Health Services for People with Haemoglobin Disorders

Barking, Havering and Redbridge University Hospitals NHS Trust

Visit Date: 26th September 2019

Report Date: December 2019

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Introduction

This report presents the findings of the peer review of health services for children and young people with haemoglobin disorders in Barking, Havering and Redbridge University Hospital NHS Trust that took place on 26th September 2019. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V4, 2018 which were developed by the UK Forum on Haemoglobin Disorders working with the Quality Review Service (QRS). The peer review visit was organised by QRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

- Specialist Haemoglobinopathy Teams (SHT)
- Local Haemoglobinopathy Teams (LHT) or linked providers

The Haemoglobin Disorder Network and Commissioning Quality Standards were not reviewed as part of the 2019-20 review programme, although reviewers did enquire about the local network and commissioning arrangements during the course of the review visit.

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 risk identified includes the Trust's proposed actions to mitigate the risk and QRS's response to those proposals. Appendix 1 lists the visiting team that reviewed the services at Barking, Havering and Redbridge University Hospital NHS Trust. Appendix 3 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:

- Barking, Havering and Redbridge University Hospital NHS Trust
- NHS England Specialised Commissioning – Haemoglobinopathies
- NHS Barking, Havering and Redbridge University Clinical Commissioning Group

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioners in relation to this report are NHS England & NHS Lead Commissioner for Haemoglobinopathies, and NHS Barking, Havering and Redbridge University Clinical Commissioning Group.

About the Quality Review Service

QRS is a collaborative venture between NHS organisations to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews (often through peer review visits), producing comparative information on the quality of services and providing development and learning for all involved.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more confidence and competence in reviewing the quality of clinical services. More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Acknowledgments

We would like to thank the staff of Barking, Havering and Redbridge University Hospital NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are also grateful to the users and carers who took time to come and meet the review team. 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 and young people with haemoglobin disorders. The Trust had two hospital sites, Queen's Hospital in Romford and King George Hospital in Ilford, and served a combined population of over 750,000. The service continued to have an expanding population of haemoglobinopathy patients, with a 20% increase in the number of children and young people since the last peer review visit in 2014 (from 301 to 363 patients). A high carrier rate across the local health economy led to a high rate of affected births, with between 16 and 24 births per year.

The Barking, Havering and Redbridge University Hospitals NHS Trust (BHRUT) haemoglobin disorder service was run from Queen's Hospital. Emergency departments (ED) and paediatric in-patient facilities were available on both sites, and staff from the haemoglobin disorders team attended King George Hospital site on a daily basis, to review any children and young people with haemoglobin disorders who were in-patients on the children's ward and to provide an out-patient service.

The Barking, Havering and Redbridge University Hospitals NHS Trust was reviewed as a Local Haemoglobinopathy Team (LHT) for paediatric services, and was part of the East London and Essex Haemoglobin Network.

During the course of the visit, reviewers met with two parents and with staff providing the services, and visited the Emergency Department, the children's day unit, out-patients and wards at the Queen's Hospital site. Services at King George Hospital were not visited, but reviewers enquired about the patient pathway at King George Hospital for children and young people with haemoglobin disorders.

Since the review visit the Trust has applied to become an Specialist Haemoglobinopathy Team (SHT). The UK Forum on Haemoglobin Disorders Steering Group, when considering the report as part of their programme quality assurance process in December 2019, agreed that it would be helpful to the service at this stage of their transition to an SHT, if a gap analysis was included as an appendix to this report which has been added, see appendix 2.

CHILDREN AND YOUNG PEOPLE

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
Barking, Havering and Redbridge University Hospital NHS Trust	LHT	316	18	24

Local Team (Children and Young People Services): Barking, Havering and Redbridge University Hospital NHS Trust

General Comments and Achievement

This was a relatively new team who were clearly enthusiastic and had many ideas for developing the service for children, young people and their families.

For three years after the last visit in 2014, the service had been without a permanent lead consultant, which had had an impact on the service's ability to provide senior medical leadership for the service and medical support to patients and their families. While the service had had no permanent lead consultant, a service level agreement had been in place with The Royal London Hospital, Barts Health NHS Trust (RLH), to provide in-reach clinics and additional advice and support.

Since May 2019 a locum consultant had joined the team, and, just before the visit, this individual had been recruited to the substantive consultant post. A clinical nurse specialist (CNS) for the community service had commenced in post in July 2019 and the CNS for the acute service had been in post for 12 months. The acute service CNS had worked with staff to develop link nurses in both the ED and the ward. One full-time psychologist was in post, providing support to both the adult and the children's haemoglobinopathy services. The psychologist was part of the 'Special Interest Group' that met regularly to discuss service development issues, in line with the UK Standards for the Clinical Care of Children and Adults with Sickle Cell Disease or Thalassaemia.

From April 2018 the BHRUT children's haemoglobinopathy team had moved from working jointly with the adult service to working as part of the Child Health division.

