

# Health Services for People with Haemoglobin Disorders

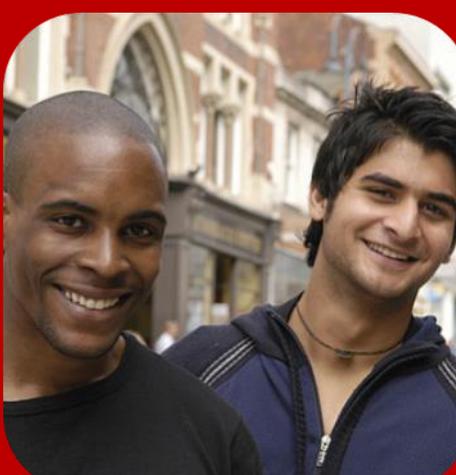
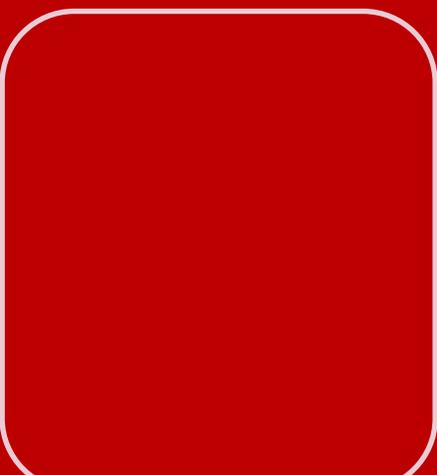
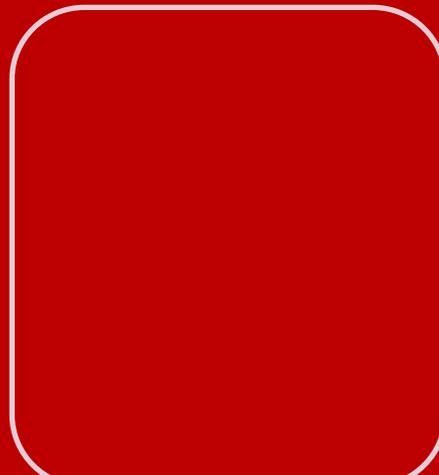
## South Central Network

### Oxford University Hospitals NHS Foundation Trust

Visit Date: 19th November 2015

Report Date: March 2016

*Images courtesy of NHS Photo Library*



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## INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Oxford University Hospitals NHS Foundation Trust (part of the South Central Network), which took place on 19<sup>th</sup> November 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:

- Oxford University Hospitals NHS Foundation Trust
- NHS England Specialised Commissioning
- NHS Oxfordshire 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 Oxford University Hospitals 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 SOUTH CENTRAL NETWORK

Oxford University Hospitals NHS Foundation Trust (OUH) was designated at the Specialist Haemoglobinopathy Centre for the South Central Network although more patients were linked with Milton Keynes General Hospital (MK) which is part of Milton Keynes University Hospital NHS Foundation Trust. The service at Milton Keynes was not reviewed as part of the visit.

### Adults

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long term red cell transfusions
Oxford University Hospitals NHS Foundation Trust : Churchill Hospital	SHT	44	8	8
Milton Keynes University Hospital NHS Foundation Trust	LHT	80	0	0
Royal Berkshire NHS Foundation Trust	LHT	30	<5	<5
Frimley Health NHS Foundation Trust	LHT	30	5	5

### Children and Young People

Trust	Reviewed as:	No. children with sickle cell disease	No. children with thalassaemia	No. children on long term red cell transfusions
Oxford University Hospitals NHS Foundation Trust	SHT	12	<5	<5
Milton Keynes University Hospital NHS Foundation Trust	LHT	57	5	10
Royal Berkshire NHS Foundation Trust	LHT	27	0	0
Great Western Hospitals NHS Foundation Trust	LHT	11	<5	0
Frimley Health NHS Foundation Trust	LHT	16	5	<5

## ADULT SERVICES – CHURCHILL HOSPITAL

### EMERGENCY CARE

All adult patients with haemoglobin disorders were given details for the triage service run through the Haematology and Cancer Centre. Triage provided a dedicated service for patients known to the haematology service, staffed by haematology/oncology nurses with access to haematology specialist registrars as the first line of assessment for all patients. Specially trained triage nurses took details of the patient's problem, and liaised with the haematology registrar from the ward to arrange review and/or admission. This service was accessed via telephone from 8am to 8pm Monday to Friday, and from 8am to 6pm Saturday and Sunday. Outside these hours, the triage number was diverted directly to the haematology ward, where ward nursing staff took the patient's details and arranged an immediate return call by the duty haematology registrar. Audit

data demonstrated that the majority of acute admissions for patients with sickle cell crises were managed by this team. For patients not known to the service the alternative route of admission was directly through the emergency department (ED) at John Radcliffe Hospital but this was not commonly used. When this occurred, the on-site registrar reviewed the patient and arranged for transfer to the Haematology Ward at the earliest opportunity. A guideline for emergency care was available on the haematology department's website. Access to the guideline was not restricted to Trust computers as it was hosted on the widely-used regional protocol portal provided for all haematological disorders.

