WM QRS West Midlands Quality Review Service

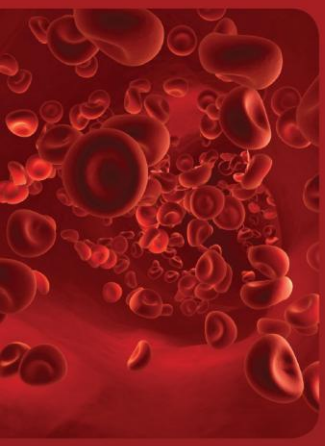
UK Forum on Haemoglobin Disorders

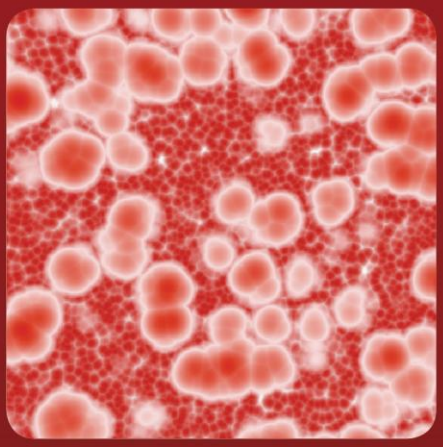
# Health Services Caring for Adults with Haemoglobin Disorders

## North Yorkshire

Leeds Teaching Hospitals NHS Trust

Visit date: May 10th 2012 Report Date: October 2012

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## INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia in the Leeds Network. The purpose of the visit was to review compliance with the '*Quality Standards for Health Services Caring for Adults with Haemoglobinopathies',* 2011. The visit was organised by the West Midland Quality Review Service and supported by the UK Forum on Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Programme.


## ACKNOWLEDGEMENTS

We would like to thank the staff of Leeds Teaching Hospitals NHS Trust and Calderdale and Huddersfield NHS 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.


## ADULT HAEMOGLOBIN DISORDERS SERVICES IN NORTH YORKSHIRE

| Trust | Abbrev-iation | Hospital/s | Abbrev-iation | Reviewed as: | Abbrev-iation |
|---|---|---|---|---|---|
| Leeds Teaching Hospitals NHS Trust | LTH | St James University Hospital<br><br>Leeds General Infirmary | SJUH<br><br>LGI | Specialist Haemoglobinopathy Team | SHT |
| Calderdale and Huddersfield NHS Foundation Trust | HFT | | CHT | Local Haemoglobinopathy Team | LHT |

| Trust | Reviewed as: | No. patients with sickle cell disease | No. patients with thalassaemia | No. patients on long-term red cell transfusions |
|---|---|---|---|---|
| Leeds Teaching Hospitals NHS Trust | SHT | 61<br>(82 Annual Reviews) | 16 | 12 Thal<br>< 5 SCD |
| Calderdale and Huddersfield NHS Foundation Trust | LHT | 19 | 5 | 5 |
| York Teaching Hospital NHS Foundation Trust | - | <5 | | |
| North Lincolnshire and Goole Hospitals NHS Foundation Trust | - | <5 | | |
| Mid Yorkshire Hospitals NHS Trust | - | | | <5 |

## NETWORK

Leeds Teaching Hospitals provided local services to a population of approximately 700,000 and regional services to approximately 3 million. The Trust had four sites in the city. The main sites were Leeds General Infirmary (LGI) and St James's University Hospital (SJUH). Seacroft and Chapel Allerton Hospitals were smaller units that provided out-patient services. Wharfedale Hospital in Otley was also part of the Trust and provided out-patient services, minor surgery and a minor injuries unit. Adult haematology services, including haemoglobinopathies, were centralised on the SJUH site in 2008 in a new PFI building.

The largest local centre outside Leeds was Calderdale and Huddersfield NHS Foundation Trust (24 patients). Less than five patients were referred from each of Harrogate, York, Grimsby, Wakefield, Pontefract and Dewsbury.

## SPECIALIST TEAM: LEEDS TEACHING HOSPITALS NHS TRUST

**Accident and Emergency**

Patients with sickle crises or acute complications of sickle cell or thalassaemia were advised to attend the Accident and Emergency Department at SJUH although there were A&E departments at both SJUH and LGI. The Accident and Emergency Department at SJUH was reviewed.