Local Haemoglobinopathy Centre	Links with Specialist Haemoglobinopathy Team
Barking, Havering and Redbridge University Hospitals NHS Trust	Barts Health NHS Trust

Support groups available for patients and carers	Y/N
Sickle Cell Disease	Y
Thalassaemia	Y

The BHRUT paediatric haemoglobinopathy team was reviewed as a local haemoglobinopathy team (LHT) providing some shared care in terms of undertaking annual reviews. There are no NHS England recommended staffing figures for an LHT, but as BHRUT was one of the largest local centres in the UK, and given the large number of patients for which this service was responsible, the staffing required was assessed against that for a specialist haemoglobinopathy team (SHT).

Staffing

Recommended staffing for a SHT Paediatric Haemoglobinopathy Service [1]	Staffing for BHRUT LHT (2019)		NHSE recommended staffing for an SHT
	Number of patients[2]	Actual WTE	
Consultant haematologist/paediatrician with >0.6 wte per 150 patients, dedicated to work with patients with haemoglobinopathies	334	0.5	1.3
At least 0.25 wte allocated to haemoglobinopathies CPD in the paediatric consultant job	334	Y	-
A clinical psychologist for paediatric patients who has >0.5 wte per 150 patients dedicated to work with patients with haemoglobinopathies	334	0.5	1.1

Emergency Care

At the time of the visit the emergency department (ED) saw approximately seven to ten patients with sickle cell every month. Staff told reviewers that patients would receive analgesia within 30 minutes of arrival, and that they were seen by the paediatric team within one hour of presentation. Children and young people attending as an emergency were referred to the paediatric team during normal working hours and to the on-call paediatrician at other times. During working hours, patients were also seen by one of the two specialist nurses.

A system for adding an alert to the patients' electronic records in the ED was in the process of being implemented for children and young people with haemoglobin disorders. Once implemented, ED staff would be prompted to access the child or young person's individual care plan (ICP), which would include their emergency care plan.

In-patient Care

Tropical Lagoon was a children's in-patient ward (for patients aged 0-15 years inclusive), and at the time of the visit the ward was able to provide in-patient care for up to 30 children. The ward consisted of 16 bed/cot spaces, six cubicles with en-suite facilities, and two further bays. The bed base included four beds that were used for 'level 2' high dependency care (HDU).

From ED, patients were transferred to the ward under the care of the on-call paediatric consultant, who would review them within 12 hours of admission. Out of normal working hours, the child or young person was reviewed by the paediatric medical team at Queen's Hospital, who had access to telephone advice from the Child Health haematology consultant on call at the RLH as required.

The lead consultant for the children's haemoglobinopathy service carried out a ward round on Mondays and Fridays, and more frequently if necessary. The speciality doctor deputised for the lead consultant and was available Monday to Friday for telephone advice. The children's haemoglobinopathy CNS also performed daily ward rounds (Monday to Friday between the hours of 9am and 5pm).

Children and young people requiring emergency exchange transfusions, continuous positive airway pressure (CPAP) or other higher dependency care were transferred to the RLH.

For patients attending the King George Hospital ED, a similar pathway was in place, with children and young people being transferred to Queen's Hospital if high dependency care was required or transferred directly to the RLH.

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[1] *Recommended Staffing: national NHS England compliance exercise for designations of SHTs 2019.*
[2] *Figure excludes non-clinically significant haemoglobinopathy variants.*

Day Care

The Tropical Bay day care facility was very spacious. The facility had ten bed spaces, two cubicles and a treatment room. The unit was operational five days a week between 7.30am and 8pm, and was closed on weekends and bank holidays.

On Tuesdays, part of the facility was set up to deliver a haematology out-patient, treatment and assessment unit with the majority of children on transfusion programmes attending to receive their 'top up' transfusion.

Children with haemoglobinopathies could also be reviewed on Tuesdays in the day unit by prior arrangement, and on other days if the speciality doctor was available; otherwise, children could be reviewed in the ED.

A booked appointment system was in operation, led by the CNS for the acute service, to arrange for children and young people to attend on a Monday, either before or after school, for their pre-transfusion blood tests. Children with known antibodies were seen on the ward on the Sunday afternoon prior to transfusion.

Out-patient Care

A dedicated haemoglobinopathy clinic was held on a Wednesday afternoon, apart from the third Wednesday of each month. A haemoglobinopathy baby clinic was held within these clinics to ensure that all new babies were reviewed by 12 weeks of age and started on Penicillin V. The acute and community paediatric nurse specialists attended these clinics.

A TCD (Trans-Cranial Doppler) clinic was held on the first and second Monday afternoon of each month and the third Thursday of each month. A nurse-led clinic hydroxycarbamide/exjade telephone monitoring clinic was held on the Monday afternoon in conjunction with the TCD clinic.

Community-based Care

The community service was based on Tropical Bay at Queen's Hospital. The community specialist haemoglobinopathy nurse was also the lead for the transition of young people to the adult service.

The children's community nursing team would also undertake pre-transfusion blood tests for some children.