#### **IN-PATIENT CARE**

High quality haematology ward facilities were adjacent to the triage unit in the Oxford Haematology and Cancer Centre, Churchill Hospital. The ward consisted of ten twin bays and five single rooms including ten positive pressure hepa-filtered rooms. The ward was specific to patients with haematological disease and had a teenage and young adult area for the patients between 16 and 25 years old. Priority for admission was given to patients with major haemoglobinopathies including acute painful crises. Formal twice-weekly consultant ward rounds were conducted with additional consultant reviews as necessary. Specialist registrars for haematology and two ward doctors were responsible for routine care with access to advice and input from the specialist haemoglobinopathy team.

#### **DAY CARE**

The Day Unit operated between 8am and 6pm Monday to Friday, with a Saturday morning service also available for transfusion. This facility also provided out-patient chemotherapy and transfusions for patients with haematological malignancies and haemoglobinopathy patients requiring out-patient top- up transfusion. Elective exchange transfusion was performed at the NHSBT apheresis unit based at the John Radcliffe site which was not visited as part of the review. Patient reviews at the Churchill Hospital were conducted by specialist registrars in haematology in the triage area with access to input and advice from the specialist haemoglobinopathy team.

#### **OUT-PATIENT CARE**

The haemoglobinopathy clinics were held on the first and third Friday of each month, in the out-patient department on level 0 of the Haematology and Cancer Centre, Churchill Hospital. This clinic was managed by the lead clinician and deputy, plus a clinical research registrar with a special interest in red cell disorders and a haematology specialist registrar on a rotational basis. Core medical trainees and medical students were encouraged to attend. The clinic was supported by a non-specialist clinic nurse.

#### **COMMUNITY-BASED CARE**

At the time of the review haemoglobinopathy community nursing was not available for patients attending OUH. Community-based haemoglobinopathy nursing was available to patients from Milton Keynes Hospital. Community-based care was not provided for people with major haemoglobin disorders in the Oxford region.

### **CHILDREN AND YOUNG PEOPLE – JOHN RADCLIFFE HOSPITAL**

#### **EMERGENCY CARE**

Children with haemoglobin disorders were admitted directly to the Kamran Ward, which was a nine-bedded paediatric haematology /oncology ward. Occasionally patients were admitted to adjacent paediatric wards if beds on Kamran Ward were not available. Parents were encouraged to phone in advance when they felt the need for urgent medical input and a bed was made available to them upon their arrival. During office hours urgent clinical assessments for such children were also arranged in the adjacent Kamran Day ward.

Any patient admitted to hospital during office hours was seen by the ward-based haematology/oncology team and a consultant review was provided by the 'attendance' consultant. This attendance rota was staffed by haematologists and oncologists although the haemoglobin disorders clinical lead was contactable for advice if

needed. If the patient presented outside normal working hours they were reviewed by the on- call junior doctor who was responsible for management of all admissions at the Children's Hospital.

#### **IN-PATIENT CARE**

Kamran Ward was the designated in-patient ward for haematology and oncology and had nine beds. Patient controlled analgesia (PCA) was set up and administered by staff proficient in the use of this modality of pain relief. The hospital acute pain team was generally not involved in the setting up and management of PCA. Daily consultant ward rounds were undertaken in order to review all new overnight admissions.

#### **DAY CARE**

Kamran Day Ward was a designated haematology/oncology day care ward where blood transfusions took place. Additionally, urgent assessment of patients with sickle cell disease could be arranged there prior to their admission to the in-patient ward.

#### **OUT-PATIENT CARE**

Annual reviews took place in a dedicated haemoglobinopathy clinic run by the clinical lead. Transcranial Doppler testing was undertaken on the same day as the clinic appointment. The lead clinician also attended joint clinics at the Churchill Hospital with the adult haemoglobinopathy team if there was a teenage patient who required transition to the adult services.

#### **COMMUNITY-BASED CARE**

At the time of the review haemoglobinopathy community nursing was not available for children who attended the treatment centre in Oxford University Hospital. Community-based haemoglobinopathy nursing was available to patients from Milton Keynes Hospital.

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

The visiting team met a small number of patients and carers with sickle cell disease and received feedback from them. They received responses to 13 questionnaires from adults and five from children and young people.

