MLCSU Clinical

NHS
Midlands and Lancashire
Commissioning Support Unit

UK FORUM FOR HAEMOGLOBIN DISORDERS

Health Services for People with Haemoglobin Disorders

Sheffield Children's NHS Foundation Trust

Visit date: 10th November 2023

Report date: 1st February 2024

Contents

Introduction

This report presents the findings of the review the Specialist Haemoglobinopathy Team based at Sheffield Childrens' NHS Trust that took place on 10th November 2023. The purpose of the visits was to review compliance with the Health Services for People with Haemoglobin Disorders Quality Standards Version 5.1, November 2021 which were developed by the UK Forum for Haemoglobin Disorders (UKFHD). The peer review programme and visit was organised by the Nursing and Urgent Care Team (NUCT) at the Midlands and Lancashire Commissioning Support Unit (MLCSU). The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

- Haemoglobinopathy Coordinating Care 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 key issues raised during 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 Sheffield 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:

- Sheffield Childrens' NHS Foundation Trust
- NHS England - North East and Yorkshire
- South Yorkshire 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 using appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for acting and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioners in relation to this report is NHS England North East and Yorkshire and South Yorkshire Integrated Care System

About the UKFHD and MLCSU

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

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

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

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

Acknowledgements

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

Return to Index

Review visit findings

Trust-wide

General comments

This review looked at the health services provided for children and young people with haemoglobin disorders at Sheffield Children's NHS Foundation Trust (SCH). During the visit, reviewers visited the emergency department, day unit, inpatient ward, and the paediatric haematology outpatient department, and met with patients and carers and with staff providing the services for the local health economy.

Sheffield Children's Hospital provided acute and tertiary specialist services for 2.5 million children residing across Yorkshire and Humberside.

The Trust was a provider of specialist services for haemoglobin disorders and had been formally recognised as a Specialist Haemoglobinopathy Team in April 2019 following the national compliance exercise conducted by NHS England (NHSE).

Several issues in this report will require executive focus and support from the Trust for the Specialist Haemoglobinopathy Teams (SHT) to continue to function and therefore some issues are duplicated in the trust wide and specialist haemoglobinopathy team sections. Further support from the Trust executive team and commissioners will also be required for the SHT to fulfil its role.

Trust-wide Good Practice

1. Clear patient pathway for seeing emergency care had been implemented, recognising the need to provide quicker analgesia for patients on presentation to the ED. Further work to improve the pathways was in progress, which would result in all patients with sickle cell disease attending the ED in an emergency, being classed as a 'category B' on triage. Service users who met with the visiting team knew how to access emergency care.
2. The sickle cell painful crisis sheet in use in the ED was comprehensive form had sections to facilitate prescribing of analgesia according to NICE guidelines with regular pain scoring recording, and highlighted prompts for identifying early signs of acute trust syndrome. The form had also been designed to include a process for reviewing analgesia effectiveness at 30-minute intervals.
3. Reviewers were impressed by the trust-wide transition team who supported those with complex needs to transition to adult services.

Trust - wide Concern

1. Consultant Staffing

Consultant staffing was insufficient for the number of patients and leadership of the SHT. The lead consultant has 1.75 PA for Haemoglobinopathy work and 0.37 PA for general and haemoglobinopathy ward rounds. Cover for the haemoglobinopathy lead consultant was on maternity leave and at the time of the visit cover provided by a paediatric oncologist.

2. Access to Psychology

Patients with haemoglobinopathies did not get access to psychology other than those who needed a cognitive assessment and only those who had an abnormal TCD. Funding for 0.3wte had been identified through SHT funding but as this is only for three years, previous recruitment had been unsuccessful.

Readvertisement for a 0.3/0.7 oncology psychologist was ongoing. The Trust and commissioners should consider if 0.3wte is enough with the rising number of patients accessing the service and if any resource from the dedicated Health Inequalities funding, accessible through Integrated Care Board, would be available to support this.

