

# Health Services for People with Haemoglobin Disorders

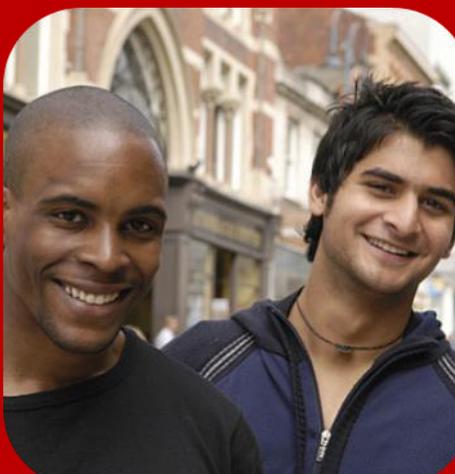
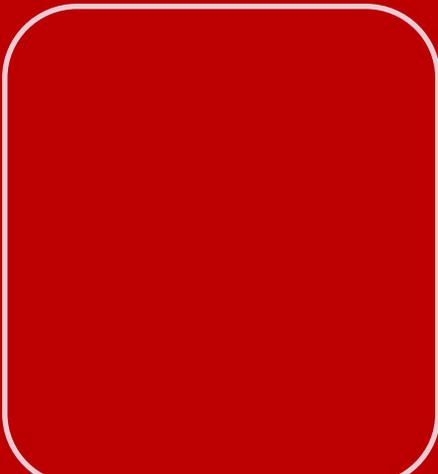
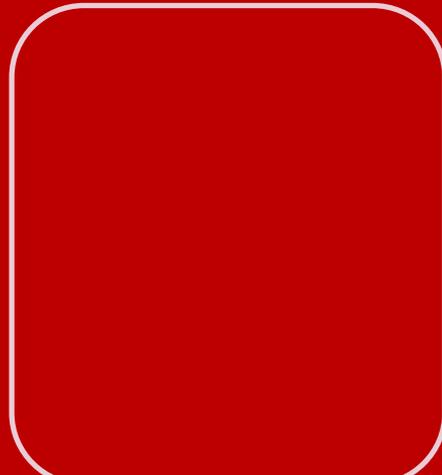
West Midlands Network

Birmingham Children's Hospital NHS Foundation Trust

Visit Date: 14<sup>th</sup> October 2015

Report Date: February 2016

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## INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Birmingham Children's Hospital NHS Foundation Trust (part of the West Midlands Network), which took place on 14<sup>th</sup> October 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014 which were developed by the UK Forum on Haemoglobin Disorders working with the West Midland Quality Review Service (WMQRS). The peer review visit was organised by WMQRS 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 Centre (SHC)

Accredited Local Haemoglobinopathy Team (A-LHT): A Local Team to which the Specialist Centre has delegated the responsibility for carrying out annual reviews

Local Haemoglobinopathy Teams (LHT): These are sometimes also called 'Linked Providers'

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. Appendix 1 lists the visiting team and Appendix 2 gives 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:

- Birmingham Children's Hospital NHS Foundation Trust
- NHS England Specialised Commissioning
- NHs Birmingham South Central 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. The lead commissioner in relation to this report is NHS England; Specialised Cancer and Blood.

### Acknowledgements

We would like to thank the staff of Birmingham Children's Hospital NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review. The NHS Sickle Cell and Thalassaemia Screening Programme funded this peer review programme.

### About West Midlands Quality Review Service

WMQRS is a collaborative venture between NHS organisations in the West Midlands 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. More detail about the work of WMQRS is available on [www.wmqrs.nhs.uk](http://www.wmqrs.nhs.uk)

## HAEMOGLOBIN DISORDERS SERVICES IN THE WEST MIDLANDS NETWORK

At the time of the visit Birmingham Children's Hospital NHS Foundation Trust (BCH) was part of the West Midlands Network and was a Specialist Haemoglobinopathy Centre (SHC) for children and young people in the region.

### 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
Birmingham Children's Hospital NHS Foundation Trust	SHT	350	83	112

Annual reviews undertaken for children from linked hospitals numbered 104 for sickle cell disease and 20 for thalassaemia.

Birmingham Children's Hospital is a large tertiary hospital that provides a vast range of specialised services. The haemoglobinopathy service was an established and well-embedded service located within the clinical division of Blood, Stem Cell Transplant and Cancer (BSC). The clinical lead for haemoglobinopathy also provided clinical leadership to the 'blood' division. The service catered to a very large number of children with haemoglobinopathy and had one of the largest number of children on regular transfusions in the UK. Building work was underway to develop a larger unit for the BSC division. Once completed, the facilities were expected to provide additional day case spaces and in-patient beds along with larger facilities for out-patient services.

The haemoglobinopathy service was run by two consultants with a total of four programmed activities allocated for haemoglobinopathy work. A weekly haemoglobinopathy clinic was held in BCH and the consultants provided an outreach clinic service to a number of local hospitals across the region.

### Emergency Admissions

All children with haemoglobinopathies attended the emergency department (ED) and were triaged according to clinical need. The triage team had a patient group directive (PGD) for the administration of paracetamol and ibuprofen for children who were in pain. During normal working hours the ED medical and nursing team provided immediate clinical care and the advanced nurse practitioner (ANP) for haemoglobinopathy was called to review some cases needing admission. The haematology medical team Specialist Trainee (ST) was also notified and undertook clinical reviews. A named haematology consultant was rostered to attend to all new admissions. An audit undertaken shortly before the review showed that the majority of children attending ED received analgesia within 30 minutes of presentation, thus fulfilling the National Institute for Health and Care Excellence (NICE) guideline criteria.