Common themes raised by patients and carers were:

- Unanimous appreciation of the good quality personalised care provided by the lead consultant for children and young people
- Patients were appreciative of the direct access to the designated paediatric haemato/oncology ward.
- Concerns regarding long waiting time to receive analgesia upon admission, particularly in outlying wards or the Emergency Department
- Need for community-based nursing support for the Oxford area

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# REVIEW VISIT FINDINGS

## NETWORK

### GENERAL COMMENTS AND ACHIEVEMENTS

#### Adult Services

The adult network served by OUH is unusual in that the largest numbers of patients are based at Milton Keynes. Other hospitals served by the team at OUH included the Royal Berkshire and Wexham Park Hospitals. Wexham Park had merged with Frimley Park Hospital but there was a considerable distance between the two hospitals and clinicians and patients at Frimley Park Hospital linked with another SHC. The team at OUH provided outreach care and advice for an estimated 200 patients mainly with sickle cell disease. The specialist team had developed a strong vision of how the network care would operate and had made significant changes in a short time frame.

#### Paediatrics

This was the first peer review visit undertaken for the paediatric haemoglobinopathy service at Oxford. However, the adult service had been reviewed previously and a great deal of progress had been made in developing a functioning network, with financial support from specialist commissioning. The Network was planning to employ a data manager who would compile network-wide data.

The majority of patients within the paediatric network were from Milton Keynes, which had previously linked to Imperial College Healthcare NHS Trust for tertiary input. This arrangement was changed shortly before the visit to bring services in line with those in the adult haemoglobin disorders network and in the paediatric oncology network. An outreach service from Oxford had been established at Milton Keynes and the first ever outreach clinic for annual reviews had taken place a few weeks prior to the review. At the time of the visit an outreach transcranial Doppler service was provided by a neurologist from Oxford who used a non-imaging ultrasound technique at a combined clinic. Additionally, well-established links existed between Oxford University Hospital and other local hospitals based on the paediatric oncology shared care arrangements. Outreach services were provided to patients in Royal Berkshire Hospital and Buckinghamshire Healthcare NHS Trust where the lead clinician provided annual reviews to haemoglobinopathy patients in local joint clinics. All transcranial Doppler scans for these patients were undertaken at OUH. A teleconference was held during the visit but a representative from Milton Keynes General Hospital was not able to join the call.

### PROGRESS SINCE LAST VISIT

#### Adult services

A range of positive developments had been implemented since the previous visit which took place in 2013. An additional red cell consultant had been appointed and contributed to the monthly outreach clinics in Milton Keynes, Royal Berkshire and Wexham Park Hospitals. The reviewing team spoke to representatives from the surrounding hospitals. Strong cooperative relationships had been developed and all the clinicians recognised the improvement to the services provided for the haemoglobinopathy patients in the region.

Prior to the review visit a consultant post had been approved for the team at Milton Keynes where the largest population of patients with sickle cell disease resided. The appointee had sessions specifically allocated to the haemoglobinopathy service. The service at Milton Keynes was expected to be further strengthened by additional local clinical nurse specialist support.

**Paediatric Services:** This service had not been reviewed previously.

#### Progress since last visit

- 1 Joint clinics for adult patients had been developed with several hospitals in the network.

- Paediatric haemoglobinopathy services at Milton Keynes had been aligned with the South Central Network and so aligned with adult services and paediatric oncology services. This should improve access to allied specialist services such as surgery and intensive care as well as improving transition to adult services.

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

#### Concerns

- Considerable commissioning and Trust input had been devoted to the development of the adult network. It will be important to ensure that development of the paediatric network is also adequately supported. Owing to the relatively small numbers of patients local to OUH compared to those in the linked Trusts, it will be important to ensure that expertise within the network is strengthened in order to provide high quality in-patient and out-patient care for all children within the network.

#### Further Consideration

- Although funding had been identified for 1.6 w.t.e. specialist nurses to support both the SHC and network hospitals these posts were vacant at the time of the visit.
- Development of network-wide education and psychological support for adult patients would be of benefit.
- Clarification of network referral pathways for both adults and children should be considered.
- Continued improvement in patient registration on the National Haemoglobinopathy Registry (NHR) was needed. At the time of the review only a small percentage of patients were registered.
- Development of network protocols and audits should be considered.
- Network-wide multi-disciplinary team meetings would help to encourage review and learning across the network's teams.

#### NETWORK CONFIGURATION

The network configuration at the time of the review was as follows.