**Outpatient and Day Case Facilities**

The Haematology Day Unit was co-located with out-patient and the inpatient wards. It was open during normal working hours for transfusions and apheresis. A weekly clinic was held on Wednesday afternoon for haemoglobinopathy patients, attended by the clinical lead, the nurse specialist and a specialist registrar. A haemoglobinopathy obstetric clinic was held weekly on Tuesday mornings, which the clinical lead attended on an ad hoc basis if one of the haemoglobinopathy patients was pregnant. A transition clinic was held periodically in the children's hospital.

**In-Patient Facilities**

Patients were admitted directly under the haematology team to the haematology wards or the acute admissions haematology/oncology ward. There was a young person's facility.

**Community Services**

Community services were based in Chapel Allerton at the Reginald Centre.

**User Feedback**

The majority of patients who met reviewers were from Leeds.

### Local Team: Calderdale and Huddersfield NHS Foundation Trust

As part of the review a teleconference was held with the clinical lead from Calderdale and Huddersfield NHS Foundation Trust

## Review Visit Findings

### Network

Whilst formal network arrangements were not yet in place there were good working relationships with local hospitals, especially Huddersfield. Out-patient annual reviews were provided by the specialist team and acute clinical advice provided by phone or email. The clinical lead was providing haemoglobinopathy teaching at a local and regional level.

**Further Consideration**

1 The local units, although having small patient numbers, may benefit from more formal network arrangements, to allow sharing of protocols and educational resources. Service level agreements between provider Trusts may also be helpful as part of the development of the formal network of care between community services, primary and secondary care.

### Specialist Team: Leeds Teaching Hospitals NHS Trust

**General Comments and Achievements**

The Adult Haemoglobinopathy Disorders service had recently been established and was still evolving. A committed clinical lead had made significant progress on the development of the service with limited resources. Well informed plans for further development were in the early stages, including the identification of resource requirements. A clinical nurse specialist had recently been appointed.

Patient feedback was very positive about the sickle cell team and the recent service improvements. Excellent patient information, newly developed protocols and guidelines were available. These were also available on the intranet. There were plans to make them more readily available to users including via a patient web-site.

Patients with alternative pain needs had personal protocols which were available on the Accident and Emergency Department computer system. When they attended the Accident and Emergency Departments it was flagged up and printed on the front of their A&E notes. Some patients presented directly to the day unit or acute assessment unit, but there was no 'drop-in' day service. They were admitted to the acute assessment service and then assessed by the medical or nursing team. It was not clear how timely analgesia was given in this situation.

Nurses on the haematology wards were familiar with the Sickle Cell Protocol, which was available on the intranet, and with the use of Patient Controlled Analgesia devices. Weekly training sessions on haemoglobinopathies had just been instigated but were focussed on patient-controlled analgesia. Nursing staff on these wards might also benefit from training on the acute management of haemoglobinopathies. The new haemoglobinopathy clinical nurse specialist was planning to provide this in the future.

In-patient medical cover was provided by the haematology team. The lead consultant and three other consultants provide cover on a 1 in 4 weekly rota, supported by junior medical staff. Out of hours cover was provided by a haematology specialist registrar and on-call haematology consultant.

The environment in the young person's facility was of high quality. This was primarily for oncology patients and it was not clear if it could readily be accessed by haemoglobinopathy patients.

Patient information and clinical protocols were available on the intranet in clinic rooms and could be printed if required.

Patients were beginning to be offered annual reviews in the clinic, and this was provided for patients from outside Leeds but was not yet routine for local patients. There was a clinical protocol and, on review of the notes, all the elements of annual review were being performed but were not being recorded systematically. Clinic letters were being copied to the patients and to the sickle cell and thalassaemia community team. There was evidence of good liaison with other specialties, in particular with the orthopaedic and renal teams.

The transition patient information was very brief and may benefit from expansion.

The out-patient area was crowded and the chairs provided for patients having all day transfusions did not appear to be very comfortable. There were no televisions or wi-fi access. Patients on long term transfusion commented that they had previously waited for several hours for cross-matched samples or for cannulation. Waiting times had, however, improved since the introduction of a new appointment system. Automated red cell exchange was provided by the NHS Blood Transfusion Service (NBTS) on the day unit and by the bedside for acutely unwell patients. An out of hours service was not routinely available but had not been required in the previous five years. Weekend emergency exchange could be arranged via the on-call NBTS consultant. The service for vascular access for exchange transfusions was provided by interventional radiology on three days of the week and patients sometimes had line insertion on one day and stayed in the patient hotel overnight, receiving their transfusion the following day.

