

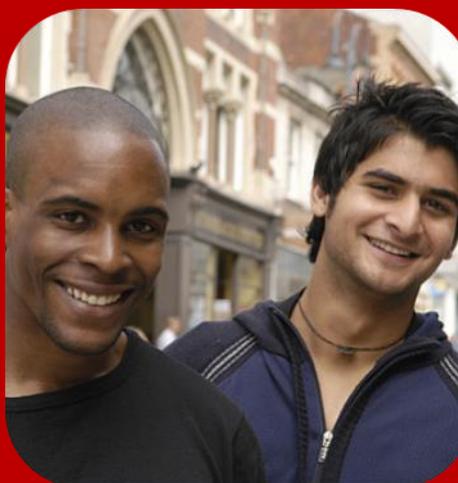
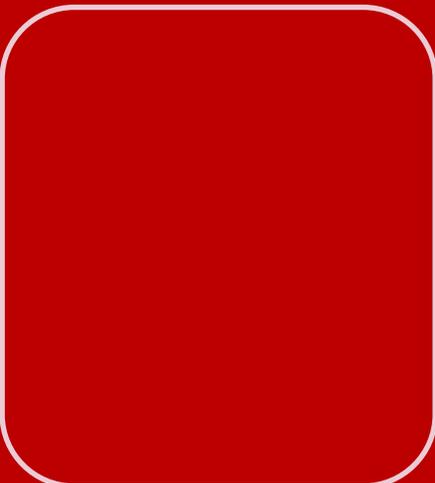
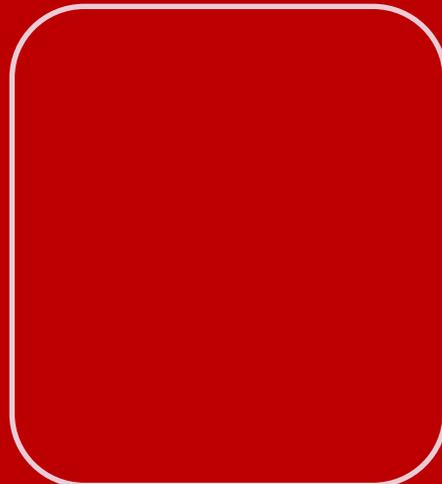
# Health Services for People with Haemoglobin Disorders

## Yorkshire Network

### Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Children's NHS Foundation Trust

Visit Date: 26th March 2015

Report Date: July 2015



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## INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Sheffield Children's NHS Foundation Trust and Sheffield Teaching Hospitals NHS Foundation Trust (part of the Yorkshire Network), which took place on 26<sup>th</sup> March 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 Midlands 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:

- Sheffield Children's NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- NHS England Specialised Commissioning
- Sheffield 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 both Trusts 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 was set up as a collaborative venture by 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 YORKSHIRE NETWORK

Sheffield Children's NHS Foundation Trust and Sheffield Teaching Hospitals NHS Foundation Trust were part of the Yorkshire Network and were both commissioned as Specialist Haemoglobinopathy Centres.

### ADULTS

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long-term red cell transfusions
Sheffield Teaching Hospitals NHS Foundation Trust (Royal Hallamshire Hospital)	SHC	86	13	13
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	LHT	<5	0	0
Hull and East Yorkshire Hospitals NHS Trust	LHT	6	0	0

### 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
Sheffield Children's NHS Foundation Trust (Sheffield Children's Hospital)	SHC	60	15	11
Northern Lincolnshire and Goole NHS Foundation Trust	LHT	<5	<5	0
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	LHT	8	<5 (but transfused in Sheffield Children's Hospital)	0
Barnsley Hospital NHS Foundation Trust	LHT	<5	0	0

Chesterfield Royal Hospital NHS Foundation Trust and United Lincolnshire Hospitals NHS Trust were identified as linked hospitals, but no children with haemoglobin disorders from these hospitals were known to the services at the time of the review.

### ADULT SERVICES – ROYAL HALLAMSHIRE HOSPITAL

#### EMERGENCY CARE

Adult patients with acute complications had direct access to the haematology in-patient wards and day unit. Patients were encouraged to attend the day unit within working hours (8am to 8pm) Monday to Friday and on Saturday (8am to 4pm). At other times patients contacted the ward directly for admission. Patients who attended the day unit during working hours with acute pain were assessed by haematology medical staff. Analgesia was administered either in the day unit or on the ward.

Initial out of hours assessments were carried out by the senior house officer (SHO) who was part of the 'Hospital at Night' team. The non-resident on-call haematology Specialist Registrar was available for advice. Patients not reviewed during the night by a senior haematology decision-maker were reviewed the next morning.

