care out of a significant workload of 14 PAs. The Lead was also ward attending 1:3 for myeloma/myeloid/general haematology inpatients and participated in a 1:6 on-call rota covering the bone marrow transplantation/acute leukaemia ward. The lead clinician did not actually participate in an on-call rotation for patients with haemoglobin disorders as this was covered by the general haematology on call rota which meant that teams potentially would contact the lead clinician 24/7 including during leave and weekends. If the lead clinician was not contactable then decisions would be made either without specialist input or following contact with the on-call red cell consultant of the HCC based at the Oxford University Hospitals NHS Foundation Trust.

   b. There was a named deputy for the SHT but not with time allocated for clinical work with haemoglobin disorders which resulted in the lead clinician being contacted for advice when not on site.

   c. In the absence of the lead clinician there was no cover to provide clinics and regular reviews.

2. **Reviewers were also concerned about the capacity of the SHT for the following reasons;**

   a. The potential changes in the LHT service provided by Portsmouth Hospitals University NHS Trust due to the imminent retirement of the haemoglobinopathy lead consultant, which could result in an increase in service users for the SHT at UHS. Reviewers were told that the Portsmouth Hospitals University NHS Trust had plans to recruit a consultant with time allocated for red cell work, but due to low prevalence, recruitment to this post may be difficult.

   b. At the time of the visit 2/3 of annual reviews across the region had been completed. The annual review completion rate of the LHTs within the network was significantly lower.

   c. Patient numbers across the SHT and linked LHTs had trebled in the last four years and were predicted to increase further in the near future. Patient longevity and complexity were also increasing.

Concern

1. **Notification of patients admitted under the care of other specialities**

During the visit reviewers were made aware of patients having been admitted under the care of other specialty teams without notification to a member of the haemoglobinopathy service to provide haematology advice. Development of an appropriate mechanism should be considered to ensure an appropriate review of this group of patients by the haematology team**.**

2. **Access to Psychology**

The SHT had 0.2WTE psychologist to provide support for approximately 146 adult patients across the region and no cover for absence. The lack of capacity meant that they had not been able to be involved in transition or the haemoglobinopathy clinics. The available time did not meet the British Psychological Society Special Interest Group in Sickle Cell and Thalassaemia (2017) recommendation of one WTE for 300 patients. 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, patient longevity and complexity.

3. Competence Framework

Emergency Department staff and Ward nurses had received training in haemoglobinopathies, but a formal competence framework was not yet in place. Nursing staff on the wards visited had competences in transfusion and cannulation but staff commented that they would value more specific training in haemoglobin disorders. The CNS were planning to introduce the competence framework available from the Wessex and Thames Valley HCC and reviewers commented that any future training should include more training on the care of patients with thalassaemia or a RIA and the APPG report: No one's listening: an inquiry into the avoidable deaths and failures of care for sickle cell patients in secondary care.

Further Considerations

1. The process for transitioning young people to adult care was on an ad hoc basis. Reviewers were told that this was because of the low numbers of young people transitioning at any one time. However, reviewers considered that formalising the process and ensuring MDT involvement would ensure there was a robust pathway and support for young people transitioning from paediatric to adult services.
2. Staff in the areas visited by the reviewing team did not appear to be as knowledgeable about the care of patients with thalassaemia as they were about sickle cell disorders. It will be important for the SHT to make sure that training and the competence framework when implemented covers all haemoglobin disorders. Liaising with TRCN for thalassaemia and RIA about resources available may be helpful.
3. Reviewers did not see any signage for red cell services in any of the areas visited. It was also notable that no part of any information displayed related to red cell conditions, which has the potential to make patients with haemoglobin disorders feel less important than patients with other conditions. Reviewers were told that the team had recently moved to the haemophilia outpatient area and reviewers considered that once settled that there was the potential for posters and patient information to be displayed. For patients it would also be helpful if the feedback from surveys was more visible.
4. All the patients who met with the visiting team, commented that they would like more support and information. On the visit day some of the patients were not aware of the patient 'WhatsApp' group but joined during the meeting. Reviewers considered that the development of a support group, in addition to the informal group, would provide a more structured and governed forum for information, support, discussion and education and that the CNS team may need to provide support and guidance in facilitating the group until established.
5. The CNS team were relatively new in post in the last 12 months. Reviewers considered that it was important that the team have sufficient and dedicated time for training and development of their CNS roles so that they can develop key areas including transition and liaison, support and to the LHTs within their region.
6. The SHT covered a wide region with LHTs crossing multiple ICB boundaries. At the time of the visit the service level agreements (SLA) between the SHTs and LHTs had not been agreed. Reviewers considered having approved SLAs with the LHTs could have the potential to clarify clinical responsibilities between teams, improve engagement and ease the commissioning transition planned for 2025.
7. The SHT had adopted the Wessex and Thames Valley HCC (NSSG) guidelines and had access to all the resources, including patient information and videos via the NSSG website link. Reviewers considered that UHS staff outside of the haematology teams and patients may not be aware of how to access the useful resources if they were not familiar with the NSSG name and it may be helpful to adapt the search functionality by haemoglobin condition. Reviewers were also unclear of the governance process for adopting external guidelines as it was not covered in the Trust document control policy.