Progress since last visit

The previous review had taken place in 2014. Since then, the team had been re-formed and there had been significant progress, as well as a number of improvements in the last 12 months:-

- A lead consultant for paediatric haemoglobinopathies had been appointed.
- The lead nurses were providing a comprehensive out-patient service, with plans to develop community-based support and services.
- A transition programme had commenced as part of the NHS Healthcare Transition of Children and Young People collaborative. The programme ran every Tuesday, with six or seven young people attending.
- Annual reviews for children and young people had commenced following the appointment of the locum consultant. At the time of the visit, annual reviews had been completed for 193 out of the 363 patients cared for by the Trust, with a plan that every child would have an annual review by the end of the year.
- A weekly multidisciplinary team (MDT) meeting had been established and was attended by the lead haemoglobinopathy clinician, the deputy clinician and the CNSs.
- Guidelines and procedures were in the process of being reviewed and updated.
- ICPs were in the process of being developed with patients. Patients were given a copy, and the plans were also available electronically and in paper format in the ED at both Queen's and King George Hospitals.
- Patients accessing the service were being asked again to give their permission for the service to submit their data to the national haemoglobin register (NHR).
- A parent peer support group met on the second Saturday of each month, and a transition group for young people had been recently been re-established.

- A sickle cell disease awareness day had taken place in July 2019, involving members of the public as well as haemoglobinopathy families.

Views of Service Users and Carers

The visiting team only met with two parents during the course of the visit, and although one parent represented a group of families the feedback may not be representative of the other service users who were cared for by the team at BHRUT.

Overall, the parents were complimentary about the new team and felt that the team were committed and enthusiastic. They did, however, express concern about the care over the last few years and the challenges they had faced during the 'difficult times'. They said that they had felt vulnerable when members of the previous team had suddenly 'resigned'. This had left them with a feeling of uncertainty about the lack of continuity in their children's care during this time.

Parents also commented that children with sickle cell disease had not been given the attention or the priority they deserved on the ward, and that access to analgesia was not always timely, which was extremely distressing for both the child and the parent.

Good Practice

1. The health transition plans seen for patients with sickle cell disease and patients with thalassaemia were very comprehensive. The information covered all stages of the disease, for both patients and their families, and included a checklist to ensure that all aspects relating to transition had been covered. Reviewers were also impressed with the section in the booklet that provided advice to ED staff about children who were transitioning to the adult service.
2. The team had implemented the 'Harvey's Gang' initiative, in which children and parents were able to visit the blood laboratory to help them understand the laboratory aspects of their transfusion treatment.
3. The school care plans for children and young people seen by the reviewers were very detailed. The plans included information for education staff about who to contact in an emergency and how to contact a member of the haemoglobinopathy team for advice, and support and information about transition for children who had commenced on the transition to adult services pathway.
4. The transfusion information booklet for staff was very comprehensive, providing clear guidance for staff and a one page checklist about the process for delivering blood transfusions.
5. Frequencies and times of out-patient clinics had been reviewed following an increase in the 'did not attend / was not brought' rates (DNA). Feedback from patients and families using the 'what matters to me' initiative identified a lack of flexibility in appointment times, with children and young people missing school and parents having to miss work. The clinics were rescheduled and their frequency increased to weekly from monthly, and the clinic times were extended to run until 6pm. The Trust had written to parents to acknowledge their feedback and the changes made as a result. Early indications from the data available showed that engagement with families had improved and the DNA rate had been significantly reduced.
6. The frequency of the MDT meetings at BHRUT had been increased from monthly to weekly so that more timely decisions regarding the recommended treatment of individual children and young people could be agreed. Telephone conference MDT meetings took place every month, and quarterly MDT meetings were held with the specialist haemoglobinopathy team based at the RLH to discuss patients with more complex needs.
7. The psychology team had developed a website so that the public could access information about what the service could offer and how to access support and information on haemoglobinopathy conditions. The website also included testimonials from patients who had accessed the service, in order to minimize the stigma around psychological and mental health and to encourage people to contact the service for support.

8. The sickle cell disease awareness day held in the summer had enabled children, young people and families to choose the topics for discussion, to help them understand their condition and receive advice on self-management of their illness. Feedback from attendees had been positive and further events were in the process of being planned. The team had also instigated coffee morning sessions to offer additional support for new parents to meet and share ideas.

Immediate Risks: None identified at the time of the visit

Serious Concern

1. **Patients who may be lost to follow up and routine monitoring**

   Reviewers were seriously concerned that there may be children and young people from the local catchment area who, at the time of the visit, were not accessing follow up care and routine monitoring. For a given population of 363 children in the service, the admission rate was very low (57 in-patient admissions) and only 30 children were on hydroxycarbamide, which suggested that the population actually accessing care at the Trust was below 363. Reviewers were told by staff and patient representatives that some patients had moved to receiving care at the RLH or other services when the previous team members left. Although work was being undertaken at the time of the visit to repatriate patients, screening of the local population had not been completed to identify the number of patients who may not be linked to any service.