Occasionally patients attended the Emergency Department at the Trust's Northern General Hospital where they were triaged as urgent, given an initial dose of analgesia and then transferred to a haematology bed. During working hours they could be reviewed by the haematology liaison team at the Northern General Hospital.

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

P3 and P4 were dedicated adult haematology wards, but there was also access to up to 14 beds on ward O2 (shared with rheumatology, oncology and haematology). Patients were generally admitted to P3, which included facilities for the treatment of young adults. Patients were admitted under the 'green team', which consisted of two consultant haematologists who worked an alternate monthly attending system supervising the in-patient facility, haematology Specialist Registrars and SHOs.

Medical cover for the haematology wards was provided by a ward-based SHO between 9am and 9pm. The covering haematology Specialist Registrar was normally on the ward until 8pm to 9pm. After 9pm resident cover was provided by the Hospital at Night team, who were encouraged to contact the non-resident haematology Specialist Registrar for advice relating to patients with haemoglobinopathy disorders. Haematology consultants worked a one in six on-call rota. At weekends and bank holidays daily consultant-led ward rounds took place.

Automated erythrocytapheresis was available 24 hours a day, and out of hours vascular access could be arranged by either the intensivists or the on-call vascular radiologists.

#### **DAY CARE**

Adult day care took place on ward O2 where there were also facilities for teenagers and young adults. Service provided included:

- Automated red cell exchange transfusions within the apheresis unit run by NHS Blood and Transplant (NHSBT)
- Blood transfusions, which could be administered up to 8pm on weekdays and from 8am to 4pm on Saturdays
- Blood tests
- Urgent or planned clinical review
- Urgent management of acute pain crises and other complications

The unit was staffed by a nursing team, led by a senior nurse, and three medical staff.

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

Adult haemoglobinopathy clinics were run on alternate Monday afternoons in the medical out-patient department. They were attended by the lead consultant, the Specialist Registrar, the haemoglobinopathy nurse specialist and the community nurse. The community nurse operated a text reminder service for patients due to attend, and followed up those patients who failed to attend. Annual reviews were carried out at these clinics.

#### **COMMUNITY BASED CARE**

The long-standing lottery-funded support group had stopped functioning, but a new thalassaemia support group had been launched in March 2015 and there were plans to start a new sickle cell support group.

## **CHILDREN AND YOUNG PEOPLE – SHEFFIELD CHILDREN’S HOSPITAL**

### **EMERGENCY CARE**

All children and young people with haemoglobin disorders had direct access to the haematology/oncology ward, and all patients were given written and verbal instructions on how to access help and care via the clinical staff and the dedicated ward. The majority of patients therefore did not have to access the Emergency Department (ED). If patients did attend the ED they were triaged as urgent, and the necessary care was given whilst the haematology team was contacted. Patients were then transferred to the haematology ward for further management as appropriate. If a child presented with a problem unconnected to their haemoglobinopathy disorder, the alert section of the notes instructed the admitting team to contact the haematology team for appropriate haemoglobinopathy management advice.

Children and young people who lived close to a linked hospital sometimes chose to go to their local hospital for emergency care. Local hospitals had access to shared care guidelines, which included instructions to contact Sheffield Children’s NHS Foundation Trust to discuss any haemoglobinopathy patients. The local paediatrician was sent copies of letters of all attendances at Sheffield Children’s NHS Foundation Trust, and parents were also given copies of correspondence to act as a patient/carer record and care plan.

### **IN-PATIENT CARE**

M3 was the dedicated paediatric haematology/oncology ward and had 14 in-patient beds. A dedicated school room and a play room with play specialists were located in close proximity to the ward, to allow children to attend school whilst undergoing treatment. The hospital school liaised with local schools in order to provide continuity of education and ensure that children were marked present if they attended school in hospital. The ward served all haematology, haemoglobinopathy, haemostasis and thrombosis patients. The Research and Medical Treatment Lounge (RMTL) took planned transfusion patients if there was no availability on M3.

Haemoglobinopathy patients who required urgent treatment were admitted directly to an in-patient bed and were reviewed by the on-call junior paediatric haematology doctor. The lead clinician or deputy lead undertook daily ward rounds. When neither haemoglobinopathy consultant was available, the remaining two paediatric haematologists provided cover. Paediatric haematology consultant cover was provided 24/7 by a one in four rota for benign haematology, and patients had direct access to the consultants during normal working hours. The direct patient access was available to all haemophilia and haemoglobinopathy patients. An acute pain team provided clinical oversight for all patient-controlled analgesia and provided consultative support to patients with complex pain issues.