3. **Access to welfare and benefits support**

   Patients with haemoglobinopathies did not have access to welfare and benefits support. Reviewers were told that the clinical team and particular the CNSs were spending significant time supporting patients with non- clinical issues. The benefits for patients in improving their quality of life by having this level of support should not be underestimated and essential that they should have wrap around support for areas such as social prescribing for immigration, housing and applying for Disabled Living Allowance (DLAs).

4. **CNS Workload**

   The reviewers considered that the CNS workload was not sustainable in the long term, the absence of community nursing support has resulted in the acute trust CNSs trying to cover the community requirement alongside supporting with the families wider social and financial needs. More formalised community provision should be considered supporting patients to receive care close to home by the most appropriate person.

Trust - wide Further consideration

1. Following the publication of the All-Party Parliamentary Group on Sickle Cell and Thalassaemia report; NO ONE'S LISTENING: an inquiry into the avoidable deaths and failures of care for sickle cell patients in secondary care, all trusts were requested to submit to the HCC and regional leads in NHSE, their local action plan to address the report findings. From discussions and evidence, it was not clear that the action plan had been reviewed since submission and implementation monitored.
2. Reviewers considered that a forward plan was required which considered the rise in demand for the service and any impact on current and future immigration. Data showed that there had been an increase in patient numbers since 2022 by 45%. Reviewers observed little change in resources available since the last peer review in 2019, and unless there is work to address these growing health inequalities both at ICB and Trust level the service will continue to feel under increasing pressure.
3. Reviewers considered it important that the commissioners and Trust management liaise to gain clarity around maximising funding streams for the SHT and HCC and to ensure that the trust funding to support the HCC and for the SHT is ring fenced going forward.

Return to Index

Specialist Haemoglobinopathy Team (Children and Young People Services)

General Comments and Achievements

This was a small team with strong medical and nursing leadership evident throughout. The team were extremely proud of what they had achieved since the last visit in 2019 and it was clear to the reviewers that the team worked well together and were highly committed and enthusiastic in their vision to provide a high-quality service.

The team consisted of the lead consultant, three clinical nurse specialists (CNS) (total 2.5 whole time equivalent and increase of 1.1wte since the last visit) covering haemoglobin disease and benign haematology including haemophilia and a pharmacist who provided specific support for any patients with a red cell disorder. The haemoglobinopathy team were very patient centred, providing holistic care.

Since the last visit in 2019 the nurse counsellor, who was community-based, and liaised with new-born screening had retired and the funding for this post was repurposed. During the Covid 19 pandemic some outreach work was provided by the CNS and some community provision had continued. The data manager left in 2021 and had not been replaced. Some temporary support had been available from the haemophilia data manager, but this had ceased in January 2023.

The team at SCH had good collaborative working relationships with the adult SHT at Sheffield Teaching Hospitals NHS Foundation Trust. Monthly multidisciplinary team (MDT) meetings were held, with a joint MDT meeting held every two months with the adult SHT to discuss.

The patients reported having a 'wonderful experience' and there was clearly a committed team working hard.

CARE OF ADULTS	
Sheffield Children NHS Foundation Trust	Linked Haemoglobinopathy Coordinating Centres (HCC)
	North East and Yorkshire Sickle Cell HCC North of England Thalassaemia and Rare Inherited Anaemias HCC
	Linked Local Haemoglobinopathy Teams (LHT)
	Children from Rotherham, Barnsley, Doncaster, Bassetlaw, Scunthorpe, and Grimsby have their care at Sheffield Children's Hospital.

PATIENTS USUALLY SEEN BY THE SPECIALIST HAEMOGLOBINOPATHY TEAM							
Condition		Registered patients	Active patients *[1]	Annual review **	Long-term transfusion	Eligible patients - hydroxycarbamide	In-patient admissions in last year
Sickle Cell Disease	Children	99	99	83 (all children will be offered but not all have been under our care for more than 1 visit)	1	46 (66%) the SHT expected this to increase as many new pts recently and not given first visit until diagnosis confirmed locally	44
Thalassaemia	Children	21	21	18 (3X pts have only been seen 1-3x since birth	15	N/A	1