Concerns

1. **Consultant staffing**

   Reviewers were concerned that the service had insufficient consultant medical staff time available for the care of people with haemoglobin disorders in order to carry out regular reviews (annual reviews, hydroxycarbamide and routine monitoring), emergency care and clinics. At the time of the visit, the consultant had only 0.5 wte time allocated to working in the haemoglobinopathy service for approximately 363 children and young people. Reviewers were concerned that the number of patients being cared for by the service was likely to increase once patients who had been cared for by other services over the last three years were repatriated. The service will need to ensure there is sufficient capacity to care for the expanding local population of haemoglobinopathy patients. Cover for the lead consultant was available from the speciality doctor (0.5 wte). The Trust was aware of the situation, and recruitment of an additional ten paediatric consultant posts was planned, with the view that recruitment would include additional consultant medical staff with appropriate competences in the care of people with haemoglobin disorders.

2. **Access to psychology**

   One full time psychologist provided support for both the adult and the children's haemoglobinopathy services. Reviewers considered that this was insufficient to provide a comprehensive psychology service for the number of children and young people (approximately 363 children and young people) being cared for by the service, and that it did not meet the national workforce recommendations of 1 wte for every 300 patients.

Further Consideration

1. Reviewers acknowledged that there were a number of initiatives that had commenced very recently or were in the pipeline to be developed. The quality of the service provided by BHRUT would have been of greater concern had this not been the case. It will be important for the Trust and the service to ensure that there is appropriate support and an action plan agreed, to ensure that these initiatives are fully implemented and that patients

receive the standard of care that would be expected from a comprehensive paediatric local haemoglobinopathy service.

2. Many of the Trust guidelines were in draft form and were in the process of being ratified. Agreed network guidelines were in use and available on the Trust intranet.
3. Protocols covering routine monitoring were not yet in place. However, the clinic letters seen at the time of the visit covered all aspects of routine monitoring.
4. An operational policy covering working arrangements for the service was in the process of being agreed.
5. No patient information for patients with thalassaemia was available.
6. Since the service had moved to the Child Health division there was no lead nurse for the paediatric haemoglobinopathy service with responsibility for leadership of the service, liaison with the network SHT and service development. Some support was available from the lead nurse from the adult haemoglobinopathy service and the matron for the Child Health division.
7. An agreement with the SHT on roles and responsibilities was not yet in place. Reviewers considered that it would be important to formalise any shared care arrangements for undertaking annual reviews, the level of support required from the SHT and ongoing provision of continuing CPD for the lead consultant, for example.
8. A training plan to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders was not yet in place, although some training for staff was planned.
9. As work with parents is developed, reviewers commented that the team may find it helpful to utilise some of the national information that is available, such as the handbooks for parents and schools.
10. At the time of the visit, an apheresis machine was available and there was a plan to train staff to provide this service. Reviewers supported this development, as it would be of considerable benefit to patients who were currently travelling out of area to receive apheresis. It would also be important to ensure that this service was appropriately commissioned, including sufficient staff with the relevant competences to deliver the service.
11. The service at BHRUT was reviewed as a local haemoglobin disorder service but the numbers of patients meant that BHRUT was fulfilling some aspects of an SHT service. Discussions with Trust representatives and local commissioners revealed an inconsistency of views as to the future commissioning arrangements for the service (see also the Commissioning section of the report). Since the visit, the Trust has applied to be an SHT and a gap analysis has been undertaken; this is included in Appendix 2.

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Commissioning

The service had good links with both local and specialised commissioners.

The report contains a number of issues which would need to be addressed in order for the paediatric teams to function as comprehensive Local Haemoglobinopathy Teams (LHTs).

Since the visit the Trust has applied to be an SHT. A gap analysis has been undertaken to show the progression needed for the service to become a fully functioning SHT, and this is included in Appendix 2.

Further Consideration

1. As identified at the last visit in 2014, a review of commissioning arrangements, including specialist and co-commissioned services, should be considered, as this was a very large local service providing many functions of an SHT, including initiation of transfusion, annual reviews and initial and amendment of iron chelation. Some patients with complex needs were referred to the specialist centre at RLH for review. A service level agreement with RLH to provide in-reach clinics had been in place while there was no consultant within the service, but at the time of the visit, there was no formal agreement between the specialist centre and the Trust as to which specialist functions were delegated and how data would be reported to the specialist centre.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Nkechi Anyanwu	Clinical Nurse Manager	Evelina Children's Hospital, Guy's and St Thomas' NHS Foundation Trust
Dr Julie Brent	Consultant Paediatrician	The Royal Wolverhampton NHS Trust
Roanna Maharaj	Patient representative	UK Thalassemia Society
June Okochi	Patient representative	
Dr Mark Velangi	Consultant Paediatric Haematologist and Clinical Lead for the visit	Birmingham Women's and Children's NHS Foundation Trust

Quality Review Service		
Sarah Broomhead	Assistant Director	Quality Review Service

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APPENDIX 2 Gap analysis

Quality Standards section	LHT position at the time of the review visit	Required to function as a comprehensive SHT
Information and Support for Patients and Carers (QSs HN-101 – HN-199)		
Information for patients and families	Some information was not in place, particularly for patients with thalassaemia	Review information available to cover HN- 101 and 102. Information should be updated to cover changes to the service once providing SHT function.
Information to primary health care team	Information was not available for people with thalassaemia. Information did not cover contraception and sexual health	Review information to cover any changes in pathway.
Transition Process	Transition process not fully implemented. Transition plans were in place	Review guidelines to include SHT process and changes in transition pathway.
Staffing (QSs HN-201 –HN-299)		
Consultant Staff	One Consultant Paediatrician with 0.5WTE time for haemoglobinopathy service for approximately 363 children and young people. The deputy for the lead consultant was a speciality doctor	The SHT required a named medical deputy at consultant level responsible for haemoglobinopathy care. Arrangements for the access of 24/7 advice for other clinical teams both within the hospital and with other local hospitals. This may be either directly or as part of a shared-care arrangement with other SHTs. *(NHSE Service Specification 170126S).*