### **DAY CARE**

Four dedicated day beds were located within the M3 in-patient ward space and were also used as overnight beds for resident parents. Although physically situated between in-patient bed spaces, the day beds were reserved for day care patients and would only rarely be deployed as in-patient beds. The day beds were open until 8 pm on weekdays, and Saturday transfusions were available on request. The number of nurses competent in cannulation and phlebotomy had increased since the last review, and the recently-established hospital-wide phlebotomy and cannulation team was available for expert help in cannulation if necessary (after three unsuccessful attempts).

### **OUT-PATIENT CARE**

A range of clinics took place in the paediatric out-patient area, including a weekly haemoglobinopathy clinic, a weekly general haematology clinic and a review clinic for unplanned cases on a Friday morning.

A dedicated haematology/oncology clinic, with blood-taking facilities in the same area, was used for routine clinics and unplanned reviews. The community nurse specialist attended clinics and visited patients when they were admitted to the wards.

## **COMMUNITY BASED CARE**

Paediatric community based care was provided by the haemoglobinopathy nurse counsellor, haematology nurse consultant and nurse specialist. The community nurse specialist attended some schools to provide support with school care plans and training, and had well-established communication links with schools that she was unable to visit. Community support by the Children's Hospital team was not provided to children who lived outside Sheffield, although contact would be made with these children when they were admitted to hospital or attended clinics. Community nursing services outside Sheffield also provided help with establishing school care plans.

Her role also included work relating to the neonatal and antenatal screening programmes.

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

The visiting team met a large number of patients and carers with both sickle cell and thalassaemia, and received feedback from them. They also reviewed responses to 16 patient questionnaires relating to the adult service and 25 questionnaires for the paediatric service.

Common themes raised by patients and carers were:

### **Adult service**

- Very positive feedback about the lead clinician and nursing team
- High satisfaction with the good access to Wards P3/P4, the frequency of out-patient clinics and the referral to other experts to monitor complications
- Concerns that, outside the haemoglobinopathy team, medical and nursing staff were not well informed about sickle cell disease
- Concerns about long waits for blood transfusion in the day unit (over two hours) and for analgesia in the Emergency Department
- Patients feeling like 'second class citizens' and feeling that the oncology patients received preferential treatment
- Transition was difficult and patients did not feel well supported
- Lack of staff availability to support care of portacaths
- A perception that some staff were very busy and did not have time either to understand their condition or to receive feedback or complaints, which were sometimes misinterpreted

### **Paediatric service**

- A great deal of satisfaction with the service provided by the clinical team
- Concerns regarding waiting time to analgesia, particularly in the Emergency Department (ED), and an apparent lack of knowledge in the ED about the urgency of providing analgesia at the time of crisis
- Lack of school care plans
- A perceived reduction in the clinical priority given by non-specialist nursing staff in comparison with that provided for oncology patients

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# REVIEW VISIT FINDINGS

## NETWORK

### General Comments and Achievements

The Network consisted of three specialist centres (Leeds, Sheffield and Bradford), with services commissioned by specialist commissioners. Leeds and Sheffield were meeting the majority of requirements for specialist centres, and offered numerous specialist services. All three hospitals acted as hubs for a number of local hospitals, providing clinical support and guidelines and offering annual review clinics. The adult services were aware of the majority of haemoglobinopathy patients in the region and offered annual review appointments. Local haemoglobinopathy services had access to the guidelines from Leeds or Sheffield (depending on location), were able to call these centres for clinical advice and referred patients for annual review to one of them. Formal network arrangements were not yet in place for the paediatric services but most patients attended the nearest specialist centre for review.

### Progress since Last Visit

Whilst the Yorkshire Network did not meet many of the network standards, for example network education and training or network data collection, there was evidence of good informal working networks with the local haemoglobinopathy centres which had developed since the previous peer review visits. This had been achieved largely through the endeavour of the Clinical Leads at Sheffield and Leeds. A small number of meetings between the three centres had taken place over the 12 months before the review. These meetings had been co-ordinated by the commissioners. Business meetings were taking place between the major centres in Yorkshire to plan the way forward.

### Good Practice

- 1 Since January 2015 NHS Blood and Transplant had provided a 24 hour apheresis service for the whole of Yorkshire. This was a mobile service which travelled to anywhere in the region if required.

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

### Concerns

- 1 The service at Bradford was not providing several elements of a specialist service.
- 2 The majority of network standards were not met at the time of the review visit.