Commissioning

Due to technical difficulties the reviewers were unable to meet virtually with the regional NHS specialist commissioner representative and the local commissioner representatives from NHS Hampshire and Isle of Wight Integrated Care System. We would like to thank them for their willingness to engage with the review team on the day. 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		
Nkechi Anyanwu	Clinical Nurse Manager	Guy's and St Thomas' NHS Foundation Trust
Nazma Chowdhury	Consultant Paediatrician	Croydon Health Services NHS Trust
Stephanie George	User Representative	Red Cells R Us
Amy Heap	Paediatric Haemoglobinopathy Nurse Specialist	University Hospitals Coventry & Warwickshire
Fiona Leacock	Associate Director of Quality	Southeast London ICS
Romaine Maharaj	Executive Director	UK Thalassaemia Society
Heather Rawle	Consultant Clinical and Health Psychologist	Guy's and St Thomas' NHS Foundation Trust
Edel Robinson	Haemoglobinopathies Screening Practitioner	Birmingham Women's & Children's Hospital NHS Trust
Elizabeth Rhodes	Consultant Haematologist	St George's University Hospitals NHS Foundation Trust

Clinical Leads		
Arne De Kreuk	Consultant Haematologist	King's College Hospital NHS Trust
Sabiha Kausar	Consultant Paediatric Haematologist	Manchester University Hospital NHS Trust

MLCSU Team		
Sarah Broomhead	Professional Lead	NHS Midlands and Lancashire
Justine Howe	Head of Urgent Care	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
Specialist Haemoglobinopathy Team (SHT) Children and Young People	49	29	59%
Specialist Haemoglobinopathy Team (SHT) Adults	45	25	56%

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)	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	Y	
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	N	Due to small numbers of young people transferring to adult service the process was undertaken on an individual basis. The process would benefit from more structure to ensure robust information sharing, clarity around the named coordinator and the planned preparation period.
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	N	The UKTS survey had not been undertaken in the last three years. The SHT had undertaken a survey covering help in the emergency situation.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a. Mechanisms for receiving feedback b. Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c. Examples of changes made as a result of feedback and involvement	N	There was no formal specific feedback mechanisms in place for CYP and their families ('b') Changes were planned as a result of the feedback from the emergency care survey.
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The lead consultant had 2 PAs for 96 patients across the network.
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.	Y	There was a nominated Lead Nurse who was supported by an additional CNS. Both CNSs worked across the paediatric and adult SHTs
HC-204	**Medical Staffing and Competences: Clinics and Regular Reviews** The service should have sufficient medical staff with appropriate competences in the care of children and young people with haemoglobin disorders for clinics and regular reviews. Competences should be maintained through appropriate CPD. Staffing levels should be appropriate for the number of patients cared for by the service and its role. Cover for absences should be available.	N	The lead clinician had 2 PAs for all red cell work. The named deputy cover e NTD Thalassaemia and RIA but not other haemoglobin disorders

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
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	
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	A competence framework in the care of people with haemoglobin disorders was not yet in place. 'e' was met.

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 0.2WTE psychologist to provide support for approximately 96 children, young people and their families and cover was only available for inpatients.
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.	Y	
HC-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HC-602) as required: a. Social worker / benefits adviser b. Play specialist / youth worker c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Child and adolescent mental health services	N	There was no access to a social worker or benefits advice.

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	
HC-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HC-304	**Urgent Care – Staff Competences** Medical and nursing staff working in the Emergency Departments and admission units should have competences in urgent care of children and young people with haemoglobin disorders.	N	Staff who met with the reviewing team had a good understanding haemoglobin disorders, but a competence framework to assess knowledge was not in place. The most recent audit of NICE guidance showed that only 25% of CYP attending the PED had received analgesia within 30 mins.

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h. Responsibilities for giving information to the young person and their family or carer (QS HC-195)	N	There were no guidelines, no named coordinator and no communication between HCCs, SHTs and LHTs in place.
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.	N	Standardised guidelines were not in place covering first outpatient appointment or annual review.

