WM QRS West Midlands Quality Review Service

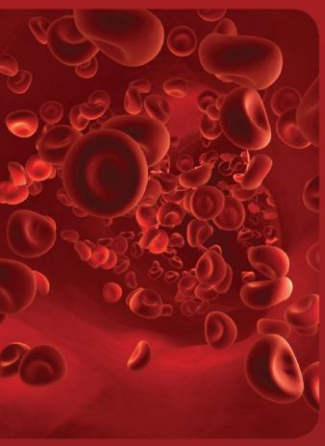
UK Forum on Haemoglobin Disorders

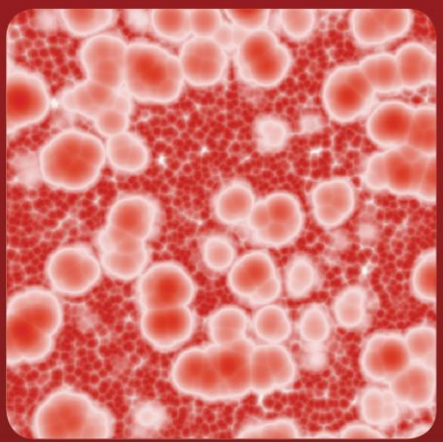
Health Services Caring for Adults with Haemoglobin Disorders

North East England

The Newcastle upon Tyne Hospitals NHS Foundation Trust
South Tees Hospitals NHS Foundation Trust

Visit Date: March 29th 2012 Report Date: July 2012

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INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease or thalassaemia in the North East of England, in particular The Newcastle upon Tyne Hospitals NHS Foundation Trust and South Tees Hospitals NHS Foundation Trust, which took place on March 29th 2012. 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 The Newcastle upon Tyne Hospitals NHS Foundation Trust and South Tees Hospitals NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review.

ADULT HAEMOGLOBIN DISORDERS SERVICES IN NORTH EAST ENGLAND

Trust	Hospital/s	Abbrev-iation	Reviewed as:	Abbrev-iation
The Newcastle upon Tyne Hospitals NHS Foundation Trust	Royal Victoria Infirmary Freeman Hospital	RVI FRH	Specialist Haemoglobinopathy Team	SHT
South Tees Hospitals NHS Foundation Trust	The James Cook University Hospital	JCUH	Accredited Local Haemoglobinopathy Team	SHT

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long-term red cell transfusions
The Newcastle upon Tyne Hospitals NHS Foundation Trust	SHT	8	<5	<5
South Tees Hospitals NHS Foundation Trust	SHT	7	<5	<5

NETWORK

The specialist teams for care of patients with haemoglobin disorders worked together through the North East Haematology Network. Formal arrangements for networking between the two specialist teams were not in place but informal arrangements worked well.

SPECIALIST TEAM: THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST

Haemoglobinopathy patients in Newcastle were seen at the Royal Victoria Infirmary (RVI). At the time of the visit there were small numbers of adults with haemoglobin disorders although the number of children with these conditions had increased significantly in recent years. Inpatient episodes were managed either in the Medical Unit at the RVI or in the Haematology Ward at the Freeman Hospital. The team at the RVI worked closely with the haemophilia team with which it shared outpatient and day care facilities, and multidisciplinary support.

Accident and Emergency

Patients at both the RVI were encouraged to present directly to the ward and rarely used the A&E department, but the occasional new patient would attend directly to A&E. Facilities in Newcastle were not visited. Patients presenting with uncomplicated sickle crisis at the RVI were managed in the medical unit by medical and haematology teams. Patients were transferred to the haematology ward at the Freeman Hospital, FRH 33, if they required complex intervention or when a more prolonged stay was anticipated.

Outpatient and Day Case Facilities

Outpatients in Newcastle were seen in the haematology department. Outpatient facilities were shared with the haemophilia unit. Children with other non-malignant disorders were also seen in the department and at a bi-monthly combined paediatric and adult sickle cell clinic which had been introduced recently. Any pregnant sickle cell patients were managed in the joint haematology/obstetric clinic. Day case facilities were shared with other haematology patients.

In-Patient Facilities

Inpatients were cared for on the medical unit at the RVI or at the Freeman Hospital depending on clinical complexity and bed availability. Both sites had high dependency and intensive care facilities.

Community Services

There were no formal community services for adults with haemoglobin disorders. The specialist nurses were part-time and were employed primarily to undertake work in relation to the national screening programmes and follow up of affected and trait infants. Social work support was provided by the hospital service.

User Feedback

Users from Middlesbrough took part in the review but those from Newcastle were unable to attend due to the distance involved.

SPECIALIST TEAM: SOUTH TEES HOSPITALS NHS FOUNDATION TRUST

Patients from the Middlesbrough area were managed at the The James Cook University Hospital (JCUH).