### Further Consideration

- 1 The services at Sheffield and Leeds both provided strong leadership for their own service and for their local hospitals. With relatively little support from commissioners or Trust managers the network standards could be met which should lead to improvements in the quality of care across the whole region. This could include provision of:
  - a. Network involvement of patients and carers
  - b. Network programme of education and training
  - c. Development of network guidelines (the majority of guidelines had already been developed by Sheffield/Leeds and would need only minor modifications to be suitable for use across the network)
  - d. Data collection on network outcomes
  - e. Collation of network audits
  - f. Network review and learning events.

- 2 Both The Leeds Teaching Hospitals NHS Trust and Sheffield Teaching Hospitals NHS Foundation Trust had set up informal arrangements for supporting their local haemoglobinopathy units, including providing them with guidelines and clinical advice. Reviewers suggested that commissioners should consider reviewing the specialist centre status of their hospitals, utilising the outcomes of the peer review reports. In particular, reviewers suggested that the service at Bradford should consider working with one of the other specialist centres to ensure that all patients have access to specialist care.
- 3 Northern Lincolnshire and Goole NHS Foundation Trust were reported as linking with specialist centres at both Leeds (for adults) and Sheffield (for children and young people). The network may wish to consider the benefits of patients from this Trust linking with a single centre, especially to improve the process of transition to adult care.

## NETWORK CONFIGURATION

The network configuration at the time of the review was as follows. The network had no Accredited Local Haemoglobinopathy Teams.

Specialist Haemoglobinopathy Centres	Local Haemoglobinopathy Teams
<ul style="list-style-type: none"> <li>Sheffield Teaching Hospitals NHS Foundation Trust (Royal Hallamshire Hospital)</li> <li>Sheffield Children's NHS Foundation Trust</li> </ul>	<ul style="list-style-type: none"> <li>Doncaster and Bassetlaw Hospitals NHS Foundation Trust</li> <li>Barnsley Hospital NHS Foundation Trust</li> <li>Chesterfield Royal Hospital NHS Foundation Trust</li> <li>The Rotherham NHS Foundation Trust</li> <li>Hull and East Yorkshire Hospitals NHS Trust</li> <li>Northern Lincolnshire and Goole NHS Foundation Trust</li> <li>United Lincolnshire Hospitals NHS Trust (Lincoln County Hospital and Pilgrim Hospital Boston)</li> </ul>
<ul style="list-style-type: none"> <li>Leeds Teaching Hospitals NHS Trust (St James's University Hospital)</li> </ul>	<ul style="list-style-type: none"> <li>York Teaching Hospital NHS Foundation Trust</li> <li>Harrogate and District NHS Foundation Trust</li> <li>Calderdale and Huddersfield NHS Foundation Trust</li> <li>The Mid Yorkshire Hospitals NHS Trust (Pinderfields Hospital and Dewsbury and District Hospital)</li> <li>Northern Lincolnshire and Goole NHS Foundation Trust</li> <li></li> </ul>
<ul style="list-style-type: none"> <li>Bradford Teaching Hospitals NHS Foundation Trust (Bradford Royal Infirmary, St Luke's Hospital)</li> </ul>	<ul style="list-style-type: none"> <li>Airedale NHS Foundation Trust<sup>1</sup></li> </ul>

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<sup>1</sup> No information on links for Airedale NHS Foundation Trust was available. This Trust has been linked with Bradford Teaching Hospitals NHS Foundation Trust because of the shared consultant haematologist rota.

## SPECIALIST TEAM (ADULT SERVICES): SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST

### General Comments and Achievements

This service provided care of a high quality. Clinical leadership was strong and patient feedback about the clinical team was very positive.

### Progress since Last Visit

Some good progress had been made since the previous review (March 2012), including the establishment of annual reviews (previously raised as a concern) and data entry onto the National Haemoglobinopathy Registry (NHR). The service had also secured further data management support to increase the amount of data entered onto the NHR.

More guidelines and protocols were in place and a 0.5 w.t.e haemoglobinopathy clinical nurse specialist had been appointed. Haematology Specialist Registrars attended the haemoglobinopathy clinics regularly during their training, and joint multi-disciplinary team meetings had been established with Sheffield Children's NHS Foundation Trust. MRI liver iron quantification had also become available locally.

### Good Practice

- 1 A high quality analgesia service was in place, with close liaison between the haemoglobinopathy team and the palliative care team for both in-patients and out-patients. Patient feedback about the service was excellent. Reviewers were particularly impressed with the close follow-up of patients discharged on opiates to supervised dose reduction.
- 2 The checklist for new patients and the annual review proforma were comprehensive. The proforma could be of use to other centres to help ensure consistent NHR data collection, as it was based on the database fields.
- 3 A 24 hour apheresis service was in place across Yorkshire, provided by NHS Blood and Transplant (NHSBT).