Out of hours transfusion was not available. There were plans for a new, larger haematology-oncology ambulatory day unit with extended hours of opening but, at the time of the visit, it was not clear if haemoglobinopathy patients would be able to access this service.

Outreach facilities, including a facility for blood transfusion, were provided at Wharfedale Hospital.

The PCT-commissioned community service was based in a local PCT building in Chapel Allerton. The service was staffed by a part-time service manager, a counsellor, a staff nurse and an administrator. Neonatal and antenatal screening services were provided as well as support services for paediatrics and adults with haemoglobinopathies. All patients were contacted at least twice a year, once for an annual face to face appointment invitation and once for a structured telephone call. Patients who met the visiting team did not feel that they were adequately supported in the community, that it was not easy to access the community services, and that the community team was focussed on children. The community nurse expressed a desire to establish a more integrated approach.

All people identified as sickle or thalassaemia trait were offered face to face counselling appointments and reviewers commented this may not be the best use of the community team's time.

Support groups were not yet active locally and there was no patient forum. Patients had reported problems with both the Accident and Emergency and ambulance service to the community team, but there did not appear to be any way of feeding back to the acute Trust or to patients on any action taken.

There was no evidence of community support for patients living outside Leeds, although patients would be offered telephone advice if requested.

Feedback from service users about the specialist team was positive and the team was thought to provide good care. Several comments were made about service improvements in the last few years since the clinical lead had been appointed and patients were very supportive of the new clinical nurse specialist post. There were concerns about the long waiting times for cross-matching and cannulation in the Day Unit.

Patients also commented that access to a psychology service would be of benefit. A patient survey to assess these concerns may be helpful and a draft questionnaire for a planned survey was seen. A patient survey would provide an initial baseline against which to measure progress as the service develops.

**Immediate Risk**

No immediate risks were identified.

**Concerns**

1 Patients were waiting a long time for analgesia in the Accident and Emergency Department. Staff in the Accident and Emergency Departments reported that patients with sickle cell disease were triaged as a

'priority 2' and should be seen within ten minutes, but this did not always happen in practice. Patient feedback suggested that they often waited considerable lengths of time to be seen and then analgesia offered was not always adequate. A recent audit (although the data had not been fully analysed) showed that only 13% of patients received a first dose of analgesia within 30 minutes.

2 No protocol for emergency care of patients with sickle cell disease was in place at the time of the visit but the protocol was going through the Trust governance procedure and was planned to be available shortly after the visit. Patients were treated using a generic acute pain protocol.

3 There was no formal teaching programme about haemoglobin disorders for Accident and Emergency medical and nursing staff, although the new sickle cell acute nurse specialist was planning to address this.

4 The lead consultant's job plan had no time specifically allocated for work with patients with haemoglobin disorders or for leading the service and liaison with other hospitals in the network. There was no named deputy for the lead consultant, with regular experience caring for people with haemoglobin disorders

5 The service had only a part-time clinical nurse specialist. This post was funded from a two year charitable grant. There was no cover for absences of the clinical nurse specialist and no guarantee that the post would continue to be funded after the two year period. The continuation of this post is essential for the sustainability of a specialist service.

6 The service had no administrative / data collection support.

7 Whilst a community service was available, there was no evidence of regular communication between the community and acute teams and patients who met the review team did not seem to be aware of the community service. There were plans for a meeting to address this.

**Further Consideration**

1 The Specialist Team was not yet functioning fully at the level of a specialist centre. As part of the development of the service work needs to continue to ensure that all Quality Standards are met. Areas to be addressed through this work include:

a. Formal arrangements for undertaking and recording specialist annual reviews should be implemented for all patients in the area.

b. Ward nursing staff training should be undertaken as there was no evidence of competences needed in the care of people with haemoglobin disorders.

c. Psychology support for adults with haemoglobin disorders was not available in the region, and the need for this service was highlighted by patients.

d. Whilst the majority of the patients were entered on the National Haemoglobinopathy Registry and systematic adverse event reporting was performed in the majority of cases, annual reviews were not being entered. Consideration should be given to the provision of administrative / data collection support to meet this requirement.

e. Ensuring guidelines and protocols include an appropriate level of detail

f. Ensuring multi-disciplinary meetings and regular review of performance data are implemented.

g. Implementing arrangements for out of hours access to transfusion and improving the environment within the day case areas.