### In-Patient

Most haemoglobinopathy patients were admitted to Ward 15 which was the dedicated haematology/oncology ward. Additionally, other outlying wards also received haemoglobinopathy patients, notably the teenage ward. An outreach intensive care team supported any ill children on the ward prior to transfer to intensive care (ITU). The ITU was a very large open plan unit where children were managed when they needed intensification of treatment, including emergency red cell exchange. Manual exchanges were undertaken by the ITU medical team and the automated exchanges were undertaken during normal working hours by the apheresis team. An acute pain service was available to help with managing patient controlled analgesia (PCA) for pain and advice on other complex pain issues including post-operative pain.

## **Out-Patients**

All phlebotomy for transfusions was undertaken on Thursdays to minimise hospital visits. Transcranial Doppler scanning was provided at the same appointment.

## **Day Care**

The day care unit provided transfusions to patients four days a week. On Thursdays the day care area was converted to an out-patient waiting area. Children attending the day unit for transfusions were visited by the hospital school teachers regularly and were registered as 'present' in hospital school, thereby maintaining school attendance. The day care team worked hard to ensure that appointments met patient and family needs and rescheduling was relatively easy. All venepunctures and cannulations were undertaken by trained nurses.

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## **VIEWS OF SERVICE USERS AND CARERS**

The visiting team met a small number of patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They received responses to 48 questionnaires coordinated by the haemoglobinopathy team.

Common themes raised by patients and carers were:

- Overall the group gave excellent feedback about the service and expressed strong confidence in both medical and nursing staff in the team who they felt were very supportive and generated trust
- The views of patients were always considered when implementing changes within the service
- The consultant who replaced an established and eminent colleague had ensured a high quality service continued
- Community nurses helped with dissemination of information at school and preparing care plans, as well as improving compliance with medications. However the community nurses worked within strict geographical boundaries and many patients outside Birmingham were not able to access the service and said that they felt isolated in their communities.
- Care of children with co-existing other medical conditions was coordinated well so for example, the diabetes nursing staff would coordinate with the thalassaemia treatment by visiting patients while having transfusions
- A suggestion was made that a youth club for children with thalassaemia and sickle cell disease similar to that run for diabetes would be useful
- Patients appreciated home and school visits by staff
- For carers with more than one child having a different hospital site for the eldest one after transition was a concern and carers hoped that arrangements could be made for both children to transition to adult services at the same time
- The distance to the hospital was an issue for some patients
- More support at the time of diagnosis would be appreciated by some patients and carers
- There was some concern about the difficulty of obtaining a GP appointment quickly and getting the GP to prescribe medication as directed by the hospital, although not everyone at the meeting had this problem
- Analysis of the 48 questionnaires received showed that 27 respondents would welcome a Saturday transfusion service so as not to miss school
- There were also 12 responses to a survey about the role of the Advanced Nurse Practitioner all of which were very positive

- Following patient feedback the provision of food had been improved with a wider choice of menu including hot meals
- The extended opening hours for cross-matching offered on clinic days was appreciated
- Improvements had been made to the waiting area and its environment

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## REVIEW VISIT FINDINGS

### NETWORK

#### General Comments and Achievements

##### Children and Young Peoples Services

Birmingham Children’s Hospital NHS Foundation Trust (BCH) was the only SHT in the West Midlands for children and young people and had developed an informal/formal network across the region. The paediatric services at University Hospitals Coventry and Warwickshire NHS Trust (UHCW) and The Royal Wolverhampton NHS Trust (RWT) were operationally well-embedded within the Birmingham Children’s Hospital NHS Foundation Trust (BCH) haemoglobinopathy network as Local Haemoglobinopathy Team (LHT). Outreach clinics were established and attended by a consultant from BCH. Clear referral pathways and escalation of care policies were in place.

Although no formal network arrangements had been agreed in the West Midlands a functional informal network was in place in line with the regional Paediatric Cancer Network, with BCH as the specialist haemoglobinopathy hub and a large number of local hospitals as ‘spokes’. Outreach clinics for annual reviews were in place at the time of the review. Some clinics served to provide tertiary reviews to children with cancer as well as haemoglobin disorders, whereas others were solely for follow up of haemoglobinopathy patients. This arrangement was responsive to local needs. The lead and deputy consultants were easily available for advice and an on-call rota for paediatric haematology consultants was in place, providing round- the- clock consultant advice. Children with sickle cell disease, apart from those in Coventry, attended BCH clinics for annual Trans-cranial Doppler monitoring. The escalation of care policy for critically ill children was clear and the whole region was served by a single retrieval team (KIDS). About 120 children in the region received chronic blood transfusions and all MRI monitoring was undertaken at BCH. Data were reviewed centrally at BCH and uploaded regularly as part of the NHS England dashboard dataset. Shared protocols for research and audit were not yet in place.

##### Progress since Last Visit

The children’s network was to becoming formalised with a network coordinator appointed at BCH.