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

### Concerns

- 1 The service did not have support from a psychologist with an interest in haemoglobin disorders. Access to generic psychology services was poor, with long waiting times reported. There was also a lack of specialist knowledge within the generic psychology service. At the time of the visit the Trust was trying to gain funding for a specialist psychologist and a counsellor to support the service.
- 2 Time taken to provide initial analgesia on the wards was outside recommended NICE guidance. The NICE audit showed that initial pain relief had been administered within the required 30 minute timescale in 50% of cases. Patients also reported experiencing long waits, often in excess of one hour, for transfusion therapy on the day unit.
- 3 Some staff were not up to date with mandatory safeguarding training.
- 4 Whilst the nursing team provided a good service and a new member of staff had recently been appointed, nursing support was a concern for two reasons:
  - a. The community nurse was employed by the Sheffield Children's NHS Foundation Trust, and did not have a formal contract or time in her job plan for the support of adult patients. She provided in-patient and out-patient support that was highly rated by the patients interviewed. There was no cover available for her absences. This had been raised as a concern in the previous visit and the situation had not changed.

- b. Arrangements for the formal training of nursing staff on the wards and day unit was sporadic. This was part of the job plan for the recently appointed clinical nurse specialist.

#### **Further Consideration**

- 1 Transition services were not yet well established. New patient leaflets and guidelines had been produced shortly before the review but were not yet in consistent use. Reviewers were also told about patients' dissatisfaction with the transition process.
- 2 Evaluation of liver iron loading was being performed by an un-validated MRI methodology. Reviewers suggested that further expert opinion should be sought on this.
- 3 Whilst some of the patient information was of high quality, reviewers suggested that it could be more comprehensive for topics such as transfusion and iron chelation. The majority of patient information seen by reviewers was contained on the Trust intranet, so it was not clear how accessible the information was for patients.
- 4 Regular training in the care of patients with haemoglobin disorders did not take place for Emergency Department (ED) staff. A virtual training package was available but staff were not using it. The number of patients attending the ED was, however, low (11 patients in the 12 months before the review), a comprehensive protocol was available on the intranet and ED staff were aware of this protocol.
- 5 The majority of guidelines were comprehensive but a few guidelines for the management of thalassaemia were not yet in place.
- 6 The service had not yet completed all the recommended audits and did not have a rolling plan of audits.

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## **SPECIALIST TEAM (PAEDIATRIC SERVICES): SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST**

#### **General Comments and Achievements**

The paediatric haemoglobinopathy service provided high quality tertiary care to patients and was greatly valued by patients and carers. The clinical leadership was strong and responsive to local needs.

The service was in the process of increasing the quantity of patient and carer information available and of providing more information for older teenagers. In 2014 a 'Next Steps' transition event and a 'Staying Positive' expert patient event had been held.

#### **Progress since Last Visit**

The service had previously been reviewed in March 2010. A concern that was raised at that time was the loss of the clinical nurse specialist. The service had subsequently secured funding for a part-time permanent haematology nurse specialist who covered benign haematology, including haemophilia. Her caseload included 200 haemophilia patients. Joint multi-disciplinary team meetings had been established with Sheffield Teaching Hospitals NHS Foundation Trust, and the Trust was working on the development of improved communication between hospital and community paediatric and adult teams. There was 24/7 direct access to paediatric haematology consultant advice. Dietetic and psychological input was available to the team. Ferriscan and T2\*MRI had also become available on site.

#### **Good Practice**

- 1 Excellent clinical documentation was in place, including comprehensive clinic letters, letters to parents from the lead clinician following a first visit to clinic, and letters to parents from the community nurse specialist following a first visit to a family with a newborn child affected with a significant haemoglobinopathy.
- 2 A 24 hour apheresis service was in place across Yorkshire, provided by NHS Blood and Transplant (NHSBT).

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

#### Concerns

- 1 Staff in the Emergency Department (ED) had not received training on the management of children with haemoglobin disorders. The patient group who met reviewers raised concerns about long waiting times to analgesia. No clear pathway of care was in place in the ED.
- 2 Time taken to provide initial analgesia on the wards was outside recommended NICE guidance. An audit showed that initial pain relief had been administered within the required 30 minute timescale in 46% of cases.
- 3 Data collection support was insufficient and annual reviews were not being entered onto the National Haemoglobinopathy Registry (NHR). The consultant entered patient registrations onto the NHR. Activity data were not collected in a routine manner.
- 4 Whilst the nursing team provided a good service and a new member of staff had recently been appointed, nursing support was a concern for a number of reasons:
  - a. No cover for absences of the community nurse was available.
  - b. Formal training of nursing staff on the wards and in the day unit was sporadic. This was part of the job plan for the recently appointed clinical nurse specialist.