2 No support groups were active locally. A patient survey may be of help to identify patient need and interest in such groups.

**Good Practice**

1 The high 'did not attend' rate had been tackled by texting prior to clinic.

2 The annual review proforma used for patients from outside Leeds was thorough.

## LOCAL TEAM: CALDERDALE AND HUDDERSFIELD NHS FOUNDATION TRUST

**General Comments**

The majority of patients in the local area were known to SJUH and were reviewed there on an annual basis.

A new lead consultant at Huddersfield had recently been appointed and since then patients were referred for annual review in Leeds. Less than five of their patients attended Manchester for annual review. The clinical lead contacted the lead clinician at Leeds by phone or email if patients were admitted with acute complications or with concerns about outpatient issues. This arrangement appeared to work well. Local guidelines for acute sickle cell management were in place. Patients attending Accident and Emergency in Huddersfield were admitted under the on call medical team and treated with patient-controlled analgesia. Haematology input was then provided. There was no named sickle nurse and no community services although transfusions for the thalassaemic patients was organised by a named nurse.

Services were provided from a number of locations and some patients were reported as being transfused in Calderdale.

**Further Consideration**

There were no network guidelines and consideration might be given to sharing the Leeds guidelines.

## COMMISSIONING

**General Comments**

The Commissioner Manager from Yorkshire and Humber Specialised Commissioning Group (SCG) confirmed that the SCG was not commissioning tertiary level services for haemoglobinopathies. Problems with counting and coding activity were reported. At the time of the visit the service was commissioned by the Primary Care Trust (PCT) / Clinical Commissioning Group.

## APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

| | | |
|---|---|---|
| Dr Jo Howard | Consultant Haematologist – Clinical Lead for Peer Review Programme | Guy's & St Thomas' NHS Foundation Trust |
| Dr Bernard Davis | Consultant Haematologist | Whittington Hospital NHS Trust |
| Dr Marie Donohue | Consultant Haematologist | Nottingham University Hospitals NHS Trust |
| Lindy Defoe | Advanced Nurse Practitioner | The James Cook University Hospital NHS Trust, Middlesbrough |
| Nicola Howe | Senior Commissioning Manager | London Specialised Commissioning Group |
| Ms Evelyn Schiller | Service User | Bristol |
| Elaine Miller | Voluntary Sector Representative | Thalassaemia Society |
| Sharon Ensor | Quality Manager | Haemoglobin Disorders Review *on behalf of WMQRS* |
| Sue McIldowie | Observer | WMQRS |

# APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

**The Quality Standards are in the following sections:**

**HN - Services for Adults with Haemoglobin Disorders**

**HY - Haemoglobin Disorders Network (Adults):**
Quality Standards for Haemoglobin Disorders Clinical Networks are given separately from those for Specialist Haemoglobinopathy Teams. These Standards are the responsibility of Specialist Haemoglobinopathy Teams but, by agreement, the functions may be delegated to other organisations or coordinating groups.

**HZ - Haemoglobin Disorders – Commissioning**
These Quality Standards are the responsibility of commissioners.

Each section covers the following topics:

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

NOTE. Different Quality Standards (QSs) are not comparable in terms of their importance or likely impact on the quality or outcomes of the service, and a figure summarising the number of QS's met cannot be used to assess the overall standard of the services provided or to compare this Trust's services with others.