Staffing

Specialist Haemoglobinopathy Team	Number of patients	Actual WTE (at time of visit)
Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies	120	1 PA for clinic 0.5 PA for clinic admin 0.25 PA ad hoc clinic reviews 0.37 PA ward round (general and haemoglobinopathies)
Clinical Nurse Specialist for paediatric patients dedicated to work with patients with haemoglobinopathies	120	2.5 WTE clinical nurse specialists (covering non-malignant haematology)
Clinical Psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies	120	0 (currently out to advert as 1.0 WTE for which 0.3 will be dedicated to haemoglobinopathy care

Support Group available for patients and carers	Y/N
Sickle Cell Disease – Children, young people and their families	N
Thalassaemia – Children, young people and their families	N

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

[2] ***Recommended staffing: national NHS England compliance exercise for designations of SHTs 2019. Excludes HCC Network role PA. The Quality Standards for psychology staffing (HA-208) references the recommendation from the British Psychology Society Special Interest Group for Psychologists working in Sickle Cell and Thalassaemia (2017) which suggests 1WTE for every 300 patients.*

Urgent and Emergency care

All children and young people with haemoglobin disorders had direct access to the haematology/oncology ward. The emergency care pathway for children and young people had been revised following the last 'time to analgesia' audit in 2018, which had identified large differences in the timeliness of care provided to children presenting via ward and the Emergency Department (ED) and the ward. The audit had demonstrated that overall, only 56% of patients were receiving analgesia within 30 minutes and if they came to the ward only 47% received appropriate analgesia within 30 minutes compared to 83% if they presented via ED. This was believed to be due to delays in doctor availability out of hours as doctors in training were covering the whole hospital.

The pathway had been changed so that parents or carers could call the ward directly if a child was unwell and a decision would then be made (depending on whether the haematology medical staff would be immediately available) about where best to see the child for a clinical review. During working hours children would normally be seen in Ward 6 or the haematology outpatient department (HOPD). Out of hours, the ward would call the ED to notify them to expect a patient. Reviewers were told that patients and carers were reminded of these pathways when attending clinics and telephone contacts are always checked.

If children and young people from the surrounding areas needed to access their local hospital for emergency care the team would contact the ward and where possible they would travel to the Children's hospital, For some children then an emergency transfer could be arranged using 'Embrace' the regional retrieval service for critically ill infants and children. Reviewers were told that Local hospitals had access to shared care guidelines. If children and young people attended their local emergency departments or paediatric wards, then local teams could contact the Sheffield Children's Hospital team to discuss any patients with haemoglobin disorders.

During the review service users were able to describe clearly how to assess urgent and emergency care both in and out of hours and spoke positively about the timeliness and quality of the care received.

Out-patient, inpatient, and day care

Patients were seen in a purpose-built out-patient and day care department (HOPD) for the exclusive use of haematology/oncology patients. The outpatient clinic and day unit were accessible via separate entrance and there was a large waiting area with toys and activities available. The outpatient, day care and inpatient ward (ward 6) were collocated.

The haematology/oncology clinic was a dedicated area with blood-taking and counselling facilities and four clinic rooms. The clinic was located adjacent to the day unit area and was used for routine clinics and unplanned reviews. A weekly haemoglobinopathy clinic was held each Thursday morning which often ran into the afternoon. During the Covid -19 pandemic all consultations had taken place via the telephone. As a result of feedback from children, young people, and families they had the option to have alternate appointments via the telephone.

The day unit was open Monday to Friday between the hours of 8am and 6pm. Patients were able to attend for analgesia, blood sampling, exchange transfusions and top-up transfusions. The unit had 9 spaces in total with a mixture of beds and reclining chairs.

Ward 6 was the dedicated paediatric haematology/oncology ward and had 19 in-patient beds (nine cubicles and two bays with 2 and four beds). A dedicated school room and a playroom with play specialists were located in close proximity to the ward, to allow children to attend school whilst undergoing treatment. At the time of the visit due to a water leak the parent's room had moved to the school room. The playroom had recently been refurbished and included an 'interactive wall'. An acute pain team provided clinical oversight for all patients on patient-controlled analgesia (PCA) and provided consultative support to patients with complex pain issues.

The inpatient and day unit were staffed by one team of nurses supporting clear continuity and flexibility between the 2 areas.