Quality Standards section	LHT position at the time of the review visit	Required to function as a comprehensive SHT
Lead Nurse	No lead nurse for the paediatric haemoglobin disorder service. A lead nurse for the adult service could be accessed for advice and support.	A lead nurse with responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders. Liaison with other services within the network. The lead nurse should have competences in caring for people with haemoglobin disorders and the care of children and young people. The lead nurse should also have appropriate time for their leadership role and cover for absences should be available.
Specialist Nursing	1WTE for acute paediatric service 1WTE for community service Approximately 363 children and young people.	Consideration of workload as children with more complex needs will be repatriated for care by the SHT.
Ward and day unit staffing	-	Training and education required for staff to care for children and young people with more complex needs.
Psychology Staffing	1WTE psychologist covered both the adults and children's services.	The SHT is able to provide psycho-social/psycho-neurological support to complex patients struggling to manage their condition. Psychology is support available to meet the national workforce recommendation of 1WTE:300 paediatric patients.
Training and education	A training plan to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders was not yet in place	Development of a training plan for all staff to provide more complex care (including ED staff). The SHT, with support from its HCC, needs to oversee and support the production of a training and development plan for all healthcare staff involved in the delivery of haemoglobinopathy care in its network area. The responsibility for resourcing appropriate training for healthcare staff remains with the employing organisations. *(NHSE Service Specification 170126S)*

Quality Standards section	LHT position at the time of the review visit	Required to function as a comprehensive SHT
Support Services (QSs HN-301 – HN-305		
Specialist On-site Support Access to specialist staff and services is easily available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Erythrocytapheresis c. Acute pain team including specialist monitoring of patients with complex analgesia needs d. High dependency care, including non-invasive ventilation e. Level 2 and 3 critical care	At the time of the visit, an apheresis machine was available with the view to training of staff to provide a service. Service would need to be appropriately commissioned, including sufficient staff with the relevant competences to deliver the service. Patients requiring level 3 critical care were transferred to the SHT or paediatric intensive care unit (PICU) at the RLH.	The SHT will have responsibility for initiation, modification and cessation of long-term blood transfusion regimes. Access to automated red cell exchange transfusion on site for sickle cell patients needing long term transfusion therapy Review of arrangements with the RLH re pathway for critical care to reflect changes of care provided at BHRUT. *(NHSE Service Specification 170126S: If PICU not on site then formal arrangements should be in place with either other SHTs or other acute Trusts with PICU).*
Specialist Services - Network	N/A to LHTs Arrangements were in place across the network for access to specialist services	The SHT will be able to clinically manage or have formal arrangements within the network to access services with specialist expertise in the care of people with haemoglobin disorders (HN-304 has more detail about the specialist staff and services). The SHT will be able to manage or have agreed referral pathways the complications for thalassaemia and rare inherited anaemias. The SHT will need to demonstrate close liaison between haematologists, paediatricians, surgeons and anaesthetists. Where possible all emergency surgery, should be carried out in at the SHT. Surgeons and anaesthetists will need to have experience in the effective peri-operative management of SCD&T patients. For practical purposes it will be for the Local Area Team and the SHT to agree surgical pathways. The SHT is required to have pathways in place to manage emergency scenarios.

Quality Standards section	LHT position at the time of the review visit	Required to function as a comprehensive SHT
Guidelines and Protocols (QSs HN-501 – HN-599)		
Monitoring Protocols	Protocols covering routine monitoring were not yet in place. Seeing newly diagnosed babies for their first out-patient appointment and delegation of any annual reviews of patients were the responsibility of the SHT at the RLH.	Development of processes and guidance for the SHT to cover; first out- patient appointments; routine monitoring and annual review.
Clinical guidelines: LHT management and referral	-	Development of guidance with any referring LHTs. Guidelines should specify the indications for telephone advice, early referral and immediate transfer to the specialist centre. Guidelines should also include any two way communication between SHTs and LHTs.
Guidelines: Chelation Therapy	N/A LHT Network guidelines were in place	The SHT will have responsibility for initiation and amendment of long-term iron chelation regimes, blood monitoring and dose escalation as appropriate. Arrangements for prescription and routine monitoring of iron chelating drugs. The SHT will required pathways in place to access to cardiac and liver magnetic resonance scanning (this does not necessarily need to be on site).