Accident and Emergency

Patients at the JCUH were encouraged to present directly to the ward and rarely used the A&E department, but the occasional new patient would attend directly to A&E. Sickle cell patients in crisis were asked to contact the haematology ward at JCUH where they would have a telephone assessment and were asked to attend the ward or day unit if appropriate. Facilities existed on the ward for assessment day and night by the haematology or resident medical team. Patients were then admitted to the haematology ward if necessary. No patients had presented to the A&E department for the last two years.

Outpatient / Day Case Facilities

Outpatients in Middlesbrough were seen in the haematology day unit. Day case facilities were shared with other haematology patients. There was a facility for automated red cell exchange available at JCUH. The day unit, outpatients and ward at JCUH were due to co-locate in refurbished facilities in 2013.

In-Patient Facilities

Inpatients at JCUH were managed on the haematology ward.

Community Services

There were no formal community services for adults with haemoglobin disorders. The specialist nurses were part-time and were employed primarily to undertake work in relation to the national screening programmes and follow up of affected and trait infants. Social work support was provided by the hospital service.

User Feedback

The review team met patients from South Tees who were very positive about the caring approach of the team and the individualised care they received.

Local Team / Linked Hospitals

There were no linked hospitals. Due to the small numbers, it was possible for all patients to be seen at the RVI or JCUH with occasional patients seen by the teams at other local hospitals.

Commissioning

The team met with the Commissioner for the North East (NE) who had been involved in the review of Paediatric Haemoglobinopathy services in the NE. The focus was clearly on the screening programmes and services for children. There were no arrangements for specialist commissioning of haemoglobinopathy services from April 2012 due to the small numbers of patients involved. Commissioning responsibilities continued to reside with local PCTs until arrangements were clearer. There were no immediate plans to increase specialist nursing. There was a good understanding of the regional prevalence of haemoglobin disorders. It was acknowledged that, while the best possible care was provided within the resources available, it might be difficult to deliver all expected aspects of care with relatively small patient numbers.

Review Visit Findings

Network

General Comments and Achievements

A network of services specific for haemoglobinopathy patients had not yet been formalised although it existed informally within the established North East Haematology Network. Shared guidelines were in place but it was not clear that the centres were working together outside the screening multi-disciplinary team (MDT). Both hospital teams showed a clear commitment to the care of patients with haemoglobin disorders. Dedicated leadership and specialist nursing support were evident, even though patient numbers were small. This was reflected in the excellent feedback from patients at South Tees (there were no Newcastle patients present). The teams were working together to deliver the quality standards for patients in the North East but it was acknowledged that the low patient numbers presented difficulties in terms of service infrastructure, training and dedicated nursing time. Due to the low incidence of haemoglobin disorders in the region, both hospital teams would seek specialist advice from other hospitals outside the region if required. Overall, both teams were delivering as good care as possible within the resources available.

Further Consideration

1 The number of patients within the north east region may be too small to justify an independent network and two specialist teams. Consideration should be given to collaborating with other networks to provide the full range of specialist services and expert management of complications. This might be achieved, for example, by outreach clinics from a larger Centre.

2 Arrangements for MDT review should be formalised and documented. Given the small numbers it might be helpful to consider a joint MDT between Newcastle and Middlesbrough.

3 The system of annual review was not yet formalised. More formal, documented arrangements may help to ensure that all long term systematic chronic disease monitoring processes are in place. Collaboration with a Specialist Team with a larger number of patients, as part of new network arrangements, may also be helpful.

4 Service level agreements between provider Trusts maybe helpful as part of the development of the formal network of care.

SPECIALIST TEAM: THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST

General Comments and Achievements

The review team was impressed by the individualised care given to patients with the majority having direct access to the haematology ward and the specialist team.

Immediate Risk

No immediate risks were identified.

Concerns

1 Patient data, including annual reviews and adverse events, were not entered onto the National Haemoglobinopathy Registry although the site had registered for this.

2 Several aspects of the service were not yet fully developed:

a. Guidelines and protocols were not fully documented, including arrangements for annual review, though all patients were seen regularly.

b. Nursing staff on the wards and day units did not yet have evidence of the expected competences in the care of people with haemoglobin disorders.

c. There was no access to a psychologist with experience in these disorders.

d. There were no formal arrangements for MDT discussion.

e. Although local specialists for the management of specific complications had been identified, they would only see patients with haemoglobin disorders infrequently and would not have the opportunity to develop and maintain the necessary specialist expertise in the care of people with haemoglobin disorders.

Further Consideration

1 Some patient information was available and patients were directed to nationally available sources. Further development of information about the local services and support available locally may be helpful.

2 Specialist nurses were employed primarily to undertake work related to screening and care of children. They were not funded to care for adults and had no allocated time within their job plan for this. This should be reviewed in light of the need for support to adult patients.