If ward 6 was full, then children were admitted to another ward under the care of the haemoglobinopathy team. Where possible this was ward 4 which on the floor above. For those patients whose primary reason for admission was not their haemoglobin disorder then they would be admitted to the relevant specialty ward and receive daily reviews from the haematology consultant/SPR.

Two ANPs covered the ward and in clinics which had bridged the reduced allocation of doctors in training. The lack of ANP applicants and difficulties in securing backfill funding has meant that the plan for three ANPs had not yet been achieved although the team aspire to support career progression for internal candidates.

Community-based care

There was no dedicated community-based care. When the community nurse/genetic counsellor retired, in 2020 funding was repurposed. The clinical nurse specialists were providing a significant amount of amount of care in the community; visiting families at home, supporting those families with NBS results and to take bloods, deliver medications etc prior to clinics and for hydroxycarbamide monitoring. The lead CNS also contacted all families with carrier status found via newborn screening and sent information leaflets.

Significant time was taken by the CNS team to deliver holistic care including supporting families to access financial support, although applauded this required focus on non-clinical activities proved challenging for the CNS considering the increasing numbers of patients accessing the service.

The SCH haemoglobinopathy CNS would also provide some support to patients in the community in Sheffield and attended some schools to provide support with school care plans and training when capacity allowed.

Views of Service Users and Carers

The visiting team met with one service user with sickle cell disease and three service users with thalassaemia during the visit.

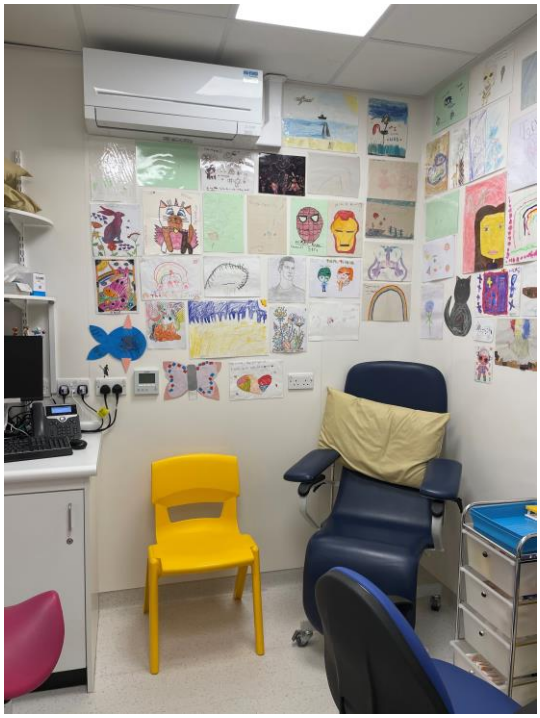
The review team would like to thank those who met with the visiting team for their openness and willingness to share their experiences. Overall, the patients and carers were highly complementary about the care they received at the hospital, and they were particularly appreciative about the support from the haemoglobinopathy team. Specific areas highlighted were:

- The importance of parallel transition planning for complex cases. An example given was for those in the process of transplant preparation at the age of transition.
- All highlighted that they would welcome dedicated psychology input to support both children and parents through all stages of their journey from initial diagnosis to coping with taking GCSEs.
- There were occasions when children with Sickle Cell Disorder were admitted to other wards in the hospital with priority being given on ward 6 to the oncology patients on Ward 6. Although they understood and sympathised with the needs of the oncology service users, they did not feel that they received the level of treatment when cared for on other wards as staff did not always understand their needs.
- Parents were clear about the support that they needed and what level of support could access. They reported feeling well educated and able to contact the ward or specialist team at any time.
- Those who met with the reviewing team commented that they considered there was a need for both practical and emotional support to parents who face the challenge of working while caring for a child with HD, the cost of food when staying at the hospital, alongside a feeling of isolation.

- Patients recognised that there was no transfusion service at the weekend, and they considered that a weekend service would be valued especially to support children around exam times.
- The service users commented that they did not wish to go local hospitals stating a preference to travel to access care at the SCH.
- Easy access to medication which was ready when attending clinics without having to chase beforehand or wait for. Parents felt that having a direct link to the dedicated pharmacist would support this.
- One parent reported that they were informed of a Thalassaemia diagnosis over the phone without warning resulting in considerable stress for the family without immediate support.
- All users were very positive about the care they get from the team stating that the unit was like a second home and family.