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: 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	
HC-507	**Hydroxycarbamide and Other Disease Modifying Therapies** Guidelines on hydroxycarbamide and other disease modifying therapies should be in use covering: a. Indications for initiation b. Monitoring of compliance and clinical response, including achieving maximum tolerated dose for hydroxycarbamide c. Documenting reasons for non-compliance d. Monitoring complications e. Indications for discontinuation	Y	
HC-508	**Non-Transfusion Dependent Thalassaemia (nTDT)** Guidelines on the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy d. Consideration of options for disease modifying therapy	Y	

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

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

Ref.	Quality Standards (Children)	Met? Y/ N/	Reviewer Comment
HC-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by an HCC / SHT b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 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	N	A formalised SOP was not in place although in practice the requirements of the QS were undertaken.

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)	N	Draft documents dated April 2023 were available which had not been ratified.
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).	N	Local MDTs were not held. Reviewers were told this was due to the low numbers of patients for MDT discussion. A representative from the SHT would attend the HCC wide MDTs which were held monthly and LHTs were invited to attend.
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 SLA with NHS Solent who provided community services was not in place
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).	N	Representatives from the SHT did not attend the TRCN business meetings
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	N	Clinical audits covering the requirements of the QS had not been undertaken or completed in the previous two years: a. Commenced May 2024, results yet to be analysed b. Data not available for patient and clinical feedback
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.	N	The MDT had not yet reviewed with patient and carer representatives the requirements of the QS.
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.	N	Not all the documentation seen included the Trust logos and the process for ratifying external documents was not clear

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Specialist Haemoglobinopathy Team for Adults with Haemoglobin Disorders

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

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	Some patient information had been developed for use across the network and included all SHT and LHT main contacts. Patients who met with the reviewing team commented that they would value receiving more information.
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	A range of examples were seen although some were quite brief in content.
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	Templates and examples of clinic letters were seen.
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**	There was little information visible about haemoglobin disorders in the areas visited.
HA-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. Information and support on taking responsibility for their own care b. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f. Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	N	The team were using the 'Ready Steady Go' programme but it was not clear that there was a robust process in place as transition was undertaken on an ad hoc basis. Reviewers were told that this was due to the low numbers of young people transitioning to the adult service. However, the CNS team were relatively new in post and had plans to develop the transition pathway.

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 had not been undertaken in the last three years. The SHT had been active in seeking views relating to other patient surveys relating to aspects of the service at UHS including a patient experience with the UHS service for SCD and thalassaemia; a survey of patients with SCD; help in emergency and patient experience and for the red cell exchange service.
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	N	The SHT had mechanisms for receiving feedback but compliance with 'b' was not yet met.
HA-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The Lead Clinician had 3 PAs for SHT leadership and for direct clinical care out of a significant workload of 14PAs. The Lead was also ward attending 1:3 for myeloma/myeloid/general haematology inpatients and participate 1:6 on-call covering the bone marrow transplantation/acute leukaemia ward. There was a named deputy for the SHT but not with time for clinical work and the lead clinician was contacted when not on site.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services c. Competences in caring for people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	2 WTE clinical nurse specialists were in post who worked across the adult and paediatric services. 1WTE clinical nurse specialist works 0.8 WTE for the service, with an additional 0.2 WTE in the apheresis unit.
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	In the absence of the lead clinician there was no cover to provide clinics and regular reviews.
HA-205	**Medical Staffing and Competences: Unscheduled Care** 24/7 consultant and junior staffing for unscheduled care should be available. **SHTs and HCCs only:** A consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients during normal working hours. Cover for absences should be available.	Y	
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	Although the doctors in training handbook/ presentation did not appear to cover haemoglobin disorders apart from lead names and a brief sentence about acute admissions.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-207	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences, 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	A competence framework in the care of people with haemoglobin disorders was not yet in place. A training plan was seen that listed all staff groups and included a timeframe for ongoing monitoring. 'e' was met
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	0.2 wte 8a Clinical Psychologist for 146 patients did not meet the recommended 1WTE:300 patients and there was no cover for absences. This meant that they had limited capacity to input fully into the services MDT and governance activities. 'c' was met.
HA-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	0.5 WTE A Data Manager was in post for the Adults and Paediatric SHTs. A Nursing Administrative Assistant (0.2 WTE) also provided some support for both the adult and paediatric services.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-301	**Support Services** Timely access to the following services should be available with sufficient time for patient care and attending multidisciplinary meetings (QS HA-602) as required: a. Social worker / benefits adviser b. Leg ulcer service c. Dietetics d. Physiotherapy (inpatient and community-based) e. Occupational therapy f. Mental health services	Y	
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	
HA-303	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HA-304	**Urgent Care – Staff Competences** Medical and nursing staff working in Emergency Departments and admission units should have competences in urgent care of people with haemoglobin disorders.	N	Training was provided to staff in the ED but none of the staff who met with the reviewing had thought they had received any training in the urgent care of patients with haemoglobin disorders. Induction training had covered how patients were 'flagged' on the system.