## Services for Adults with Haemoglobin Disorders: Leeds Teaching Hospitals NHS Trust

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-101 All | **General Support for Service Users and Carers**<br>Service users and their carers should have easy access to the following services. Information about these services should be easily available:<br>a. Interpreter services, including access to British Sign Language<br>b. Independent advocacy services<br>c. PALS<br>d. Social workers<br>e. Benefits advice<br>f. Spiritual support<br>g. *HealthWatch* or equivalent organisation | Y | Information was excellent and clear. It was available on the intranet and was made available to service users and carers by being printed and systematically handed out in clinic. |
| HN-102 All | **Haemoglobin Disorder Service Information**<br>Written information should be offered to patients and, where appropriate, their carers covering at least:<br>a. Brief description of the service, including times of phlebotomy and transfusion services<br>b. Clinic times and how to change an appointment<br>c. Ward usually admitted to and its visiting times<br>d. How to contact the service for help and advice, including out of hours<br>e. Staff of the service<br>f. Community services and their contact numbers<br>h. Relevant support groups<br>g. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns<br>h. How to get involved in improving services (QS HN-199) | Y | A patient feedback survey had been developed but mechanisms to gather patient views may benefit from further consideration. |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-103 All | **Information about Haemoglobin Disorders**<br><br>Written information should be offered to patients and, where appropriate, their carers covering at least:<br>a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment<br>b. Problems, symptoms and signs for which emergency advice should be sought<br>c. How to manage pain at home (SC only)<br>d. Where to go in an emergency<br>e. Health promotion, including:<br>i. Information on contraception and sexual health<br>ii. Travel advice<br>iii. Vaccination advice<br>iv. Staying well through a healthy diet, exercise and not smoking.<br>f. Where to go for further information, including useful websites and national voluntary organisations | N | Information on the intranet was excellent and clear although accessibility to staff and to service users and carers could be improved. There was no information on thalassaemia. |
| HN-104 All | **Information for Primary Health Care Team**<br><br>Written information for the patient's primary health care team should be available covering their roles and responsibilities, including:<br>a The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC)<br>b Information covering side effects of medication, including chelator agents [SC and T]<br>c Guidance for GPs on shared care for hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). | N | Guidance for GPs was not available. |
| HN-105 All | **Care Plan**<br><br>All patients should be offered:<br>a An individual care plan or a written summary of their annual review<br>b A permanent record of consultations at which changes to their care are discussed | N | Care Plans were not routinely offered but plans to provide these were in place. |
| HN-106 SHT<br><br>A-LHT | **Transition Information**<br><br>Information should be available for young people covering arrangements for transition to adult care. This information should cover all aspects of QS HN-501. | N | This was previously considered to be the remit of the paediatric service but the team had the intention to review this for haemoglobin disorders. |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-199 All | **Involving Patients and Carers**<br><br>The service should have:<br>a. Mechanisms for receiving feedback from patients and carers<br>b. A rolling programme of audit of patients' and carers' experience<br>c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service. | N | Trust-wide general feedback mechanisms were in place but these were not specific to adult haemoglobin disorders. A detailed survey had been developed but was not yet in use. |
| HN-201 All | **Lead Consultant**<br><br>A nominated lead consultant haematologist 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. | Y | |
| HN-202 All | **Cover for Lead Consultant**<br><br>Cover for absences of the lead consultant should be available. In SHTs this should be a named deputy within the SHT with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHT. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHT advice and support. | N | Cover was not provided by a deputy with regular experience of caring for people with haemoglobin disorders. |
| HN-203 All | **Lead Nurse**<br><br>A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders. | Y | There was a new lead nurse post as a result of a successful bid for charity funding but the post was only part-time and the funding was limited to two years. |
| HN-204 All | **Cover for Lead Nurse**<br><br>Cover for absences of the lead nurse should be available. | N | Cover was provided by the haematology day unit. |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-205 All | **Staffing Levels and Competences**<br>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>a. Medical staffing<br>b. Nurse staffing on the ward and day unit<br>c. Nurse specialist or counsellor who provides support for patients in the community.<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available. | N | Patients reported long waits for blood matching and cannulation but a new appointment system had reduced time to half hour slots. There was no specialist nurse staffing on the ward and therefore no cover for their absence. |