Good Practice

1. The ward 6 playroom had recently been refurbished and included an 'interactive wall'. Programmes could be changed and included 'balloon popping', musical tunes and landscapes.
2. The ward had a dedicated adolescent area, 'Teen Lounge', which included games consoles, refreshment facilities and was sound proofed so that they could listen to music without disturbing other patients.
3. The service had good support from a dedicated pharmacist who was also a prescriber. The pharmacist would have a pre-discussion with the team and would attend clinic so that medications could be prepared. This had resulted in a reduction in the time that the patients were waiting for medications, especially as some would be travelling long distances to attend and reduced the likelihood of patients leaving without their medication.
4. As the ward was collocated with the oncology service there was a designated phlebotomy area, which meant that children and their families did not have go to other departments as part of their hospital visit for phlebotomy.
5. There was a clear patient pathway for seeking emergency care. Changes to the pathway had been implemented following the recognition that there was a need to provide quicker analgesia. Patients with haemoglobin disorders who attended the emergency department were automatically defined as a category B on triage which meant they were seen more quickly. Service users who met with the visiting team knew how to access emergency care.
6. The sickle cell painful crisis sheet in use in the ED was comprehensive. The form had sections to facilitate prescribing of analgesia according to NICE guidelines with regular pain scoring recording, and highlighted prompts for identifying early signs of acute trust syndrome. The form had also been designed to include a process for reviewing analgesia effectiveness at 30-minute intervals.
7. The documented transition pathway was very clear and comprehensive with clearly defined responsibilities for each stage of the transition pathway.
8. QR codes on the notice board in Ward 6 provided easy access to information which could easily be updated by staff on the trust system.



Phlebotomy Room

Patient Information QR codes

Immediate Risks - No immediate risks were identified during the visit.

Concern

1. Consultant staffing

Consultant staffing was insufficient for the number of patients and leadership of the SHT. The lead consultant has 1.75 PA for Haemoglobinopathy work and 0.37 PA for general and haemoglobinopathy ward rounds. Short of 1.62 PAs. Cover for the haemoglobinopathy lead consultant was on maternity leave as the time of the visit. Just before the visit an agreement had been reached for one of the consultant paediatric-oncologists to provide cover on Mondays and Tuesdays when the lead consultant was not working.

2. Access to psychology

Patients with haemoglobinopathies did not get access to psychology other than those who needed a cognitive assessment and only those who had an abnormal TCD. Funding for 0.3wte had been identified through SHT funding but as this is only for three years, previous recruitment had been unsuccessful. Readvertisement for a 0.3/0.7 oncology psychologist was ongoing. The Trust and commissioners should consider if 0.3wte is enough with the rising number of patients accessing the service and if any resource from the dedicated Health Inequalities funding, accessible through Integrated Care Board, would be available to support this.

3. Clinical Nurse Specialist workload

The reviewers considered that the CNS workload is not sustainable in the long term, the absence of community nursing support has resulted in the acute trust CNS trying to cover the community requirement alongside supporting with the families wider social and financial needs.

a) The CNS covering some aspects community, newborn counselling, and school support. Newborn screening will contact the CNS who will liaise with the family. The previous postholder who provided good links with antenatal care teams has now retired.

b) CNSs were spending time travelling to undertake phlebotomy which ideally could be undertaken by community providers or local hospital services.

c) There was a post covid legacy of providing individualised care in the community which has raised patient expectations that were now unsustainable.

d) The CNS team were providing outreach phlebotomy locally for those patients on hydroxycarbamide. The need for this provision had increased as patients were now having alternate face to face/ telephone appointments.

e) The increase in the number of children and young people with haemoglobin disorders in the area was having an impact on the capacity of the CNS team being able to support children and young people in education. The CNSs attended schools for development of school care plans, undertaking phlebotomy to prevent the children missing lessons and were providing education and training for school staff in the care of patients with haemoglobin disorders.

f) The CNS team were relatively new with one in post two years and two in post for one year. Reviewers considered that it was important that the team have sufficient and dedicated time for training and development of their CNS roles.