**Immediate Risks:** No immediate risks were identified.

##### Further Consideration

- 1 Reviewers suggested that additional paediatric consultant time to provide strategic leadership to the paediatric network to improve service provision and patient satisfaction throughout the region and to engage in network-wide research and audit may be helpful.
- 2 Introduction of Network review and learning meetings would be beneficial.

## NETWORK CONFIGURATION

The network configuration at the time of the review was as follows. Although no formal network arrangements had been agreed in the West Midlands a functional network operated across the region.

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
<b>Birmingham Children's Hospital NHS Foundation Trust</b>	<ul style="list-style-type: none"><li>• Sandwell and West Birmingham Hospitals NHS Trust</li><li>• The Royal Wolverhampton NHS Trust</li><li>• University Hospitals Coventry &amp; Warwickshire NHS Trust</li><li>• Burton Hospitals NHS Foundation Trust</li><li>• George Eliot Hospital NHS Trust</li><li>• Heart of England NHS Foundation Trust</li><li>• South Warwickshire NHS Foundation Trust</li><li>• The Dudley Group NHS Foundation Trust</li><li>• The Royal Wolverhampton NHS Trust</li><li>• The Shrewsbury and Telford Hospital NHS Trust</li><li>• University Hospitals of North Midlands NHS Trust</li><li>• University Hospitals Birmingham NHS Foundation Trust</li><li>• University Hospitals Coventry and Warwickshire NHS Trust</li><li>• Walsall Healthcare NHS Trust</li><li>• Worcestershire Acute Hospitals NHS Trust</li><li>• Wye Valley NHS Trust</li></ul>

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## SPECIALIST TEAM: BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST

### General Comments and Achievements

This was a cohesive team providing excellent high quality specialist service to a very large number of children with haemoglobinopathies in the West Midlands. The clinical leadership was robust and the review team was impressed by the way the new clinical lead had been able to continue the development of the service following the departure of the long-standing lead, who was also a national leader in the field. Service users were very satisfied with the care provided by the team. Annual reviews had taken place for all patients although at BCH these had not been documented on National Haemoglobinopathy Registry in BCH due to time constraints and absence of a data coordinator.

### Progress since Last Visit

Since the last visit which took place in 2010, care had been taken to improve the clinic space and day care area since the last visit to allow for more space to review and treat patients. A new building was under construction which was expected to increase the space and beds available to the clinical team. The development of the West Midlands Paediatric Haemoglobinopathy Network was well under way with robust working documents in draft and a network coordinator position agreed. The advanced nurse practitioner role was well-established in the service and she provided excellent leadership and training within the department. Bed capacity issues appeared to have reduced compared to the previous visit. The replacement had been undertaken in a timely fashion. This allowed for further development of the service and had provided continuity of care to the patients. Additionally, the governance and management structure of the whole department had undergone a change with three separate service streams within the department of Blood, Stem Cell and Cancer. This was expected to enable better resource planning and governance in the future.

### **Good Practice**

- 1 The draft documents produced for the Specialist Commissioners showed good clinical leadership and collaboration between the centre and local teams.
- 2 Good quality patient information leaflets were available.
- 3 Excellent community nursing provision was available in the Birmingham area.
- 4 Good links with local schools and excellent schooling within the hospital which enabled regularly transfused children to continue with their education while they were attending the hospital for their transfusions.
- 5 A 'patient group directive' for the administration of analgesia at triage minimised waiting times for patients before analgesia.
- 6 Junior doctor feedback regarding the opportunity for training in haemoglobinopathy was good.

**Immediate Risks:** No immediate risks were identified.

### **Concerns**

- 1 A psychologist with time allocated to support the haemoglobinopathy service was not available. This was of particular concern because of the size of the service.
- 2 The job plans of the lead clinician and deputy did not reflect the extent of work being undertaken by the consultant team which included outreach clinic services.

### **Further Consideration**

- 1 Guidance on staffing levels issued by the UK Forum on Haemoglobin Disorders may be helpful in planning staffing levels.
- 2 Out of hours transfusions were not perceived by the team to be an important need but analysis of patient surveys suggested it was important to review this decision in order to remain responsive to local needs.
- 3 Community services were not available beyond the Birmingham area. The availability of community services in other parts of the region may benefit from review.
- 4 An operational policy was not in place at the time of the review.
- 5 Draft guidelines should be formalised and regularly audited.
- 6 Reviewers suggested that the service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders demonstrated by evidence of competence and a training plan to ensure that all staff are developing and maintaining appropriate competences for their roles.
- 7 Annual reviews were not being entered on the NHR but the establishment of a network administrator was expected to improve data collection.
- 8 The service had not completed all the recommended audits and did not have a rolling plan of audits.

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## COMMISSIONING

### General Comments and Achievements

The reviewers met with two members of the West Midlands regional NHS England commissioning team to discuss care of children and young people with haemoglobin disorders. The commissioning team had had several operational meetings with the paediatric haemoglobinopathy clinicians in order to formalise network arrangements within the region. A network coordinator post had been developed with additional funding from commissioners for a period of 12 months. Engagement with the clinical team was positive and the intention to formalise a clinical network was clear.

### Further Consideration

- 1 Regular meetings between the commissioners and the paediatric clinical team should be considered to ensure that good communication continues.