Quality Standards section	LHT position at the time of the review visit	Required to function as a comprehensive SHT
Clinical Guidelines: Acute Complications	Network guidelines had been adopted for use locally	Review of guidance to reflect BHRUT as SHT. The SHT must be able to initiate, modify and cease long-term medication regimes. For instance, to prevent or mitigate sickle painful episodes. The monitoring of such drug regimens is not a specialised function but any modification based on the outcomes of that monitoring remains specialised.
Specialist Management Guidelines and Non-Transfusion Dependent Thalassaemia (nTDT)	Network guidelines were in place	Review of pathway/network guidance to reflect BHRUT as SHT.
Referral for Bone Marrow Transplantation	N/A to LHT	Development of referral arrangements for children and young people to be referred for consideration for bone marrow transplantation.

Quality Standards section	LHT position at the time of the review visit	Required to function as a comprehensive SHT
Service organisation and Liaison with other Services (QSs HN-601 – HN-608)		
Service Organisation	The operational policy was in the process of being developed.	Organisation policy to cover all arrangements for the SHT (HN- 601 has more detail). Review of pathway for specialist care for patients attending King George Hospital in Ilford. Ensuring that clear pathways exist. Agreement of any specialist interventions and monitoring that is referred to other SHTs within the network.
Capacity of the SHT	At the time of the review it was not clear if patients may be lost to follow up and routine monitoring	Repatriation of patients from other SHTs and review of patient data to ensure that patients previously cared for by the LHT are accessing specialist care.
Neonatal Screening Programme Review Meetings	Not applicable to LHTs	Review of 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by the SHT. Arrangments for meeting annually with representatives of the neonatal screening programme to review progress, discuss audit results.
Multi-Disciplinary Meetings	Weekly MDTs were held locally. MDTS via conference call with the SHT were held every month, and a network MDT meeting took place every three months.	Development of a specialist MDT.
Delegation of Annual Reviews	Not applicable to LHTs	Written agreements if annual reviews are undertaken by LHT/s on behalf of the SHT.

Quality Standards section	LHT position at the time of the review visit	Required to function as a comprehensive SHT
Trans-Cranial Doppler Ultrasound	Quality assurance arrangements were in place with the SHT at the RLH to review any abnormal TCD ultrasounds.	Review of pathway for Trans-Cranial Doppler (TCD) ultrasound for all eligible children. Review of arrangements to ensure multidisciplinary team management of complex neurological abnormalities and expert clinical management of children identified at risk of stroke and other neurological impairment is available. Monitoring of the proportion of children who have been offered treatment following TCD screening. Review of standard operating procedure and quality assurance systems to reflect the responsibilities of the SHT.
National Haemoglobinopathy Registry	Not applicable to LHTs	Data on all patients, following patient or parental consent, is entered into the National Haemoglobinopathy Registry.
Governance (QSs HN-701 – HN-799)		
Audit and data	Data on length of stay and re-admission rates were not available A clinical audit programme (HN-705)	The SHT, working with the HCC, is responsible for data, audit and outcome monitoring for all the patients under its care. Development of a clinical audit programme and participation in network agreed audits.
Research	Not applicable to LHTs	The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.
Quality Dashboard	Not applicable to LHTs	The service should submit to the Quality Dashboard and have arrangements in place to monitor Quality Dashboard data.

APPENDIX 3 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.

Table 1 - Percentage of Quality Standards met

Details of compliance with individual Quality Standards can be found below.

Service	Number of applicable QS	Number of QS met	% met
Specialist Services for People with Haemoglobin Disorders	42	30	71

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Specialist Services for People with Haemoglobin Disorders

Ref	Standard	Met?	Comments
HN-101	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers 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. Interpreter and advocacy services, 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 HN-199)	N	Information seen during the visit did not include details about how to access social services, advocacy services, PALS, spiritual support, HealthWatch, or national organisations (UKTS and SCS), or how to get involved in improving services ('h'(ii), (iii), (iv), (vi)).
HN-102	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition (SC or T), how it might affect them and treatment available b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy 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	N	Information for patients with thalassaemia was not yet available, and the booklet seen at the time of the visit only included information about transition. Splenic palpation and Trans-Cranial Doppler scanning ('d') and transfusion and iron chelation ('e') were also not included in any of the information for parents (the information only included advice for the primary health care team).

Ref	Standard	Met?	Comments
HN-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. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. 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 patients' GP and their local / specialist team consultant (if applicable).	Y	The care plan template was new and in the process of being implemented.
HN-104	**Information for Primary Health Care Team** Written 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 (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on: i. Hydroxycarbamide and iron chelation therapy (if being prescribed by GPs) ii. Immunisations iii. Contraception and sexual health d. Indications and arrangements for seeking advice from the specialist service	N	Written information to the patients primary health care team did not cover thalassaemia or contraception and sexual health
HN-105	**Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)** Written information should be offered to patients and their carers 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	Reviewers considered that the booklet would benefit from review to make the section on 'd' more explicit.

Ref	Standard	Met?	Comments
HN-106	**School Care Plan (Children's Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school e. Specific health or education need (if any)	Y	
HN-194	**Environment** The environment and facilities in phlebotomy, out-patient 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 toys and books / magazines for children and young people of all ages.	Y	
HN-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services b. A named coordinator for the transfer of care c. A preparation period prior to transfer d. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards	Y	The health transition plans seen for patients with sickle cell disease and those with thalassaemia were very comprehensive. The information covered all stages of the disease for both patients and their families.
HN-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	Y	Good feedback mechanisms were in place. An away day had been held. Changes made as result of feedback included the development of weekly MDT meetings and changes to clinic times. See main report.