4. Access to social worker/ welfare and benefits support.

Patients with haemoglobinopathies did not have easy access to welfare and benefits support. Reviewers were told that the clinical team were spending significant time supporting patients with non-clinical issues. The benefits for patients in improving their quality of life by having this level of support should not be underestimated. Essential wrap around support such as social prescribing for immigration, housing and DLAs would enable the CNS team to focus on their increasing clinical workload while ensuring families gain access to dedicated financial and well-being advice.

5. Data Management

The data manager left in 2021 and had not been replaced. Some temporary support had been available from the haemophilia data manager, but this had ceased in January 2023. Since October 2023, the consultant secretary had been able to provide some data management support, but at the time of the visit this was due to cease at the end of November 2023. Reviewers were concerned that the lack of substantive data management support would continue to impact on the clinical lead, who was already spending time on data management alongside some key audits not being completed.

6. Community Care

There was no community service agreement to provide support for patients and their carers. Reviewers were told that the community post had not been continued following the retirement of the previous postholder. More formalised community provision should be considered supporting patients to receive care close to home by the most appropriate person.

Further Consideration

1. Medical and nursing staff working in Emergency Department (ED) did not have a competence framework to support working in urgent care of people with haemoglobin disorders.

2. Although audit on inappropriate admission was not available, reviewers considered that undertaking this would be important to assess the numbers of patients admitted directly to or moved to other wards. Depending on the results, reviewing the educational needs of staff, and using the education as a tool and guide to improve patient experience may be useful. The importance of parallel transition planning for

complex cases was raised during the visit. An example given was for those in the process of transplant preparation at the age of transition and the need to meet those transition needs.

3. Following the publication of the All-Party Parliamentary Group on Sickle Cell and Thalassaemia report; NO ONE'S LISTENING: an inquiry into the avoidable deaths and failures of care for sickle cell patients in secondary care, trusts had submitted to NHSE their local action plan to address the report findings. From discussions and evidence, it was not clear that the action plan had been reviewed by the trust since submission and implementation monitored.
4. Reviewers considered that a forward plan was required which considered the rise in demand for the service and any impact on current and future immigration. Data showed that there had been an increase in patient numbers since 2022 by 45%.
5. Reviewers observed little change in resources available since the last peer review in 2019, and unless there is work to address these growing health inequalities both at ICB and Trust level the service will continue to feel under increasing pressure.
6. There was no alert system in ED which meant that if the patient didn't mention that they have a care plan this could cause delay in them receiving treatment and analgesia. Reviewers considered that use of the NHS E alert card to support early identification would help address this issue.

Commissioning

The review team had discussions with the regional NHSE North East Specialist Commissioner. Several of the issues in this report will require the active involvement of the Trust and commissioners to ensure that timely progress is made.

Further consideration

1. Reviewers considered it important that the commissioners and Trust management liaise to gain clarity around maximising funding streams for the SHT and HCC and to ensure that funding for the HCC and SHT is 'ring fenced' going forward.

Return to Index

Membership of Visiting Team

Clinical Lead		
Mark Velangi	Consultant Paediatric Haematologist	Birmingham Women's and Children's NHS Foundation Trust

Visiting Team		
Nkechi Anyawnu	Clinical Nurse Manager	Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust.
Kathy Brennan	Deputy Director of Nursing and Quality (including Specialised Clinical Networks). Programme of Care Lead for Haemoglobinopathies	NHS England – London
Maria Goridari	Clinical Psychologist	South London and Maudsley NHS Foundation Trust
John James	Chief Executive	Sickle Cell Society
Lesley McCarthy	Haemoglobinopathy Nurse Specialist	Oxford University Hospitals NHS Foundation Trust
Romaine Maharaj	Chief Executive, UK Thalassaemia Society	
Janine Younis	Consultant Paediatrician	Whittington Health NHS Trust

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

Return to Index

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	37	77

Specialist Haemoglobinopathy Team for Children and Young People with Haemoglobin Disorders

Ref.	Quality Standards (Children)	Met? Y/ N/	SA 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/	SA 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/	SA 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	Information for parents, carers and young people also included those who might require transfusions as a result of an abnormal TCD and how to access urgent medical advice
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	A range of age related school care plan templates were in use. Reviewers were told that all children and young people had school care plans in place and the CNS staff would visit local schools to ensure they were updated.