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
Adults: Oxford University Hospitals NHS Foundation Trust : Churchill Hospital	<ul style="list-style-type: none"> <li>Milton Keynes University Hospital NHS Foundation Trust (Milton Keynes General Hospital)</li> <li>Royal Berkshire NHS Foundation Trust (Royal Berkshire Hospital)</li> <li>Frimley Health NHS Foundation Trust (Wexham Park and Frimley Park Hospitals)</li> </ul>
Children and Young People: Oxford University Hospitals NHS Foundation Trust: John Radcliffe Hospital	<ul style="list-style-type: none"> <li>Milton Keynes University Hospital NHS Foundation Trust (Milton Keynes General Hospital)</li> <li>Royal Berkshire NHS Foundation Trust (Royal Berkshire Hospital)</li> <li>Frimley Health NHS Foundation Trust (Wexham Park and Frimley Park Hospitals)</li> <li>Buckinghamshire Healthcare NHS Trust (Stoke Mandeville and Wycombe Hospitals)</li> <li>Great Western Hospitals NHS Foundation Trust (Great Western Hospital)</li> </ul>

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## SPECIALIST TEAM (ADULT SERVICES): CHURCHILL HOSPITAL

### General Comments and Achievements

A highly motivated team provided good care for patients within the Oxford area and had a strong sense of ownership of the care and supervision of care for the larger network. Significant changes had been made in the OUH team since the last peer review visit in February 2013 and the beginnings of a functional network approach to care were in place.

### Progress since Last Visit

- Commissioning support for development of specialist network for the care of people with haemoglobinopathies had been secured.
- Appointment of an additional consultant with an interest in red cell disorders with 4.5 programmed activities
- Funding had been secured for 1.6 w.t.e. specialist nurses for patients with haemoglobinopathies across the region and recruitment for these posts had started
- Funding had been secured for an administrator for the regional haemoglobinopathy service, to assist with entering data onto the National Haemoglobin Registry (NHR) and regional clinic coordination.
- At the last peer review visit the area covered by Milton Keynes General Hospital was identified as requiring specific input and an outreach clinic had been established
- Outreach clinics had been established at Royal Berkshire Hospital and Wexham Park Hospital
- Research activity had started with local opening of an early phase trial in sickle cell disease
- The service had successfully tendered for ongoing work as a National Haemoglobinopathy Reference Laboratory, including clinical support for this work
- Roll out of red cell next-generation sequencing panel for laboratory diagnosis of patients with red cell disorders had been designed by the clinical research fellow.
- The clinico-diagnostic multi-disciplinary team meeting was attended by laboratory and clinical consultants and scientific staff.
- The organisation of first regional education day for non-malignant haematology in the Thames Valley had been organised to include globin disorders and transfusion.

### Good Practice

- 1 A well established, nurse-led triage service provided easy access for patients without the need to attend the Emergency Department.
- 2 An excellent, easily-accessible network website allowed access to guidelines for all clinicians
- 3 Many of the guidelines were written in collaboration with specialists in the relevant disease area

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

### Concerns

- 1 The information available to patients was limited and much of the expected information was not yet available. It was recognised that this should be easily addressed once the appointment of the clinical nurse specialists was made.
- 2 Review and learning multi-disciplinary team meetings were not yet in place at the time of the visit.

## Further Consideration

- 1 The number of patients with thalassaemia across the network was low and a formal arrangement for joint care with a larger centre may be helpful.
- 2 Development of a simple-to-use triage checklist for the nurses running the service, similar in format to the UKONs documentation already used, would be advantageous.
- 3 The transition guidelines required clarification and more practical detail both at OUH and across the network.
- 4 The distribution of haemoglobinopathy patients across the region means that some of the trainees were unlikely to have sufficient exposure to acute management of these patients.
- 5 Access to a psychologist with an interest in haemoglobinopathies.
- 6 The service had not completed all the recommended audits and did not have a rolling plan of audits.

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## SPECIALIST TEAM (PAEDIATRIC SERVICES): JOHN RADCLIFFE HOSPITAL

### General Comments and Achievements

The paediatric haemoglobinopathy service at OUH formed part of a large specialised tertiary hospital with excellent support services and specialist expertise. The haemoglobinopathy clinical lead provided an excellent, dedicated service which was highly valued by patients. Prior to the visit the Trust had forged links with the paediatric haemoglobinopathy service at Milton Keynes where the largest number of patients in the network resided. The inclusion of Milton Keynes within the network had enabled more streamlined links with other specialist services in OUH. The paediatric haemoglobinopathy service demonstrated strong and enthusiastic leadership, with keen aspirations to provide specialist haemoglobinopathy care.