Ref	Standard	Met?	Comments
HN-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 within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have an appropriate number of session/s identified for this role within their job plan and cover for absences should be available.	Y	Cover was available from the speciality doctor and, once in post, the consultant oncologist.
HN-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	A lead nurse with responsibilities as defined by the Quality Standards was not yet in post. The lead nurse from the adult service was able to offer support and advice to CNSs.
HN-203	**Medical Staffing and Competences** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including: **All services:** a. Haematology or paediatric medical staffing for clinics and regular reviews b. 24/7 consultant and junior staffing for emergency care **SHCs only:** c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours d. If doctors in training are part of achieving 'a' or 'b' then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	Insufficient medical staff (lead consultant 0.5 wte, speciality doctor 0.5 wte) with appropriate competences in the care of people with haemoglobin disorders were available for the number of patients cared for by the service (334 patients).

Ref	Standard	Met?	Comments
HN-204	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses 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 in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y	
HN-205	**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 multi-disciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuro-psychology Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	One full time psychologist covered both the adult and the children's services. The level of psychology staffing available did not yet meet the national workforce recommendation of 1 wte for every 300 patients.
HN-206	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.	N	A training plan as defined in the QS was not yet in place, although a range of training for staff was planned.

Ref	Standard	Met?	Comments
HN-207	**Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)** Sufficient staff with appropriate competences for Trans-Cranial 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	Regular scans and those where abnormalities had been detected were sent to the Royal London Hospital for review and quality assurance.
HN-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	
HN-301	**Support Services** Timely access to the following services should be available. In Specialist Centres staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) as required. a. Social worker/ benefits adviser b. Leg ulcer service c. Play specialist (children's services only) d. Chronic pain team (adult services only) e. Dietetics f. Physiotherapy (in-patient and community-based) g. Occupational therapy h. Mental health services (adult and CAMHS) i. DNA studies j. Polysomnography	Y	
HN-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department/s should have competences in urgent care of people with haemoglobin disorders.	Y	The most recent pain audit was in 2016, but plans were in place to repeat the audit in 2019.
HN-303	**Specialist On-site Support** Access to the following specialist staff and services should be easily available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Erythrocytapheresis c. Acute pain team including specialist monitoring of patients with complex analgesia needs d. High dependency care, including non-invasive ventilation e. Level 2 and 3 critical care	N/A	

Ref	Standard	Met?	Comments
HN-304	**Specialist Services - Network** Access to the following specialist staff and services with an appropriate level of specialist expertise in the care of people with haemoglobin disorders should be available: a. Pulmonary hypertension team (adults) b. Consultant obstetrician with an interest in care of people with haemoglobin disorders and specialist high risk anaesthetics (adults) c. Respiratory physician with interest in acute/chronic sickle lung disease and obstructive sleep apnoea (adults & children) d. Fertility, including pre-implantation genetic diagnosis and sperm storage (adults) e. Consultant cardiologist with interest in sickle cardiomyopathy, iron overload related heart disease (adults) f. Consultant endocrinologist with interest in thalassaemia related endocrinopathy and osteoporosis (adults) g. Consultant paediatric endocrinologist with interest in growth problems related to haemoglobinopathies and thalassaemia related endocrinopathy (children) h. Hepatobiliary team with an interest in sickle hepatopathy, viral liver disease, iron overload-related liver disease (adults & children) i. Consultant neurologist and neurosurgeon with an interest in sickle vasculopathy (adults & children) j. Hyperacute stroke service (adults) k. Consultant ophthalmologist with an expertise in sickle retinopathy and chelation related eye disease (adults & children) l. Consultant nephrologist with expertise in sickle nephropathy (adults & children) m. Consultant urologist with expertise in managing priapism and erectile dysfunction (adults & children) n. Orthopaedic service with expertise in managing sickle and thalassaemia related bone disease (adults & children) o. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) p. Bone marrow transplantation services (children only) q. Physiotherapy services (in patient and community based) r. Interventional and neuroradiology for neurovascular complications	N/A	
HN-305	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	

Ref	Standard	Met?	Comments
HN-401	**Facilities and Equipment** Facilities and equipment should be appropriate for the usual number and case mix of patients. Equipment should be appropriately maintained.	Y	An apheresis machine had been purchased and the team were planning to train staff so that the service could be provided.
HN-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 carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer 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 the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y	
HN-502	**Monitoring Protocols** Protocols should be in use covering the monitoring expected at: a. First out-patient appointment (SHC only) b. Routine monitoring c. Annual review (SHC & any LHTs to which annual reviews are delegated) Protocols should cover both clinical practice and information for patients and families.	N	Protocols covering routine monitoring were not in place. The clinic letters seen at the time of the visit covered all aspects of routine monitoring.
HN-503	**Clinical Guidelines: LHT Management and Referral** Guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	Y	

Ref	Standard	Met?	Comments
HN-504	**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 carrying out a manual and automated exchange transfusion c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts	Y	Guidance on transfusions was included in both the sickle cell and the thalassaemia guidelines.
HN-505	**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. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y	
HN-506	**Clinical Guidelines: Acute Complications** Guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** 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 (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	BHRUT guidance for chelation and transition was in place. For other guidance, network guidelines had been adopted for use locally and were available on the Trust intranet.