| HN-206 All | **Training Plan**<br>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-205). | N | There was no evidence of a training plan. |
| HN-207 All | **Training Plan – Other Staff**<br>A programme of induction and training covering the care of patients with haemoglobin disorders should be run for:<br>a. Clinical staff in the Emergency Department<br>b. Non-consultant medical staff<br>c. Allied health professionals working with the SHT / LHT (QS HN-301). | N | No training programme was in place but accident and emergency had been identified as the first target area for training from the new specialist nurse. There had been some training covering non-consultant medical staff. |
| HN-298 All | **Administrative and Clerical Support**<br>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service. | N | There was no administrative or clerical support. |
| HN-301 All | **Support Services**<br>Timely access to the following services should be available:<br>a. Dietetics<br>b. Physiotherapy<br>c. Occupational therapy<br>d. Leg ulcer service | Y | |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-302 All | **Specialist Services**<br><br>Access to the following specialist staff and services should be available:<br>a. Erythrocytopheresis or manual exchange transfusion (24/7)<br>b. Acute and chronic pain team<br>c. Pulmonary hypertension team<br>d. Consultant obstetrician<br>e. Fertility services<br>f. Consultant cardiologist<br>g. Consultant endocrinologist<br>h. Consultant hepatologist<br>i. Consultant ophthalmologist<br>j. Consultant nephrologist<br>k. Consultant urologist with expertise in managing priapism and erectile dysfunction<br>l. Orthopaedic service<br>m. Psychologist with an interest in haemoglobinopathies<br>n. Specialist imaging<br>o. DNA studies | Y | Access to specialist staff and services was available but the arrangement for access to a psychologist with a specialist interest in haemoglobinopathies was under review. |
| HN-303 All | **Laboratory Services**<br><br>CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available. | Y | |
| HN-401 All | **Facilities available**<br><br>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. | N | The unit for young people was praised. The out-patient clinics were adequate but the facilities within the day unit were not appropriate. |
| HN-402 All | **Facilities for Out of Hours Care**<br><br>Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. | N | There was no service for out of hours routine phlebotomy, out-patient clinics or transfusion but a major reconfiguration of the day unit was underway and it was hoped that this would improve services. |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-501 SHT<br><br>A-LHT | **Transition Guidelines**<br><br>Guidelines on transition to adult care should be in use covering at least:<br>a. Age guidelines for timing of the transfer<br>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<br>c. Allocation of a named coordinator for the transfer of care<br>d. Communication of clinical information from paediatric to adult services<br>e. Arrangements for monitoring during the time immediately after transfer to adult care<br>f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) | Y | Although guidelines were in use, consideration should be given to providing more detailed content. |
| HN-502 SHT<br><br>A-LHT | **Clinical Guidelines: Annual Review**<br><br>Clinical guidelines should be in use covering:<br>a. First out-patient appointment<br>b. Annual review for both sickle cell disease and thalassaemia | N | There were no structured guidelines but annual reviews were being undertaken. |
| HN-503 All | **Clinical Guidelines: Routine Monitoring**<br><br>Clinical guidelines on routine out-patient monitoring and management between annual reviews should be in use. Local Haemoglobinopathy Team guidelines should specify the indications for early referral to the Specialist Haemoglobinopathy Team. | Y | |
| HN-504 All | **Transfusion Guidelines**<br><br>Transfusion guidelines should be in use covering:<br>a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion<br>b. Protocol for carrying out an exchange transfusion<br>c. Hospital transfusion policy | Y | Guidelines were available on the intranet. |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-505 All | **Chelation Therapy**<br><br>Clinical guidelines on chelation therapy should be in use covering:<br>a. Indications for chelation therapy<br>b. Dosage and dosage adjustment<br>c. Monitoring of haemoglobin levels prior to transfusion<br>d. Management and monitoring of iron overload, including management of chelator side effects<br>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2<br>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 / SHT. | Y | Although guidelines were in use, consideration should be given to providing more detailed content. |