### Good Practice

- 1 The large laboratory service, combining pre-natal, ante-natal and post-natal screening services was the only one of its kind in the UK.
- 2 A strong research base within red cell molecular haematology research laboratories was in place, with advances in diagnostic technologies based on next-generation sequencing.
- 3 An apheresis service with ability to provide emergency red cell apheresis to paediatric patients was available 24 hours a day
- 4 The acute admission care plan was stored in front of clinical notes, allowing easy access for doctors and nurses
- 5 Comprehensive annual review clinic letters included weblinks to charities such as the Sickle Cell Society and the UK Thalassaemia Society.

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

### Concerns

- 1 The low numbers of local patients precluded the steady and progressive development of specialist expertise in the care of children and young people with haemoglobin disorders within the Trust. Measures to enhance the training and development of expertise will be needed, for example by formal collaboration with larger networks or specialist centres. This model has been used in other smaller specialist units in the country.
- 2 The pathway by which affected families were informed of a positive diagnosis was not clear at the time of the review. It was likely that some families were being informed of a positive result by way of a letter or by health visitors not trained in the delivery of such diagnoses.

- 3 Thalassaemia guidelines were not available on the Trust intranet.
- 4 Time to analgesia audit demonstrated that patients were waiting for an unacceptably long time to receive their first dose of analgesia.

#### **Further Consideration**

- 1 The proportion of data manager and clinical nurse specialist time being allocated to the paediatric service was not clear.
- 2 Training of in-patient and accident and emergency nurses and doctors in the care of children with haemoglobinopathies was not taking place.
- 3 Prioritising liaison the commissioners to consolidate the network development should be considered.
- 4 Reviewers suggested that strengthening ties with the adult haemoglobinopathy teams for network development as well as developing specialist expertise should be considered.
- 5 Network-wide participation in research should be considered.

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## **COMMISSIONING**

### **General Comments and Achievements**

The specialised commissioners were highly engaged in the process of developing a functional network-wide service and recognised the need to provide an equitable cross-network service. The resultant developments showed great promise and progress was being closely monitored.

### **Good Practice**

- 1 Strong collaboration between clinicians and commissioners had been effective in driving service improvement.

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

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## APPENDIX 1 MEMBERSHIP OF VISITING TEAM

### Clinical Leads:

Dr Subarna Chakravorty	Consultant Haematologist	Kings College Hospital NHS Foundation Trust
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust

### Visiting Team:

Dr Krishna Kotecha	Consultant Paediatric Oncologist	University Hospitals of Leicester NHS Trust
Natasha Lewis	Specialist Lead Nurse	Homerton University Hospital NHS Foundation Trust
Karen Madgwick	Transfusion Practitioner	North Middlesex University Hospital NHS Trust
Elaine Miller	Co-ordinator	Thalassaemia UK
Dr Srinivasan Narayanan	Consultant Haematologist	University Hospital Southampton NHS Foundation Trust
Dr Shivan Pancham	Consultant Haematologist	Sandwell & West Birmingham Hospitals 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**

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	44	28	64
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	1	33
<b>Total</b>	56	29	52

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	50	26	52
Haemoglobin Disorders Clinical Network	9	2	22
Commissioning	3	2	67
<b>Total</b>	62	30	48