Ref	Standard	Met?	Comments
HN-507	**Specialist Management Guidelines** Guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y	Network guidelines were in place. The team were also in the process of developing local guidelines.
HN-508	**Clinical Guidelines: Chronic complications** Guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y	Network guidelines were in place. Local BHRUT draft guidance was in the process of being developed, but the draft version seen by the reviewers did not yet include guidance on chronic respiratory disease or enuresis.
HN-509	**Referral for Consideration of Bone Marrow Transplantation (Children's Services Only)** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N/A	
HN-510	**Non-Transfusion Dependent Thalassaemia (nTDT)** Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y	
HN-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, clinic and ward areas.	Y	

Ref	Standard	Met?	Comments
HN-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 a SHC (Children's SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Arrangements for liaison with community paediatricians and with schools (children's services only) e. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated (children's services only) f. Follow up of patients who do not attend g. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. h. Accessing specialist advice (QS HN-304) i. Two-way communication of patient information between SHC and LHTs j. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	N	The operational policy was in the process of being developed. Some aspects would benefit from review before finalising; for example, the identified deputy for the consultant was the specialist registrar. In practice, processes were in place covering the requirements of the QS.
HN-602	**Multi-Disciplinary Meetings** Multi-disciplinary team 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 representatives of support services (QS HN-301).	Y	Weekly MDTs were held locally. MDTS via conference call with the SHT were held every month, and a network MDT meeting took place every three months.
HN-603	**Delegation of Annual Reviews** If annual reviews are undertaken by LHT/s on behalf of the SHC, a written agreement should be in place covering: a. Monitoring protocols (QS HN-502) b. LHT management and referral guidelines (QS HN-503) c. National Haemoglobinopathy Registry data collection (QS HN-701)	N/A	The QS was not applicable to the LH, but in practice the team were undertaking annual reviews for some patients on behalf of the SHT.

Ref	Standard	Met?	Comments
HN-604	**Out of Hours Elective Care** Arrangements should be in place for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	
HN-605	**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	Community and hospital services were integrated within the Child Health division.
HN-606	**Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)** A Standard Operating Procedure for Trans-Cranial Doppler ultrasound should be in use covering at least: a. Trans-Cranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-207) d. Arrangements for ensuring staff performing Trans-Cranial 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	
HN-607	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y	
HN-608	**Neonatal Screening Programme Review Meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (QS HN-703), identify issues of mutual concern and agree action.	N/A	
HN-701	**National Haemoglobinopathy Registry** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies and patients lost to follow up.	N/A	

Ref	Standard	Met?	Comments
HN-702	**Activity Data** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	N	Data for 'b' and 'c' were not available at the time of the visit.
HN-703	**Quality Dashboard** The service should monitor Quality Dashboard data including the number and percentage of: a. Adverse events reported on the NHR for which a mortality or serious case review has taken place b. Children who have had Trans-Cranial Doppler screening undertaken within national guidelines c. Patients given pain relief within half an hour of presentation with sickle crisis d. Patients with possible sickle disorders identified by neonatal screening who have been entered on a care pathway e. Eligible children beginning penicillin at or before three months of age f. Patients registered on the National Haemoglobinopathy Registry who had an annual review undertaken within the last year g. Patients on long-term transfusion who received cardiac MRI, and the proportion of those receiving a cardiac MRI who achieved a figure of less than 20ms h. Eligible patients with sickle cell disease who received an MRI for liver iron, and the proportion of those who received an MRI for liver iron who achieved more than 7 mg/gm/DW (sickle cell and thalassaemia separately)	NIA	
HN-704	**Other Quality Data** The service should monitor on an annual basis: a. Proportion of children who have been offered treatment following Trans-Cranial Doppler Screening	N/A	

Ref	Standard	Met?	Comments
HN-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. Availability of extended red cell phenotype in all patients and the proportion of patients who have developed antibodies b. Whether all eligible patients on long term transfusion have been offered automated exchange transfusion c. Waiting times for elective: i. Phlebotomy ii. Cannulation iii. Setting up of the blood transfusion (for pre-ordered blood)	N	An audit programme as defined by the QS was not yet in place. A blood transfusion audit was in progress and an audit covering management of pain had been approved.
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	N	Evidence was not available at the time of the visit.
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N/A	
HN-708	**Trans-Cranial Doppler Quality Assurance (Children's Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-207) b. Results of internal quality assurance systems (QS HN-606) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)	Y	'c' was not applicable as a national QA scheme had not yet been established.
HN-798	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility c. Annual review of trends in National Haemoglobinopathy Registry data, activity data, Quality Dashboard, other quality data and other audits (QSs HN-701 to HN-705)	Y	

Ref	Standard	Met?	Comments
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

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