| HN-506 All | **Clinical Guidelines: Acute Complications**<br><br>Clinical guidelines on the management of acute complications should be in use covering at least:<br><br>**For patients with sickle cell disease:**<br><br>a. Acute pain<br>b. Fever, infection and overwhelming sepsis<br>c. Acute chest syndrome<br>d. Abdominal pain and jaundice<br>e. Acute anaemia<br>f. Stroke and other acute neurological events<br>g. Priapism<br>h. Acute renal failure<br>i. Haematuria<br>j. Acute changes in vision<br>**For patients with thalassaemia:**<br>k. Fever, infection and overwhelming sepsis<br>l. Cardiac, hepatic or endocrine decompensation<br>Guidelines should include the indications for referral to specialist services (QS HN-302). | N | Guidelines could not be accessed in accident and emergency but they had been written and were undergoing internal governance review.<br>Guidelines on overwhelming sepsis were not available. |
| HN-507 All | **Emergency Department Guidelines**<br><br>Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department. | N | Clinical guidelines were on the departmental quality system only but when the planned link to the accident and emergency system is introduced this standard will be achieved. |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-508 All | **Clinical Guidelines: Chronic complications**<br><br>Clinical guidelines on the management of chronic complications should be in use covering at least:<br>a. Renal disease<br>b. Orthopaedic problems<br>c. Retinopathy<br>d. Cardiological complications / pulmonary hypertension<br>e. Chronic respiratory disease<br>f. Endocrinopathies<br>g. Neurological complications<br>h. Chronic pain<br>Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team. | Y | Links and liaison with specialists were working well. |
| HN-509 LHT | **Transfer for Critical Care**<br><br>Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital. | N/A | |
| HN-510 SHT<br><br>A-LHT | **Specialist Management Guidelines**<br><br>Clinical guidelines should be in use covering:<br>a. Care of patients with haemoglobin disorder during anaesthesia and surgery<br>b. Care of patients with haemoglobin disorders who are pregnant<br>c. Hydroxycarbamide therapy | Y | |
| HN-511 All | **Thalassaemia Intermedia**<br><br>Clinical guidelines for the management of thalassaemia intermedia should be in use, covering:<br>a. Indications for transfusion<br>b. Monitoring iron loading<br>c. Indications for splenectomy. | Y | Although guidelines were in use, consideration should be given to providing more detailed content. |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-601 All | **Operational Policy**<br><br>An operational policy should be in use covering:<br>a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602)<br>b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only).<br>c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.<br>d. Notification of adverse events to the SHT(LHTs only)<br>e. Follow up of patients who do not attend<br>f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care. | N | There were no operational policies. Patients were contacted after three non-attendances. |
| HN-602 All | **Multi-Disciplinary Meetings**<br><br>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 (QS HN-205) and representatives of support services (QS HN-301). | N | Multi-disciplinary meetings were not taking place. |
| HN-603 All | **Service Level Agreement with Community Services**<br><br>A service level agreement for support from community services should be in place covering, at least:<br>a. Role of community service in the care of patients with haemoglobin disorders<br>b. Two-way exchange of information between hospital and community services. | N | Staff from community services did not believe that a service level agreement was necessary but a meeting to discuss this was planned. |
| HN-701 SHT<br><br>A-LHT | **Data Collection**<br><br>Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events. | N | Patients were registered on the National Haemoglobinopathy Registry and adverse events were beginning to be entered. |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-702 All | **Ongoing Monitoring**<br><br>The service should monitor on an ongoing basis:<br>a. Number of patients having acute admission, day unit admission or A&E attendances<br>b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year<br>c. Length of in-patient stays<br>d. Re-admission rate<br>e. DNA rate<br>f. Waiting times for transfusion | N | Ongoing monitoring was not undertaken. |
| HN-703 All | **Audit**<br><br>Clinical audits covering the following areas should have been undertaken within the last two years:<br><br>**For patients with sickle cell disease:**<br><br>a. Proportion of patients with recommended immunisations up to date<br>b. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required<br>c. 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. This audit should cover all hospitals where patients with sickle cell disease may attend.<br><br>**For patients with thalassaemia:**<br><br>d. Evidence of effective monitoring of iron overload, including imaging (QS HN-505)<br>e. Proportion of patients who have developed new iron-related complications in the preceding 12 months | Y | Some audits had been undertaken but were out of date. Raw data from a pain audit were provided but had not been analysed. |
| HN-704 All | **Guidelines Audit**<br><br>The service should have a rolling programme of audit, including:<br>a. Audit of implementation of evidence based guidelines (QS HN-500s).<br>b. Participation in agreed network-wide audits. | N | There was no programme to audit guidelines but this was under review. |
| HN-705 SHT | **Research**<br><br>The SHT should actively participate in research relating to the care of patients with haemoglobin disorders. | Y | |