### 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	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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	Information regarding social services could be clearer.	Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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. A description of the condition (SC or T), how it might affect the individual and treatment</li> <li>b. Problems, symptoms and signs for which emergency advice should be sought</li> <li>c. How to manage pain at home (SC only)</li> <li>d. Splenic palpation and Trans-Cranial Doppler scanning (children only)</li> <li>e. Transfusion and iron chelation</li> <li>f. Possible complications, including priapism and complications during pregnancy</li> <li>g. Health promotion, including: <ol style="list-style-type: none"> <li>i. Information on contraception and sexual health</li> <li>ii. Travel advice</li> <li>iii. Vaccination advice</li> <li>iv. Stopping smoking</li> </ol> </li> <li>h. National Haemoglobinopathy Registry, its purpose and benefits</li> <li>i. Self-administration of medications and infusions</li> </ol>	N	Minimal information was available and information for 'e', 'f' or 'g' was insufficient or not available.	Y	The leaflet for thalassaemia was not user friendly but did include all the necessary information.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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>a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC)</li> <li>b. Side effects of medication, including chelator agents [SC and T]</li> <li>c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs).</li> <li>d. Immunisations</li> <li>e. Indications and arrangements for seeking advice from the specialist service</li> </ol>	N	Information on thalassaemia was not available.	N	'b' was not available.
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		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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>School attended</li> <li>Medication, including arrangements for giving / supervising medication by school staff</li> <li>What to do in an emergency whilst in school</li> <li>Arrangements for liaison with the school</li> </ol>	N/A		N	A School Care Plan was not yet agreed for each child or young person.
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>Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer</li> <li>A joint meeting between children's and adult services to plan the transfer</li> <li>A named coordinator for the transfer of care</li> <li>A preparation period prior to transfer</li> <li>Arrangements for monitoring during the time immediately after transfer</li> </ol>	Y	The reviewers did not see information for 'e'.	N	A named coordinator for transfer of care was not identified.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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>	N/A		Y	
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	The small patient population and the small number of patients in the survey limited the opportunities for involvement of patients and carers.	N	'c' was not met.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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		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	A consultant with 4.5 programmed activities for red cell work had been appointed.	Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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>	N	Although funding was identified for 1.6 w.t.e. posts for the network, appointments had not yet been made.	N	An appointment was imminent at the time of the visit.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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	The service did not have a clinical nurse specialist, community nurse or psychologist.	N	Services for 'd', 'e', 'f' and 'g', were not sufficient although access to neurocognitive service was available.
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	Although medical training was evident, nurse training was not provided.	N	A training plan was not yet in place to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-206 SHC	<b>Specialist Advice</b> During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		Y	
HN-207 All	<b>Training for Emergency Department Staff</b> The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	N	Patients were not admitted via the Emergency Department.	N	The service did not offer regular training in the care of patients with haemoglobin disorders.
HN-208 All	<b>Safeguarding Training</b> All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	<b>Doctors in Training</b> 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.	N	Only small numbers of patients were seen in Oxford and some trainees did not rotate to Milton Keynes. Exposure to patients with complex haemoglobinopathy needs was limited.	Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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>	N/A		Y	<p>The neurologist for adult services used portable non-imaging Doppler in Milton Keynes.</p> <p>All Oxford patients had imaging Trans-Cranial Doppler carried out by one radiologist.</p>
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>	N	The administrative assistant was expected to undertake this role once appointed. In the meantime data entry was performed by senior medical staff.	N	A data manager had been appointed and was expected to be in post shortly after the visit.
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	A psychologist with an interest in haemoglobinopathies was not available.	N	A psychologist with an interest in haemoglobinopathies was not available.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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> <ul style="list-style-type: none"> <li>a. Manual exchange transfusion (24/7)</li> <li>b. Acute pain team including specialist monitoring of patients with complex analgesia needs</li> <li>c. Consultant obstetrician with an interest in care of people with haemoglobin disorders</li> <li>d. Respiratory physician with interest in chronic sickle lung disease</li> <li>e. High dependency care, including non-invasive ventilation</li> <li>f. Intensive care (note 2)</li> </ul>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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> <ul style="list-style-type: none"> <li>a. Erythrocytapheresis</li> <li>b. Pulmonary hypertension team</li> <li>c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis</li> <li>d. Consultant cardiologist</li> <li>e. Consultant endocrinologist</li> <li>f. Consultant hepatologist</li> <li>g. Consultant neurologist</li> <li>h. Consultant ophthalmologist</li> <li>i. Consultant nephrologist</li> <li>j. Consultant urologist with expertise in managing priapism and erectile dysfunction</li> <li>k. Orthopaedic service</li> <li>l. Specialist imaging, including <ul style="list-style-type: none"> <li>i. MRI tissue iron quantification of the heart and liver</li> <li>ii. Trans-Cranial Doppler ultrasonography (children)</li> </ul> </li> <li>m. Neuropsychologist</li> <li>n. DNA studies</li> <li>o. Polysomnography and ENT surgery</li> <li>p. Bone marrow transplantation services</li> </ul> <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p>	Y		Y	Although a named consultant was provided for each service they were unlikely to have an appropriate level of specialist expertise, given the low numbers of patients.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-304 All	<b>Laboratory Services</b> UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		Y	
HN-401 All	<b>Facilities Available</b> 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		Y	
HN-402 All	<b>Facilities for Out of Hours Care</b> Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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> <ul style="list-style-type: none"> <li>a. Age guidelines for timing of the transfer</li> <li>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</li> <li>c. Allocation of a named coordinator for the transfer of care</li> <li>d. A preparation period and education programme relating to transfer to adult care</li> <li>e. Communication of clinical information from paediatric to adult services</li> <li>f. Arrangements for monitoring during the time immediately after transfer to adult care</li> <li>g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams</li> </ul>	Y	Guidelines were present but lacked detail of precise processes and 'g' was under development.	Y	However 'c' was not clear.
HN-502 All	<p><b>Monitoring Checklists</b></p> <p>Checklists should be in use for:</p> <ul style="list-style-type: none"> <li>a. First out-patient appointment (SHC &amp; A-LHT only)</li> <li>b. Routine monitoring</li> <li>c. Annual review (SHC &amp; A-LHT only)</li> </ul> <p>Use of the checklists should cover both clinical practice and information for patients and families.</p>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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>	N/A	Plans to develop network-agreed guidelines were in place.	N/A	
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		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-505 All	<p><b>Chelation Therapy</b></p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ul style="list-style-type: none"> <li>a. Indications for chelation therapy</li> <li>b. Choice of chelation drug/s, dosage and dosage adjustment</li> <li>c. Monitoring of haemoglobin levels prior to transfusion</li> <li>d. Management and monitoring of iron overload, including management of chelator side effects</li> <li>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2</li> <li>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.</li> <li>g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.</li> </ul>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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> <ul style="list-style-type: none"> <li>a. Acute pain</li> <li>b. Fever, infection and overwhelming sepsis</li> <li>c. Acute chest syndrome</li> <li>d. Abdominal pain and jaundice</li> <li>e. Acute anaemia</li> <li>f. Stroke and other acute neurological events</li> <li>g. Priapism</li> <li>h. Acute renal failure</li> <li>i. Haematuria</li> <li>j. Acute changes in vision</li> <li>k. Acute splenic sequestration (children only)</li> </ul> <p><b>For patients with thalassaemia:</b></p> <ul style="list-style-type: none"> <li>l. Fever, infection and overwhelming sepsis</li> <li>m. Cardiac, hepatic or endocrine decompensation</li> </ul>	Y		N	'j' was not covered by the guidelines.
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> <ul style="list-style-type: none"> <li>a. During anaesthesia and surgery</li> <li>b. Who are pregnant</li> <li>c. Receiving hydroxycarbamide therapy</li> </ul>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-508 All	<b>Clinical Guidelines: Chronic complications</b> Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: <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	Guidelines varied in the degree of detail. The ophthalmology guideline had very limited detail. Some guidelines were out of date.	N	Network-agreed clinical guidelines on the management of chronic complications were not in use.
HN-509 SHC	<b>Referral for Consideration of Bone Marrow Transplantation</b> Guidelines for referral for consideration of bone marrow transplantation should be in use.	N	Guidelines for referral for consideration of bone marrow transplantation were not yet in use.	Y	
HN-510 All	<b>Thalassaemia Intermedia</b> Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: <ol style="list-style-type: none"> <li>Indications for transfusion</li> <li>Monitoring iron loading</li> <li>Indications for splenectomy</li> </ol>	Y		N	'c' was not present.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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	An excellent haematology and network website was available.	N	Thalassaemia guidelines were not available on the intranet