Ref.	Quality Standards (Children)	Met? Y/ N/	SA Comment
HC-194	**Environment and Facilities** The environment and facilities in phlebotomy, outpatient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child-friendly environment, including age-appropriate toys, reading materials and multimedia. There should be sound and visual separation from adult patients.	Y	
HC-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a) Information and support on taking responsibility for their own care b) The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services c) A named coordinator for the transfer of care d) A preparation period prior to transfer e) Written information about the transfer of care including arrangements for monitoring during the time immediately after transfer to adult care f) Advice for young people leaving home or studying away from home including: i. Registering with a GP ii. How to access emergency and routine care iii. How to access support from their specialist service iv. Communication with their new GP	Y	Ready Steady Go Transition programme was in place. The Sheffield Children's Hospital to Sheffield Teaching Hospital cross trust transition pathway document provided clear information for clinical staff about what should happen at each stage of the young person's transition journey. Reviewers commented that further consideration should be given to transition planning for those young people who may also be undergoing more complex treatments See main report re good practice from the complex transition team.
HC-197	**Gathering Views of Children, Young People and their Families** The service should gather the views of children, young people and their families at least every three years using: a) 'Children's Survey for Children with Sickle Cell' and 'Parents Survey for Parents with Sickle Cell Disorder' b) UKTS Survey for Parents of Children with Thalassaemia	Y	Recent survey had covered patient transfusion waiting times

Ref.	Quality Standards (Children)	Met? Y/ N/	SA Comment
HC-199	**Involving Children, Young People and Families** The service's involvement of children, young people and their families should include: a) Mechanisms for receiving feedback b) Mechanisms for involving children, young people and their families in: i. Decisions about the organisation of the service ii. Discussion of patient experience and clinical outcomes (QS HC-797) c) Examples of changes made as a result of feedback and involvement	Y	
HC-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services. The lead consultant should undertake Continuing Professional Development (CPD) of relevance to this role, should have an appropriate number of session/s identified for the role within their job plan and cover for absences should be available.	N	The lead consultant did not have time allocated for leadership for the SHT
HC-202	**Lead Nurse** A lead nurse should be available with: a) Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b) Responsibility for liaison with other services within the network c) Competences in caring for children and young people with haemoglobin disorders The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The lead CNS role was split between haemoglobinopathies and other red cell conditions and the postholder did not enough time for leadership and leading with the lead consultant development and monitoring for guidelines, protocols, training, and audit relating to haemoglobin disorders
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 consultant had a total of 2.1 PAs for direct clinical care and 1.6 for haemoglobinopathy work and no time for the SHT network role At the time of the visit the named cover did not have any PAs for haemoglobinopathy work and was on maternity leave. Some cover from one of the oncology consultant team had been recently agreed for the two days that the lead consultant did not work.

Ref.	Quality Standards (Children)	Met? Y/ N/	SA 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	The first on call was responsible when a haemoglobinopathy patient was admitted. If the first on call consultant was an oncologist there was a haematologist 2nd on call who was able to give general haematology advice and advise the oncologist, if needed, regarding the haemoglobinopathy patients.
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.	N	Doctors in training covered all areas and had limited time available to gain competencies in the care of children and young people with haemoglobin disorders.
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	Clarity about the responsibilities for all the activities being undertaken by the CNS team was not clear and not fully covered by the existing induction and ongoing competence document. (a) The CNS team provided some support in the community but the level of provision for patients had diminished following the retirement of the previous postholder (b) A process for assessing staff competence was not in place. The CNS team did provide teaching for staff covering haemoglobin disorders. At the time of the visit, Ward 6 and HOPD did not have any staff vacancies. (c & d) (e.) Nurses or other staff with competences in cannulation and transfusion were available at all times. The ward induction booklet was very comprehensive and covered some information about haemoglobin disorders.