#### Further Consideration

- 1 An operational policy was not in place at the time of review, although the evidence folders contained data to support the clinical pathways that were in place.
- 2 Whilst some of the patient information was of high quality, reviewers suggested that it could be more comprehensive about how to get involved in improving services and how to access some areas of support.
- 3 Transition services were not yet well established. Patients expressed dissatisfaction with the transition process and the care provided to 16 to 19 year olds appeared inconsistent in different areas of the Trust.
- 4 The service had not completed all the recommended audits and did not have a rolling plan of audits.
- 5 Succession planning for the imminent departure of the paediatric matron had not been undertaken and may be helpful.

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## COMMISSIONING

#### Progress since Last Visit

At the time of the previous visit (March 2012) the specialist commissioning group had not been commissioning tertiary level services for people with haemoglobin disorders due to problems with counting and coding activity. Progress had been made and the three Trusts were commissioned as specialist haemoglobinopathy centres. Work to develop the network was ongoing.

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

#### Concerns

- 1 Commissioners did not meet any of the expected Quality Standards. The configuration of clinical networks had not been formally agreed. There was no regular review of the quality of care provided by the services.
- 2 Additional issues requiring commissioners' attention are included in the network section of this report. Issues identified in the Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Children's NHS

Foundation Trust sections of this report will also require commissioner monitoring and support to ensure they are addressed.

#### **Further Consideration**

- 1 Reviewers also suggested that commissioners work with their specialist centres to formalise the relationships between specialist and local centres and support the specialist centres to collect network activity data.

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## APPENDIX 1 MEMBERSHIP OF VISITING TEAM

### Clinical Lead/s:

Dr Subarna Chakravorty	Consultant Paediatric Haematologist	Imperial College Healthcare NHS Trust
Dr Jo Howard	Consultant Haematologist	Guy's and St Thomas' NHS Foundation Trust

### Visiting Team:

Dr Marie Donohue	Consultant Haematologist	Nottingham University Hospitals NHS Trust
Beryl Douglas Green	Clinical Nurse Specialist Haemoglobin Disorders	University Hospitals Coventry & Warwickshire NHS Trust
Hazel Marriot	Sickle Cell and Thalassaemia Nurse Specialist	Nottingham University Hospitals NHS Trust
Dr Shivan Pancham	Consultant Haematologist	Sandwell & West Birmingham Hospitals NHS Trust
Dr Christos Sotirelis	Service User	

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## APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varies depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but', where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