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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>	N/A		N	The protocol was not seen.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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> <ul style="list-style-type: none"> <li>a. '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>b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission</li> <li>c. Patient discussion at multi-disciplinary team meetings (QS HN-602)</li> <li>d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population</li> <li>e. Arrangements for liaison with community paediatricians and with schools (children's services only)</li> <li>f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated</li> <li>g. Follow up of patients who do not attend</li> <li>h. 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>i. Accessing specialist advice (QS HN-206)</li> <li>j. Two-way communication of patient information between SHC and LHTs</li> <li>k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together</li> </ul>	Y		N	Only 'e' was not covered.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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>	N	Multi-disciplinary team meetings were not held regularly.	N	Minutes of the meetings were not seen and the CNS was not yet in post.
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	Support from community services was not covered by a service level agreement.	N	Support from community services was not covered by a service level agreement.
HN-604 All	<p><b>Network Review and Learning Meetings</b></p> <p>At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).</p>	Y		Y	
HN-605 SHC	<p><b>Neonatal screening programme review meetings</b></p> <p>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.</p>	N/A		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-701 SHC	<p><b>Data Collection</b></p> <p>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.</p>	Y		N	Patient data were not yet all entered onto the National Haemoglobinopathy Registry.
HN-702 All	<p><b>Annual Data Collection - Activity</b></p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> <li>Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances</li> <li>Length of in-patient stays</li> <li>Re-admission rate</li> <li>'Did not attend' rate for out-patient appointments</li> </ol>	Y		N	The review team did not see evidence of annual monitoring for all listed activities.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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 SHC did not monitor network patient data.	N	The SHC did not monitor network patient data for all aspects covered by the Quality Standard.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-704 All	<p><b>Audit</b> 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> <ul style="list-style-type: none"> <li>a. At least 90% of infants with a positive screening result attend a local clinic by three months of age</li> <li>b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age</li> <li>c. Less than 10% of cases on registers lost to follow up within the past year</li> </ul> <p><b>For patients with sickle cell disease:</b></p> <ul style="list-style-type: none"> <li>d. Proportion of patients with recommended immunisations up to date</li> <li>e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required</li> <li>f. 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>g. Availability of extended red cell phenotype in all patients</li> <li>h. Proportion of children: <ul style="list-style-type: none"> <li>i. at risk of stroke who have been offered and/or are on long-term transfusion programmes</li> <li>ii. who have had a stroke</li> </ul> </li> </ul> <p><b>For patients with thalassaemia:</b></p> <ul style="list-style-type: none"> <li>i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505)</li> <li>j. Proportion of patients who have developed new iron-related complications in the preceding 12 months</li> </ul> <p><b>All patients:</b></p> <ul style="list-style-type: none"> <li>k. Waiting times for transfusion</li> </ul>	N	Clinical audits covering all the areas were not available.	N	Clinical audits covering all the areas were not available.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-705 All	<p><b>Guidelines Audit</b></p> <p>The service should have a rolling programme of audit, including:</p> <p>a. Audit of implementation of clinical guidelines (QS HN-500s).</p> <p>b. Participation in agreed network-wide audits.</p>	N	No evidence of network audit was provided.	N	No evidence of network audit was 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		N	The SHC did not actively participate in research relating to the care of patients with haemoglobin disorders.
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> <p>a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512)</p> <p>b. Results of internal quality assurance systems (QS HN-512)</p> <p>c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)</p> <p>d. Results of 'fail-safe' arrangements and any action required</p>	N/A		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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> <p>a. Review of any patient with a serious adverse event or who died</p> <p>b. Review of any patients requiring admission to a critical care facility</p>	N	The service did not have appropriate multi-disciplinary arrangements for review and learning.	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		Y	