Ref.	Quality Standards (Children)	Met? Y/ N/	SA 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 did not have a psychologist with appropriate competences in the care of children and young people with haemoglobin disorders. At the time of the visit the trust was advertising for 1 WTE psychologist of which 0.3 wte would be dedicated to haemoglobinopathy care. (see main report) There was good access to neuropsychological cognitive assessment which were provided by a separate service within the trust.
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	Children young people and their families did not have timely access to a social worker/benefits adviser All other support services were in place.

Ref.	Quality Standards (Children)	Met? Y/ N/	SA 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	A process to assess competencies for staff working in the emergency department was not in place. Educational sessions in urgent care of children and young people with haemoglobin disorders were provided by the SHT
HC-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a) Age guidelines for timing of the transfer b) Involvement of the young person, their family or carer, paediatric and adult services, primary health care and social care in planning the transfer, including a joint meeting to plan the transfer of care c) Allocation of a named coordinator for the transfer of care d) A preparation period and education programme relating to transfer to adult care e) Communication of clinical information from paediatric to adult services f) Arrangements for monitoring during the time immediately after transfer to adult care g) Arrangements for communication between HCCs, SHTs and LHTs (if applicable) h) Responsibilities for giving information to the young person and their family or carer (QS HC-195)	Y	

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

Ref.	Quality Standards (Children)	Met? Y/ N/	SA Comment
HC-505	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a) Indications for: i. Emergency and regular transfusion ii. Use of simple or exchange transfusion iii. Offering access to automated exchange transfusion to patients on long-term transfusions b) Protocol for: i. Manual exchange transfusion ii. Automated exchange transfusion on site or organised by another provider c) Investigations and vaccinations prior to first transfusion d) Recommended number of cannulation attempts e) Arrangements for accessing staff with cannulation competences f) Patient pathway and expected timescales for regular transfusions, including availability of out of hours services (where appropriate) and expected maximum waiting times for phlebotomy, cannulation and setting up the transfusion g) Patient pathway for Central Venous Access Device insertion, management and removal	Y	
HC-506	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: 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 family involvement in monitoring wherever possible	Y	

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

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

Ref.	Quality Standards (Children)	Met? Y/ N/	SA 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/A	No SHT did not have any designated LHTs
HC-604	**Local Multidisciplinary Meetings** MDT meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and, when required, representatives of support services (QS HC-301).	Y	
HC-606	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a) Role of community service in the care of children and young people with haemoglobin disorders b) Two-way exchange of information between hospital and community services	N	Service level agreements for support from community services and the two way exchange of information between hospital and community services was not in place. The acute trust CNS service provided some outreach suport to patients in the community.
HC-607S	**HCC Business Meeting Attendance (SCD)** At least one representative of the team should attend each SCD HCC Business Meeting (QS HC-702).	Y	
HC-607T	**HCC Business Meeting Attendance (Th)** At least one representative of the team should attend each Thalassaemia HCC Business Meeting (QS HC-702).	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	SA Comment
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	
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	In the absence of a data manager the lead clinician was spending time on non-clinical duties.
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	Due to staffing shortages an audit of acute admissions to inappropriate settings had not been completed. An audit covering the patient pathway for patients needing regular transfusion had been undertaken showing the average time to cannulation 10 minutes, average time to blood transfusion commencing was 29 minutes and no more than three attempts to cannulate was in place. Out of hours blood transfusions were not provided.
HC-706	**HCC Audits** The service should participate in agreed HCC-specified audits (QS HC-702d).	N /A	An HCC audit programme of audit had not been agreed but was due to be discussed at the October 2023 business meeting. Audits on the NICE Guidance on the treatment of emergency care had been undertaken within the SHTs.
HC-707	**Research** The service should actively participate in HCC-agreed research trials.	Y	

Ref.	Quality Standards (Children)	Met? Y/ N/	SA Comment
With 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	A review of patient experience and clinical outcomes with patient representatives had not yet taken place.
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	
HC-799	**Document Control** All information for children, young people and their families, policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

Return to Index