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## APPENDIX 1 MEMBERSHIP OF VISITING TEAM

### Clinical Leads:

Dr Subarna Chakravorty	Consultant Haematologist	Kings College Hospital NHS Foundation Trust
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### Visiting Team:

Claire Foreman	Senior Service Specialist	NHS England
Elaine Miller	Coordinator	UK Thalassaemia Society
Dr Jenny Welch	Consultant Haematologist	Sheffield Children's NHS Foundation Trust
Cherryl Westfield	Carer	Not applicable
Dr Olu Wilkey	Consultant Paediatrician	North Middlesex University Hospital NHS Trust

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## APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varied 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**

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	51	39	76
Haemoglobin Disorders Clinical Network	9	1	11
Commissioning	3	1	33
<b>Total</b>	<b>63</b>	<b>41</b>	<b>65</b>

### Pathway and Service Letters

HN-	Specialist services for People with Haemoglobin Disorders
HY-	Haemoglobin Disorders: Network
HZ-	Haemoglobin Disorders: Commissioning

### Topic Sections

Each section covers the following topics:

-100	Information and Support for Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment
-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

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## SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-101 All	<p><b>Haemoglobin Disorder Service Information</b></p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> <li>a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services</li> <li>b. Clinic times and how to change an appointment</li> <li>c. Ward usually admitted to and its visiting times</li> <li>d. Staff of the service</li> <li>e. Community services and their contact numbers</li> <li>f. Relevant national organisations and local support groups</li> <li>g. Where to go in an emergency</li> <li>h. How to:               <ol style="list-style-type: none"> <li>i. Contact the service for help and advice, including out of hours</li> <li>ii. Access social services</li> <li>iii. Access benefits and immigration advice</li> <li>iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent)</li> <li>v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns</li> <li>vi. Get involved in improving services (QS HN-199)</li> </ol> </li> </ol>	Y	

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-102 All	<p><b>Information about Haemoglobin Disorders</b></p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> <li>A description of the condition (SC or T), how it might affect the individual and treatment</li> <li>Problems, symptoms and signs for which emergency advice should be sought</li> <li>How to manage pain at home (SC only)</li> <li>Splenic palpation and Trans-Cranial Doppler scanning (children only)</li> <li>Transfusion and iron chelation</li> <li>Possible complications, including priapism and complications during pregnancy</li> <li>Health promotion, including: <ol style="list-style-type: none"> <li>Information on contraception and sexual health</li> <li>Travel advice</li> <li>Vaccination advice</li> <li>Stopping smoking</li> </ol> </li> <li>National Haemoglobinopathy Registry, its purpose and benefits</li> <li>Self-administration of medications and infusions</li> </ol>	Y	However 'b' and 'gii' were for sickle cell disease only as was travel advice.
HN-103 All	<p><b>Information for Primary Health Care Team</b></p> <p>Written information should be sent to the patient's primary health care team covering available local services and</p> <ol style="list-style-type: none"> <li>The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC)</li> <li>Side effects of medication, including chelator agents [SC and T]</li> <li>Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs).</li> <li>Immunisations</li> <li>Indications and arrangements for seeking advice from the specialist service</li> </ol>	Y	It was unclear whether information relating to 'b' was sent to the primary care team.

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-104 All	<p><b>Care Plan</b></p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> <li>a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> <li>i. Information about their condition</li> <li>ii. Plan for management in the Emergency Department</li> <li>iii. Planned acute and long-term management of their condition, including medication</li> <li>iv. Named contact for queries and advice</li> </ol> </li> <li>b. A permanent record of consultations at which changes to their care are discussed</li> </ol> <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p>	Y	
HN-105 All	<p><b>School Care Plan (Paediatric Services Only)</b></p> <p>A School Care Plan should be agreed for each child or young person covering, at least:</p> <ol style="list-style-type: none"> <li>a. School attended</li> <li>b. Medication, including arrangements for giving / supervising medication by school staff</li> <li>c. What to do in an emergency whilst in school</li> <li>d. Arrangements for liaison with the school</li> </ol>	Y	A very good school plan was in place that required sign-off from the parent and the school.
HN-106 SHC (A-LHT)	<p><b>Transition to Adult Services</b></p> <p>Young people transferring to the care of adult services should be offered written information covering at least:</p> <ol style="list-style-type: none"> <li>a. Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer</li> <li>b. A joint meeting between children's and adult services to plan the transfer</li> <li>c. A named coordinator for the transfer of care</li> <li>d. A preparation period prior to transfer</li> <li>e. Arrangements for monitoring during the time immediately after transfer</li> </ol>	Y	

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-107 SHC	<p><b>Information about Trans-Cranial Doppler Ultrasound</b></p> <p>Written information should be offered to patients and their carers covering:</p> <ol style="list-style-type: none"> <li>Reason for the scan and information about the procedure</li> <li>Details of where and when the scan will take place and how to change an appointment</li> <li>Staff who will be present and will perform the scan</li> <li>Any side effects</li> <li>Informing staff if the child is unwell or has been unwell in the last week</li> <li>How, when and by whom results will be communicated</li> </ol>	Y	Information about Trans-Cranial Doppler Ultrasound was comprehensive.
HN-199 All	<p><b>Involving Patients and Carers</b></p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> <li>Mechanisms for receiving feedback from patients and carers</li> <li>An annual patient survey (or equivalent)</li> <li>Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service</li> <li>Examples of changes made as a result of feedback and involvement of patients and carers</li> </ol>	Y	Over 50% of the respondents from the patient survey wanted a Saturday transfusion service. Responses had been received from 48 out of 120 surveyed.
HN-201 All	<p><b>Lead Consultant</b></p> <p>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 session/s identified for this role within their job plan.</p>	Y	
HN-202 All	<p><b>Cover for Lead Consultant</b></p> <p>Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.</p>	Y	