| Ref | Quality Standard | Met Y/N | Comment SHT |
|---|---|---|---|
| HN-798 All | **Review and Learning**<br>The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include:<br>a. Review of any patient with a serious adverse event or who died in the last 12 months<br>b. Review of any patients requiring admission to a critical care facility within the last 12 months | Y | |
| HN-799 All | **Document Control**<br>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | |

## HAEMOGLOBIN DISORDERS CLINICAL NETWORK

| Ref | Quality Standard | Met Y/N | Comments |
|---|---|---|---|
| HY-199 | **Involving Patients and Carers**<br>The network should have mechanisms for involving patients and their carers from all services in the work of the network. | N | A network of services had not been formalised so compliance with the network standards was not yet achieved. |
| HY-201 | **Network Leads**<br>The network should have a nominated:<br>a. Lead consultant and deputy<br>b. Lead specialist nurse for acute care<br>c. Lead specialist nurse for community services<br>d. Lead manager<br>e. Lead for service improvement<br>f. Lead for audit<br>g. Lead commissioner | N | There was no network but informal links to leads from other areas were in place. |
| HY-202 | **Education and Training**<br>The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-205 and HN-206. | N | The network was not functioning but some regional training was supported. |

| Ref | Quality Standard | Met Y/N | Comments |
|---|---|---|---|
| HY-501 | **Transition Guidelines**<br><br>Network guidelines on transition to adult care should have been agreed covering:<br>a. Age guidelines for timing of the transfer<br>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<br>c. Allocation of a named coordinator for the transfer of care<br>d. Communication of clinical information from paediatric to adult services<br>e. Arrangements for monitoring during the time immediately after transfer to adult care<br>f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable)<br>Guidelines should be explicit about transition directly to any accredited LHTs. | N | A network of services had not been formalised so compliance with the network standards was not yet achieved. |
| HY-502 | **Clinical Guidelines**<br><br>Network guidelines should have been agreed covering:<br>a. Annual review (QS HN-502)<br>b. Routine monitoring (QS HN-503)<br>c. Transfusion (QS HN-504)<br>d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505)<br>e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-302)<br>f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-302)<br>g. Transfer for critical care (QS HN-509)<br>h. Specialist management (QS HN-510)<br>i. Thalassaemia intermedia (QS HN-511)<br>Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHTs. | N | Network arrangements were not formalised.<br>Annual reviews for patients from Harrogate, York, and Huddersfield were provided. |
| HY-701 | **Annual Meeting**<br><br>The network should hold a meeting at least annually involving network leads (QS HY-201) and lead consultants and lead nurses for each LHT / SHT in the network (QSs HN-201 and HN-203) to review the network's progress towards achievement of Quality Standards and its implementation of agreed service development plans. | N | Initial discussions had taken place and there was interest in an annual meeting. |

| Ref | Quality Standard | Met Y/N | Comments |
|---|---|---|---|
| HY-702 | **Ongoing Monitoring**<br><br>The network should monitor on a regular basis:<br>a. Submission of data on all patients to the National Haemoglobinopathy Register (QS HN-701)<br>b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year. | N | A network of services had not been formalised so compliance with the network standards was not yet achieved. |
| HY-703 | **Audit**<br><br>The network should have an agreed programme of audit and review covering, over the whole programme, network-wide achievement of QSs HN-702, HN-703 and HN-704. | N | A network of services had not been formalised so compliance with the network standards was not yet achieved. |
| HY-704 | **Research**<br><br>The network should have agreed:<br>a. A policy on access to research relating to the care of patients with haemoglobin disorders<br>b. A list of research trials available to all patients within the network. | N | The network was not functioning, but Leeds maintained a website www.haematologyclinicaltrials.co.uk which highlighted all active haematology clinical trials by disease within the department. |
| HY-798 | **Review and Learning**<br><br>The network should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses', especially those involving more than one service within the network. | N | A network of services had not been formalised so compliance with the network standards was not yet achieved. |

## COMMISSIONING

| Ref | Quality Standard | Met Y/N | Comments |
|---|---|---|---|
| HZ-601 | **Commissioning of Services**<br><br>Commissioners should have agreed the configuration of clinical networks and, within each network, the configuration of services for people with haemoglobin disorders across each network, in particular:<br>a. Designated SHT/s for the care of adults with sickle cell disease<br>b. Designated SHT/s for the care of adults with thalassaemia<br>c. Accredited LHTs for care of adults with sickle cell disease or thalassaemia<br>d. Other LHTs/ Linked providers for care of adults with sickle cell disease or thalassaemia<br>e. Community care providers | N | Specialist commissioning did not yet cover the configuration of clinical networks or services for people with haemoglobin disorders across the network. |
| HZ-701 | **Clinical Quality Review Meetings**<br><br>Commissioners should regularly review the quality of care provided by each network, in particular, achievement of QS HY-702 and HY-798. | N | No reviews were undertaken as a formal network was not functioning. |