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## HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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	Evidence of compliance was not available.	N	Evidence for involving patients and their carers from all services in the work of the network was not available.
HY-201	<p><b>Network Leads</b></p> <p>The network should have a nominated:</p> <ul style="list-style-type: none"> <li>a. Lead consultant and deputy</li> <li>b. Lead specialist nurse for acute care</li> <li>c. Lead specialist nurse for community services</li> <li>d. Lead manager</li> <li>e. Lead for service improvement</li> <li>f. Lead for audit</li> <li>g. Lead commissioner</li> </ul>	N	Network leads were not yet identified	N	Network leads were not yet identified.
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	An education and training programme was not yet in place.	Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-501	<p><b>Transition Guidelines</b></p> <p>Network guidelines on transition to adult care should have been agreed covering:</p> <ul style="list-style-type: none"> <li>a. Age guidelines for timing of the transfer</li> <li>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</li> <li>c. Allocation of a named coordinator for the transfer of care</li> <li>d. Communication of clinical information from paediatric to adult services</li> <li>e. Arrangements for monitoring during the time immediately after transfer to adult care</li> <li>f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable)</li> </ul> <p>Guidelines should be explicit about transition directly to any accredited LHTs.</p>	N	Oxford University Hospitals NHS Foundation Trust transition guidance was available but it was not network-wide.	N	Oxford University Hospitals NHS Foundation Trust transition guidance was available but it was not network-wide.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-502	<p><b>Clinical Guidelines</b></p> <p>Network guidelines should have been agreed covering:</p> <ul style="list-style-type: none"> <li>a. Annual review (QS HN-502)</li> <li>b. Routine monitoring (QS HN-503)</li> <li>c. Transfusion (QS HN-504)</li> <li>d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505)</li> <li>e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303)</li> <li>f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303)</li> <li>g. Specialist management (QS HN-507)</li> <li>h. Thalassaemia intermedia (QS HN-510)</li> </ul> <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	Network guidelines were not yet in place.	N	Network guidelines were not yet in place.
HY-701	<p><b>Ongoing Monitoring</b></p> <p>The network should monitor on a regular basis:</p> <ul style="list-style-type: none"> <li>a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701)</li> <li>b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.</li> </ul>	N	Ongoing monitoring was not yet undertaken.	N	Ongoing monitoring was not yet undertaken.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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	An agreed network programme of audit was not yet in place.	N	An agreed network programme of audit was not yet in place.
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	Haematologists were involved in research but a network policy on research was not yet in place.	N	Haematologists were involved in research but a network policy on research was not yet in place.
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	Network review and learning meetings were not yet in place.	Y	

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## COMMISSIONING

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	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> <ul style="list-style-type: none"> <li>a. Designated SHC/s for the care of people with sickle cell disease</li> <li>b. Designated SHC/s for the care of adults with thalassaemia</li> <li>c. Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia</li> <li>d. Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia</li> <li>e. Community care providers</li> </ul>	Y		Y	
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	Regular clinical quality review meetings for services for people with haemoglobin disorders were not yet in place.	N	Regular clinical quality review meetings for services for people with haemoglobin disorders were not yet in place.

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		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
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	Regular network review and learning meetings were not yet in place.	Y	

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