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-203 All	<p><b>Lead Nurse</b></p> <p>A lead nurse should have appropriate time available for their leadership role and:</p> <ol style="list-style-type: none"> <li>Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders</li> <li>Responsibility for liaison with other services within the network</li> <li>RCN competences in caring for people with haemoglobin disorders</li> <li>Competences in the care of children and young people (children's services only)</li> </ol>	Y	Although the Royal College of Nursing competences were not demonstrated the Clinical Nurse Specialist had completed a relevant masters level course.
HN-204 All	<p><b>Staffing Levels and Competences</b></p> <p>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> <li>Medical staffing for clinics and regular reviews</li> <li>Medical staffing for emergency care, in and out of hours</li> <li>Nurse staffing on the ward and day unit</li> <li>Clinical nurse specialist/s with responsibility for the acute service</li> <li>Clinical nurse specialist/s with responsibility for the community service</li> <li>Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion.</li> <li>Clinical or health psychologist with an interest in haemoglobin disorders</li> </ol> <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT).</p> <p>Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders.</p> <p>Cover for absences should be available.</p>	N	Evidence was not seen for 'g' and competences.
HN-205 All	<p><b>Competences and Training</b></p> <p>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 (QS HN-204).</p>	N	A training plan that ensured all staff were developing and maintaining competences for their role was not seen.
HN-206 SHC	<p><b>Specialist Advice</b></p> <p>During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.</p>	Y	

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-207 All	<p><b>Training for Emergency Department Staff</b></p> <p>The service should offer regular training in the care of patients with haemoglobin disorders to:</p> <ol style="list-style-type: none"> <li>Clinical staff in the Emergency Department</li> <li>Nursing staff on general wards to which patients with haemoglobin disorders may be admitted</li> </ol>	Y	No evidence was seen but the lead nurse described the training that she provided.
HN-208 All	<p><b>Safeguarding Training</b></p> <p>All staff caring for people with haemoglobinopathies should have undertaken appropriate training in:</p> <ol style="list-style-type: none"> <li>Safeguarding children and/or vulnerable adults (as applicable)</li> <li>Equality and diversity</li> </ol>	Y	
HN-209 SHC	<p><b>Doctors in Training</b></p> <p>The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.</p>	Y	
HN-210 SHC	<p><b>Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)</b></p> <p>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.</p>	Y	
HN-299 All	<p><b>Administrative, Clerical and Data Collection Support</b></p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p>	Y	
HN-301 All	<p><b>Support Services</b></p> <p>Timely access to the following services should be available:</p> <ol style="list-style-type: none"> <li>Psychologist with an interest in haemoglobinopathies</li> <li>Social worker</li> <li>Leg ulcer service</li> <li>Play specialist (children's services only)</li> <li>Chronic pain team</li> <li>Dietetics</li> <li>Physiotherapy</li> <li>Occupational therapy</li> <li>Mental health services (adult and CAMHS)</li> </ol> <p>In Specialist Centre's these 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) if required.</p>	N	Timely access to 'a', 'b' and 'e' was not available and 'c' was not applicable.

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-302 SHC	<p><b>Specialist On-site Support</b></p> <p>Access to the following specialist staff and services should be available on the same hospital site as the specialist team:</p> <ol style="list-style-type: none"> <li>Manual exchange transfusion (24/7)</li> <li>Acute pain team including specialist monitoring of patients with complex analgesia needs</li> <li>Consultant obstetrician with an interest in care of people with haemoglobin disorders</li> <li>Respiratory physician with interest in chronic sickle lung disease</li> <li>High dependency care, including non-invasive ventilation</li> <li>Intensive care (note 2)</li> </ol>	Y	
HN-303 SHC A-LHT	<p><b>Specialist Services - Network</b></p> <p>Access to the following specialist staff and services should be available:</p> <ol style="list-style-type: none"> <li>Erythrocytapheresis</li> <li>Pulmonary hypertension team</li> <li>Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis</li> <li>Consultant cardiologist</li> <li>Consultant endocrinologist</li> <li>Consultant hepatologist</li> <li>Consultant neurologist</li> <li>Consultant ophthalmologist</li> <li>Consultant nephrologist</li> <li>Consultant urologist with expertise in managing priapism and erectile dysfunction</li> <li>Orthopaedic service</li> <li>Specialist imaging, including <ol style="list-style-type: none"> <li>MRI tissue iron quantification of the heart and liver</li> <li>Trans-Cranial Doppler ultrasonography (children)</li> </ol> </li> <li>Neuropsychologist</li> <li>DNA studies</li> <li>Polysomnography and ENT surgery</li> <li>Bone marrow transplantation services</li> </ol> <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p>	N	Access to all specialist staff and services was available except for 'm'.
HN-304 All	<p><b>Laboratory Services</b></p> <p>UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.</p>	Y	