**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	25	57
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
<b>Total</b>	<b>56</b>	<b>25</b>	<b>45</b>
Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	49	36	73
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
<b>Total</b>	<b>61</b>	<b>36</b>	<b>59</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	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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>Brief description of the service, including times of phlebotomy, transfusion and psychological support services</li> <li>Clinic times and how to change an appointment</li> <li>Ward usually admitted to and its visiting times</li> <li>Staff of the service</li> <li>Community services and their contact numbers</li> <li>Relevant national organisations and local support groups</li> <li>Where to go in an emergency</li> <li>How to: <ol style="list-style-type: none"> <li>Contact the service for help and advice, including out of hours</li> <li>Access social services</li> <li>Access benefits and immigration advice</li> <li>Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent)</li> <li>Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns</li> <li>Get involved in improving services (QS HN-199)</li> </ol> </li> </ol>	Y	<p>Information was available but could be more widely circulated. Not all patients were aware of information relating to point 'h (vi)'. Information for contacting HealthWatch could be clearer.</p>	N	<p>Information for points 'h (ii) – (iv)' and 'h(vi)' was not in place. See main report.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	<p>Information for 'a' was limited to general screening programme information for patients with sickle cell disease. Limited information was available for 'b'. Other information was available.</p> <p>See main report.</p>	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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 hydroxycarbamide was available.	Y	
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	There was no plan for management in the Emergency Department but a standard protocol was used.	Y	Clinic letters were comprehensive and covered all aspects of this QS. There was no plan for management in the Emergency Department but a standard protocol was used.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	<p>A proforma was in place but did not cover all aspects of the Quality Standard ('a' and 'c').</p> <p>The community nurse had good contacts in all schools attended by children or young people with a haemoglobin disorder.</p>
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>	N	<p>A draft leaflet was available but it was not clear if this was routinely used.</p> <p>See main report.</p>	Y	<p>A leaflet was available (also in an 'easy read' format) but this did not appear to link up with information from the adult service.</p> <p>See main report.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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> <ul style="list-style-type: none"> <li>a. Reason for the scan and information about the procedure</li> <li>b. Details of where and when the scan will take place and how to change an appointment</li> <li>c. Staff who will be present and will perform the scan</li> <li>d. Any side effects</li> <li>e. Informing staff if the child is unwell or has been unwell in the last week</li> <li>f. How, when and by whom results will be communicated</li> </ul>	N/A		Y	Information for 'c' could be clearer.
HN-199 All	<p><b>Involving Patients and Carers</b></p> <p>The service's involvement of patients and carers should include:</p> <ul style="list-style-type: none"> <li>a. Mechanisms for receiving feedback from patients and carers</li> <li>b. An annual patient survey (or equivalent)</li> <li>c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service</li> <li>d. Examples of changes made as a result of feedback and involvement of patients and carers</li> </ul>	N	It was not clear how the service involved patients and carers in decisions about the organisation of the service ('c'). There were no examples of any changes made as a result of patient feedback.	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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> <ul style="list-style-type: none"> <li>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders</li> <li>b. Responsibility for liaison with other services within the network</li> <li>c. RCN competences in caring for people with haemoglobin disorders</li> <li>d. Competences in the care of children and young people (children's services only)</li> </ul>	N	RCN competences were not yet documented but the nurse had received training in the care of people with haemoglobinopathies.	N	RCN competences were not yet documented but the nurse had received training in the care of people with haemoglobinopathies.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	<p>There was no cover available for the community nurses ('e'), or access to a psychologist with an interest in haemoglobin disorders ('g').</p> <p>A good induction book for nurses was available.</p>	N	<p>There was no cover available for the community nurses ('e').</p>
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	<p>A training plan was not in place at the time of the review.</p>	N	<p>Although a training plan was in place it did not cover all staff.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	A virtual learning package was available but staff were not accessing it. Training was not included in the induction programme. The number of haemoglobinopathy patients using the ED was very low. There was good access to protocols.	N	Emergency Department (ED) staff had declined the available training. There were few admissions via the ED but patients were critical of the service received when using the ED. See main report.
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	N	Some staff were not up to date with safeguarding training. See main report.	N	This was part of mandatory training. One clinical nurse specialist was compliant but it was not clear if other staff were up to date with relevant training.
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.	Y	Doctors received training in out-patient and in-patient care.	Y	Training was in place but some junior doctors appeared not to be aware of the available guidelines.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	
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	Support was available two days per week.	N	Insufficient data support was available. See main report.
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	There was no access to a psychologist with an interest in haemoglobinopathies, and access to generic psychology services was poor.	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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 Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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>	N	There was no access to neuropsychology ('m'). Access to erythrocytapheresis was very good. Trust physicists had developed a local R2 process which was in use for liver iron measurement but this had not yet been validated ('l (i)').	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	The day unit was often very busy, resulting in reported waits for blood transfusions of one to two hours. See main report.	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	Out of hours care was available until 8pm on weekdays and on Saturdays. Transfusions were also available although sometimes these were fully booked.	Y	Out of hours care was available until 8pm during the week. Staff were happy to provide transfusions on a Saturday but none had been requested for some time.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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>	N	The guidelines were mostly in draft form and it was not clear if they were routinely being used. The question and answer sheet was very good.	Y	
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	New patient and annual review proformas were particularly good. See main report.	Y	Letters from the first patient appointment and from the community nurse were excellent and covered all aspects of the standard. See main report.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	The service was commissioned as an SHC.	N/A	The service was commissioned as an SHC.