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts e. Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion f. Patient pathway for Central Venous Access Device insertion, management and removal	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	Wessex and Thames Valley network guidelines (W&TV NSSG) were in use with a local one page summary with indications for transfusion. Reviewers considered that it may be helpful to liaise with The Red Cell Network (TRCN) for their guidance as they provided shared care for patients with thalassaemia and RIA.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
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 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 For patients with thalassaemia: k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine	Y	Wessex and Thames Valley network guidelines were in use. For thalassaemia the guidance was brief and liaising with TRCN e with The Red Cell Network for their guidance.

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

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-512	**Fertility and Pregnancy** Guidelines should be in use covering: a. Fertility, including fertility preservation, assisted conception and pre-implantation genetic diagnosis b. Care during pregnancy and delivery c. Post-partum care of the mother and baby Guidelines should cover: i. Arrangements for shared care with a consultant obstetrician with an interest in the care of people with haemoglobin disorders, including details of the service concerned ii. Arrangements for access to anaesthetists with an interest in the management of high-risk pregnancy and delivery iii. Arrangements for access to special care or neonatal intensive care, if required iv. Indications for discussion at the HCC MDT (QS HA-605) v. Arrangements for care of pregnant young women aged under 18	N	The draft network guidance would meet the requirements of the QS once ratified and implemented.
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.	N	The Wessex and Thames Valley HCC guidance was not easily accessible on the Trust system unless staff were aware of the HCC name.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission b. Patient discussion at local multidisciplinary team meetings (QS HA-604) c. Follow up of patients who 'did not attend' d. Transfer of care of patients who move to another area, including communication with all haemoglobinopathy services involved with their care before the move and communication and transfer of clinical information to the HCC, SHT, LHT and community services who will be taking over their care e. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together f. Governance arrangements for providing consultations, assessments and therapeutic interventions virtually, in the home or in informal locations	N	The SOP did not cover 'a', 'b' in terms of frequency, 'd' was not explicit ,'f' was not included.
HA-603	**Shared Care Agreement with LHTs** A written agreement should be in place with each LHT covering: a. Whether or not annual reviews are delegated to the LHT b. New patient and annual review guidelines (QS HA-502) (if annual reviews are delegated) c. LHT management and referral guidelines (QS HA-503) d. National Haemoglobinopathy Registry data collection (QS HA-701) e. Two-way communication of patient information between HCC / SHT and LHT f. Attendance at HCC business meetings (HA-607) (if applicable) g. Participation in HCC-agreed audits (HA-706)	N	The SLAs between the SHT and LHTs were in draft form, some since 2023. The SLAs were comprehensive and met the requirements of the QS.

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).	N	Local MDTs were not held. Reviewers were told this was due to the low numbers of patients for MDT discussion. A representative from the SHTs and constituent LHTs would attend the HCC wide MDTs which were held twice monthly.
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 SLA with NHS Solent who provided community services was not in place
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).	N	The SHT were unable to attend TRCN HCC business meetings due to clinical commitments.
HA-701	**National Haemoglobinopathy Registry** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies, patients lost to follow up and the number of patients who have asked to have their name removed.	N	Evidence provided for 2022/23 showed data submitted for the number of annual reviews undertaken but none of the other data as required by the QS.
HA-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. The patient pathway for patients needing regular transfusion, including availability of out-of-hours services and achievement of expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion (QS HA-505) b. Acute admissions to inappropriate settings, including patient and clinical feedback on these admissions	N	Clinical audits covering the requirements had not been undertaken/ completed. The patient pathway (a) had commenced May 2024 and results had not been analysed. Acute admissions (b) the SHT were missing patient and clinical feedback on these admissions.

Ref.	Quality Standards (Adults)	Met? Y/ N/	Reviewer Comment
HA-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS H-702d).	Y	The audit of NICE guidelines for timeliness of analgesia was 60% met. A considerable improvement since year 2022-2023 for adults when compliance was only 20%.
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	The SHT had not met with patient representatives to discuss as per the QS
HA-798	**Review and Learning** The service should have appropriate multidisciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, serious adverse events, incidents and 'near misses'.	N	Reviewers were unclear of the multidisciplinary governance structure in place as per the quality standard. The Divisional leads who met with the reviewing team were not aware of any incidents. W&TV NSSG and SHT did have quarterly quality meetings.
HA-799	**Document Control** All patient information, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	**N**	The process for agreeing W&TV NSSG guidance was not covered in the Trust document control policy.

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