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-401 All	<p><b>Facilities Available</b></p> <p>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.</p>	Y	
HN-402 All	<p><b>Facilities for Out of Hours Care</b></p> <p>Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.</p>	N	Out of hours transfusion was not available.
HN-501 SHC A-LHT	<p><b>Transition Guidelines</b></p> <p>Network-agreed guidelines on transition to adult care should be in use covering at least:</p> <ol style="list-style-type: none"> <li>Age guidelines for timing of the transfer</li> <li>Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer</li> <li>Allocation of a named coordinator for the transfer of care</li> <li>A preparation period and education programme relating to transfer to adult care</li> <li>Communication of clinical information from paediatric to adult services</li> <li>Arrangements for monitoring during the time immediately after transfer to adult care</li> <li>Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams</li> </ol>	Y	
HN-502 All	<p><b>Monitoring Checklists</b></p> <p>Checklists should be in use for:</p> <ol style="list-style-type: none"> <li>First out-patient appointment (SHC &amp; A-LHT only)</li> <li>Routine monitoring</li> <li>Annual review (SHC &amp; A-LHT only)</li> </ol> <p>Use of the checklists should cover both clinical practice and information for patients and families.</p>	Y	The patient checklist was good.
HN-503 LHT	<p><b>Clinical Guidelines: LHT Management and Referral</b></p> <p>Network-agreed 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.</p>	Y	

		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-504 All	<p><b>Transfusion Guidelines</b></p> <p>Transfusion guidelines should be in use covering:</p> <ol style="list-style-type: none"> <li>Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion</li> <li>Offering access to exchange transfusion to patients on long-term transfusions</li> <li>Protocol for carrying out an exchange transfusion</li> <li>Hospital transfusion policy</li> <li>Investigations and vaccinations prior to first transfusion</li> <li>Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate.</li> <li>Areas where transfusions will usually be given</li> <li>Recommended number of cannulation attempts</li> </ol>	Y	The blood transfusion care pathway was good.
HN-505 All	<p><b>Chelation Therapy</b></p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ol style="list-style-type: none"> <li>Indications for chelation therapy</li> <li>Choice of chelation drug/s, dosage and dosage adjustment</li> <li>Monitoring of haemoglobin levels prior to transfusion</li> <li>Management and monitoring of iron overload, including management of chelator side effects</li> <li>Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2</li> <li>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.</li> <li>Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.</li> </ol>	Y	

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-506 All	<p><b>Clinical Guidelines: Acute Complications</b></p> <p>Network-agreed clinical guidelines on the management of acute complications should be in use covering at least:</p> <p><b>For patients with sickle cell disease:</b></p> <ol style="list-style-type: none"> <li>Acute pain</li> <li>Fever, infection and overwhelming sepsis</li> <li>Acute chest syndrome</li> <li>Abdominal pain and jaundice</li> <li>Acute anaemia</li> <li>Stroke and other acute neurological events</li> <li>Priapism</li> <li>Acute renal failure</li> <li>Haematuria</li> <li>Acute changes in vision</li> <li>Acute splenic sequestration (children only)</li> </ol> <p><b>For patients with thalassaemia:</b></p> <ol style="list-style-type: none"> <li>Fever, infection and overwhelming sepsis</li> <li>Cardiac, hepatic or endocrine decompensation</li> </ol>	Y	
HN-507 All	<p><b>Specialist Management Guidelines</b></p> <p>Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> <li>During anaesthesia and surgery</li> <li>Who are pregnant</li> <li>Receiving hydroxycarbamide therapy</li> </ol>	Y	
HN-508 All	<p><b>Clinical Guidelines: Chronic complications</b></p> <p>Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least:</p> <ol style="list-style-type: none"> <li>Renal disease</li> <li>Orthopaedic problems</li> <li>Retinopathy</li> <li>Cardiological complications / pulmonary hypertension</li> <li>Chronic respiratory disease</li> <li>Endocrinopathies</li> <li>Neurological complications</li> <li>Chronic pain</li> <li>Liver disease</li> <li>Growth delay / delayed puberty (children only)</li> <li>Enuresis (children only)</li> </ol>	Y	
HN-509 SHC	<p><b>Referral for Consideration of Bone Marrow Transplantation</b></p> <p>Guidelines for referral for consideration of bone marrow transplantation should be in use.</p>	Y	

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-510 All	<p><b>Thalassaemia Intermedia</b></p> <p>Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering:</p> <ol style="list-style-type: none"> <li>Indications for transfusion</li> <li>Monitoring iron loading</li> <li>Indications for splenectomy</li> </ol>	Y	
HN-511 All	<p><b>Clinical Guideline Availability</b></p> <p>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.</p>	Y	
HN-512 SHC	<p><b>Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)</b></p> <p>Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least:</p> <ol style="list-style-type: none"> <li>Identification of ultrasound equipment and maintenance arrangements</li> <li>Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210)</li> <li>Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound</li> <li>Ensuring all patients are given relevant information (QS HN-107)</li> <li>Use of an imaging consent procedure</li> <li>Guidelines on cleaning ultrasound probes</li> <li>Arrangements for recording and storing images and ensuring availability of images for subsequent review</li> <li>Reporting format, including whether mode performed was imaging or non-imaging</li> <li>Arrangements for documentation and communication of results</li> <li>Internal systems to assure quality, accuracy and verification of results</li> <li>Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)</li> </ol>	Y	The review team was not clear if arrangements for 'g' were in place.