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 thalassaemia guidelines were not as clear as those for sickle cell disease and there was a lack of clarity on how they were implemented. The thalassaemia guidelines were dated January 2013. See main report.	Y	Guidelines were comprehensive. See main report.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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>	N	There was no information for point 'g'. Point 'f' was not applicable to the service.	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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>	N	Guidelines did not cover 'l' or 'm'.	Y	Some guidelines were awaiting Trust approval but all were very detailed.
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	Thalassaemia management guidelines required updating in line with new Royal College Of Obstetricians and Gynaecologists guidance.	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
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> <ul style="list-style-type: none"> <li>a. Renal disease</li> <li>b. Orthopaedic problems</li> <li>c. Retinopathy</li> <li>d. Cardiological complications / pulmonary hypertension</li> <li>e. Chronic respiratory disease</li> <li>f. Endocrinopathies</li> <li>g. Neurological complications</li> <li>h. Chronic pain</li> <li>i. Liver disease</li> <li>j. Growth delay / delayed puberty (children only)</li> <li>k. Enuresis (children only)</li> </ul>	N	<p>The guidelines did not cover complications for thalassaemia. Guidelines for sickle cell disease did not cover 'e' or 'f'. See main report.</p>	Y	Guidelines were comprehensive.
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		Y	
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> <ul style="list-style-type: none"> <li>a. Indications for transfusion</li> <li>b. Monitoring iron loading</li> <li>c. Indications for splenectomy</li> </ul>	Y		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-511 All	<b>Clinical Guideline Availability</b> Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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		Y	<p>No specific written policy was available but all aspects were included in other documents.</p> <p>See main report.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-602 All	<b>Multi-Disciplinary Meetings</b> 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).	Y		Y	
HN-603 All	<b>Service Level Agreement with Community Services</b> A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N	No service level agreement was in place regarding the community nurse who was employed by Sheffield Children's NHS Foundation Trust.	N/A	The community nurse was employed by Sheffield Children's NHS Foundation Trust.
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	Review and learning meetings were in place between the adult and paediatric services but not at a network level. Network-wide business meetings were in place. See main report.	N	Review and learning meetings were in place between the adult and paediatric services but not at a network level. Benign haematology multi-disciplinary meetings were in place. Network-wide business meetings were in place. See main report.
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.	N/A		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	Patient information and annual reviews and other data were systematically entered on the NHR.	N	Insufficient data collection support was available. The consultant entered data onto the NHR. See main report.
HN-702 All	<p><b>Annual Data Collection - Activity</b></p> <p>The service should monitor on an annual basis:</p> <ul style="list-style-type: none"> <li>a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances</li> <li>b. Length of in-patient stays</li> <li>c. Re-admission rate</li> <li>d. 'Did not attend' rate for out-patient appointments</li> </ul>	Y		N	The service had data for the previous year but these data were not routinely monitored or used in service development.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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>	Y	All data were available for the South Yorkshire area.	Y	All data were available for the South Yorkshire area.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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> <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> </ol> <p>h. Proportion of children:</p> <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> <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	<p>Audits did not cover 'c', 'h'-i' and 'j'-k'.</p> <p>The audit for 'f' showed that initial pain relief had been administered within the required 30 minute timescale in 50% of cases.</p> <p>'a' and 'b' were not applicable.</p> <p>Penicillin ('e') was not routinely administered by the service.</p> <p>See main report.</p>	N	<p>Audits did not cover 'd', 'i', 'j' or 'k'.</p> <p>Audits for 'a' – 'c', 'e' – 'h' had been undertaken.</p> <p>The audit for 'f' showed that initial pain relief had been administered within the required 30 minute timescale in 46% of cases.</p> <p>See main report.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-705 All	<b>Guidelines Audit</b> The service should have a rolling programme of audit, including: <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	No audit had taken place.	N	No audit had taken place.
HN-706 SHC	<b>Research</b> The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		Y	The centre participated in a drug trial and also submitted abstracts to the British Society for Haematology.
HN-707 SHC	<b>Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)</b> The service should monitor and review at least annually: <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>	N/A		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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> <ul style="list-style-type: none"> <li>a. Review of any patient with a serious adverse event or who died</li> <li>b. Review of any patients requiring admission to a critical care facility</li> </ul>	Y		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 Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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 were not yet in place.	N	Mechanisms were not yet in place.
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	This was under discussion in network meetings.	N	This was under discussion in network meetings.
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	A network educational event was planned for summer 2015.	N	A network educational event was planned for summer 2015.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	Guidelines were not yet in place.	N	Guidelines were not yet in place.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	Guidelines were not yet in place.	N	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 being undertaken.	N	Ongoing monitoring was not yet being undertaken.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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 programme of audit was not yet in place.	N	An agreed 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	A research policy was not yet in place.	N	A research policy 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 was not yet in place.	N	Network review and learning was not yet in place.

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## COMMISSIONING

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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>	N	Some work had not yet been completed ('c' to 'e').	N	Some work had not yet been completed ('c' to 'e').
HZ-701	<p><b>Clinical Quality Review Meetings</b></p> <p>Commissioners should regularly review the quality of care provided by:</p> <ol style="list-style-type: none"> <li>Each service, in particular QS HN-703</li> <li>Each network, in particular, achievement of QS HY-702 and QS HY-798.</li> <li>Service and network achievement of relevant Qs</li> </ol>	N	The commissioners had instigated network business meetings and were planning educational meetings, but these were not yet in place at the time of the visit.	N	The commissioners had instigated network business meetings and were planning educational meetings, but these were not yet in place at the time of the visit.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	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	The commissioners had instigated network business meetings and were planning educational meetings, but these were not yet in place at the time of the visit.	N	The commissioners had instigated network business meetings and were planning educational meetings, but these were not yet in place at the time of the visit.

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