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-601 All	<p><b>Service Organisation</b></p> <p>A service organisation policy should be in use covering arrangements for:</p> <ol style="list-style-type: none"> <li>'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only)</li> <li>Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission</li> <li>Patient discussion at multi-disciplinary team meetings (QS HN-602)</li> <li>Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population</li> <li>Arrangements for liaison with community paediatricians and with schools (children's services only)</li> <li>'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated</li> <li>Follow up of patients who do not attend</li> <li>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.</li> <li>Accessing specialist advice (QS HN-206)</li> <li>Two-way communication of patient information between SHC and LHTs</li> <li>If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together</li> </ol>	N	A service organisation policy was not available.
HN-602 All	<p><b>Multi-Disciplinary Meetings</b></p> <p>Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).</p>	Y	
HN-603 All	<p><b>Service Level Agreement with Community Services</b></p> <p>A service level agreement for support from community services should be in place covering, at least:</p> <ol style="list-style-type: none"> <li>Role of community service in the care of patients with haemoglobin disorders</li> <li>Two-way exchange of information between hospital and community services.</li> </ol>	N	Arrangements with the non-BCH employed staff were informal.

		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-604 All	<b>Network Review and Learning Meetings</b> At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	N	Network review and learning meetings were not yet organised.
HN-605 SHC	<b>Neonatal screening programme review meetings</b> The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	Y	The review meetings were held twice yearly.
HN-701 SHC	<b>Data Collection</b> Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	N	Annual reviews were not being entered on the NHR but the establishment of a network administrator was expected to improve data collection. Serious adverse events were being entered regularly
HN-702 All	<b>Annual Data Collection - Activity</b> 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	Y	However evidence for monitoring of 'c' was not seen by the review team.

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-703 SHC	<p><b>Annual Data Collection – Network Patient Data</b></p> <p>The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> <li>a. Number of patients under active care in the network at the start of each year</li> <li>b. Number of new patients accepted by network services during the course of the year: <ol style="list-style-type: none"> <li>i. Births</li> <li>ii. Transferred from another service</li> <li>iii. Moved into the UK</li> </ol> </li> <li>c. For babies identified by the screening service: <ol style="list-style-type: none"> <li>i. Date seen in clinic</li> <li>ii. Date offered and prescribed penicillin</li> </ol> </li> <li>d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year</li> <li>e. Number of network patients on long-term transfusion</li> <li>f. Number of network patients on chelation therapy</li> <li>g. Number of network patients on hydroxycarbamide</li> <li>h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year</li> <li>i. Number of pregnancies in network patients</li> <li>j. Number of network patients whose care was transferred to another service during the year</li> <li>k. Number of network patients who died during the year</li> <li>l. Number of network patients lost to follow up during the year</li> </ol>	N	The network was not yet formalised and no network wide data were presented, except for 'c', 'h', 'e' and 'f'. However a clinical dashboard quarterly report was produced.

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-704 All	<p><b>Audit</b></p> <p>Clinical audits covering the following areas should have been undertaken within the last two years:</p> <p><b>Achievement of screening follow-up standards:</b></p> <ol style="list-style-type: none"> <li>At least 90% of infants with a positive screening result attend a local clinic by three months of age</li> <li>At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age</li> <li>Less than 10% of cases on registers lost to follow up within the past year</li> </ol> <p><b>For patients with sickle cell disease:</b></p> <ol style="list-style-type: none"> <li>Proportion of patients with recommended immunisations up to date</li> <li>Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required</li> <li>Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival</li> <li>Availability of extended red cell phenotype in all patients</li> <li>Proportion of children: <ol style="list-style-type: none"> <li>at risk of stroke who have been offered and/or are on long-term transfusion programmes</li> <li>who have had a stroke</li> </ol> </li> </ol> <p><b>For patients with thalassaemia:</b></p> <ol style="list-style-type: none"> <li>Evidence of effective monitoring of iron overload, including imaging (QS HN-505)</li> <li>Proportion of patients who have developed new iron-related complications in the preceding 12 months</li> </ol> <p><b>All patients:</b></p> <ol style="list-style-type: none"> <li>Waiting times for transfusion</li> </ol>	N	Clinical audits had only been undertaken for 'a', 'b', 'f' and 'h'.
HN-705 All	<p><b>Guidelines Audit</b></p> <p>The service should have a rolling programme of audit, including:</p> <ol style="list-style-type: none"> <li>Audit of implementation of clinical guidelines (QS HN-500s).</li> <li>Participation in agreed network-wide audits.</li> </ol>	N	Evidence that the guidelines were being audited was not provided.
HN-706 SHC	<p><b>Research</b></p> <p>The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.</p>	Y	Some research was being undertaken for example, transition research through the London School of Tropical Medicine.

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HN-707 SHC	<p><b>Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)</b></p> <p>The service should monitor and review at least annually:</p> <ol style="list-style-type: none"> <li>Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512)</li> <li>Results of internal quality assurance systems (QS HN-512)</li> <li>Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)</li> <li>Results of 'fail-safe' arrangements and any action required</li> </ol>	Y	Results of 'fail-safe' arrangements and actions taken were not seen and 'c' was not applicable.
HN-798 All	<p><b>Review and Learning</b></p> <p>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:</p> <ol style="list-style-type: none"> <li>Review of any patient with a serious adverse event or who died</li> <li>Review of any patients requiring admission to a critical care facility</li> </ol>	Y	
HN-799 All	<p><b>Document Control</b></p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p>	Y	

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## HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Children and Young People	
		Met? Y/N	Reviewer Comments
HY-199	<p><b>Involving Patients and Carers</b></p> <p>The network should have mechanisms for involving patients and their carers from all services in the work of the network.</p>	N	Mechanisms for involving patients and carers in the work of the network did not yet exist.

		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments
HY-201	<p><b>Network Leads</b></p> <p>The network should have a nominated:</p> <ol style="list-style-type: none"> <li>Lead consultant and deputy</li> <li>Lead specialist nurse for acute care</li> <li>Lead specialist nurse for community services</li> <li>Lead manager</li> <li>Lead for service improvement</li> <li>Lead for audit</li> <li>Lead commissioner</li> </ol>	Y	<p>The process of development of the network was underway and a draft working document was provided but network leads were not yet identified.</p> <p>There was a Trust CQUIN (Commissioning for Quality and Innovation) target and the employment of a data manager was expected to help develop the network.</p>
HY-202	<p><b>Education and Training</b></p> <p>The network should have agreed a programme of education and training to help services achieve compliance with Qs HN-204 and HN-205.</p>	N	<p>The intention for this was expressed by the team but a programme for education and training was not yet in place.</p>
HY-501	<p><b>Transition Guidelines</b></p> <p>Network guidelines on transition to adult care should have been agreed covering:</p> <ol style="list-style-type: none"> <li>Age guidelines for timing of the transfer</li> <li>Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer</li> <li>Allocation of a named coordinator for the transfer of care</li> <li>Communication of clinical information from paediatric to adult services</li> <li>Arrangements for monitoring during the time immediately after transfer to adult care</li> <li>Arrangements for communication with Local Haemoglobinopathy Team (if applicable)</li> </ol> <p>Guidelines should be explicit about transition directly to any accredited LHTs.</p>	N	<p>Formal network agreed guidelines were not yet in place but BCH guidelines were widely used in the local hospitals.</p>

		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments
HY-502	<p><b>Clinical Guidelines</b></p> <p>Network guidelines should have been agreed covering:</p> <ol style="list-style-type: none"> <li>Annual review (QS HN-502)</li> <li>Routine monitoring (QS HN-503)</li> <li>Transfusion (QS HN-504)</li> <li>Chelation therapy, including guidelines for shared care with general practice (QS HN-505)</li> <li>Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303)</li> <li>Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303)</li> <li>Specialist management (QS HN-507)</li> <li>Thalassaemia intermedia (QS HN-510)</li> </ol> <p>Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.</p>	N	A draft working document for development of the network was seen but network agreed guidelines were not yet in practice.
HY-701	<p><b>Ongoing Monitoring</b></p> <p>The network should monitor on a regular basis:</p> <ol style="list-style-type: none"> <li>Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701)</li> <li>Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.</li> </ol>	N	Data were not yet available but this was expected to change once the data manager started.
HY-702	<p><b>Audit</b></p> <p>The network should have an agreed programme of audit and review covering network-wide achievement of Qs HN-703, HN-704, HN-705 and HN-707.</p>	N	Data for audit were not yet available but this was expected to change when data manager started.
HY-703	<p><b>Research</b></p> <p>The network should have agreed:</p> <ol style="list-style-type: none"> <li>A policy on access to research relating to the care of patients with haemoglobin disorders</li> <li>A list of research trials available to all patients within the network.</li> </ol>	N	A network research policy or list of trials had not yet been agreed.

		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments
HY-798	<p><b>Network Review and Learning</b></p> <p>The SHC should meet at least twice a year with its referring LHT teams to:</p> <ol style="list-style-type: none"> <li>Identify any changes needed to network-wide policies, procedures and guidelines</li> <li>Review results of audits undertaken and agree action plans</li> <li>Review and agree learning from any positive feedback or complaints involving liaison between teams</li> <li>Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams</li> <li>Consider the content of future training and awareness programmes (QS HY-202)</li> </ol>	N	Meetings had not yet been arranged but this was expected to change once the network was formalised.

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## COMMISSIONING

		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments
HZ-601	<p><b>Commissioning of Services</b></p> <p>Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular:</p> <ol style="list-style-type: none"> <li>Designated SHC/s for the care of people with sickle cell disease</li> <li>Designated SHC/s for the care of adults with thalassaemia</li> <li>Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia</li> <li>Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia</li> <li>Community care providers</li> </ol>	Y	<p>Network development was an expressed intent by the commissioners once the network was formalised.</p> <p>The Trust had a CQUIN (Commissioning for Quality and Innovation) target for 2015/2016.</p>

		Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments
HZ-701	<p><b>Clinical Quality Review Meetings</b></p> <p>Commissioners should regularly review the quality of care provided by:</p> <ul style="list-style-type: none"> <li>a. Each service, in particular QS HN-703</li> <li>b. Each network, in particular, achievement of QS HY-702 and QS HY-798.</li> <li>c. Service and network achievement of relevant QSs</li> </ul>	N	<p>Commissioners were not yet regularly reviewing the quality of services for children with haemoglobin disorders.</p> <p>Formal network arrangements were not yet in place although this was earmarked as a CQUIN (Commissioning for Quality and Innovation) for the Trust in the next financial year and it was planned to meet this Quality Standard in the next year.</p>
HZ-798	<p><b>Network Review and Learning</b></p> <p>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.</p>	N	<p>Network review and learning meetings were not yet in place.</p>

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