3 Training for junior medical staff was limited by the small numbers of patients and specialist registrars were undertaking secondments to other centres to gain this experience. Funding arrangements for these secondments may benefit from review.

4 Arrangements for transition from paediatric to adult care were not formalised as clinicians saw both children and adult patients. Consideration should be given to ensuring specific information relevant to this age group is available and support to enable them to achieve independence in managing their condition is given.

5 There was no operational policy for the service. This is particularly important for staff covering absences of key members of the teams who will have little experience in the care of people with haemoglobin disorders.

Good Practice

1 All patients had open access to the haematology ward for acute episodes and did not need to use the A&E department.

SPECIALIST TEAM: SOUTH TEES HOSPITALS NHS FOUNDATION TRUST

General Comments and Achievements

The review team was impressed by the individualised care given to patients with the majority having direct access to the haematology ward and the specialist team. Staff in A&E and on the ward at JCUH knew how to locate protocols on the intranet and reported a good working relationship with the consultant haematologist.

Immediate Risk

No immediate risks were identified.

Concerns

1 Several aspects of the service were not yet fully developed:

a. Guidelines and protocols were not fully documented, including arrangements for annual review, though all patients were seen regularly.

b. Nursing staff on the wards and day units did not yet have evidence of the expected competences in the care of people with haemoglobin disorders.

c. There was no access to a psychologist with experience in these disorders.

d. There were no formal arrangements for MDT discussion.

e. Although local specialists for the management of specific complications had been identified, they would only see patients with haemoglobin disorders infrequently and would not have the opportunity to develop and maintain the necessary specialist expertise in the care of people with haemoglobin disorders.

Further Consideration

1 Some patient information was available and patients were directed to nationally available sources. Further development of information about the local services and support available locally may be helpful.

2 Specialist nurses were employed primarily to undertake work related to screening and care of children. They were not funded to care for adults and had no allocated time within their job plan for this. This should be reviewed in light of the need for support to adult patients.

3 Training for junior medical staff was limited by the small numbers of patients and specialist registrars were undertaking secondments to other centres to gain this experience. Funding arrangements for these secondments may benefit from review.

4 Arrangements for transition from paediatric to adult care were not formalised as clinicians saw both children and adult patients. Consideration should be given to ensuring specific information relevant to this age group is available and support to enable them to achieve independence in managing their condition is given.

5 Whilst all patients had been entered on the National Haemoglobinopathy Registry , adverse events were not being reported and annual reviews were not yet being completed on the Registry.

6 There was an operational policy for the ward and day unit but this did not cover the all the requirements of the Quality Standard (QS HN-601) or the overall organisation of services for adults with haemoglobin disorders. This is particularly important for staff covering absences of key members of the teams who will have little experience in the care of people with haemoglobin disorders.

7 The haematology ward at JCUH was not up to standard but the ward and day unit were moving to improved facilities in 2013.

Good Practice

1 All patients had open access to the ward for acute episodes and did not need to use the A&E department.

2 Patients received highly personalised care and reported very good relationships with staff

COMMISSIONING

Further Consideration

1 Consideration should be given to whether two specialist teams will be able to meet expected standards of care and whether staff will be able to develop and maintain specialist expertise in the care of people with haemoglobin disorders given the low patient numbers. As part of new network arrangements, commissioning specialist care from a Specialist Team with a larger number of patients and ensuring local access through 'Accredited Local Teams' in Newcastle and Middlesbrough may be a better alternative.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Jo Howard	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Guy's and St Thomas' NHS Foundation Trust
Dr Kate Ryan	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Central Manchester University Hospital NHS Foundation Trust
Dr Nicholas Jackson	Consultant Haematologist	University Hospitals Coventry and Warwickshire NHS Trust
Sekayi Tangayi	Service Manager/Nurse Lead & Specialist Nurse	East London NHS Foundation Trust Sickle Cell and Thalassaemia Centre
Verna Davis	Service Manager, Haemoglobin Disorders	Central Manchester University Hospital NHS Foundation Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Elaine Miller	Co-ordinator	UK Thalassaemia Society
Ajay Dattani	Service User	Representative of users and carers
Kevin Dunkley	Service User	Representative of users and carers

WMQRS members:

Sharon Ensor	Director, Key Opportunities CIC	On behalf of West Midlands Quality Review Service
Jane Eminson	Acting Director	West Midlands Quality Review Service

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

THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST (NUTH) AND SOUTH TEES HOSPITALS NHS FOUNDATION TRUST (STH)

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y	Generic information was available.	Y	Generic information was available. The small note on the availability of translation services was only in English.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-102 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy and transfusion services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. How to contact the service for help and advice, including out of hours e. Staff of the service f. Community services and their contact numbers g. Relevant support groups h. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns i. How to get involved in improving services (QS HN-199)	N	Little condition-specific information was available for sickle cell disease and none for patients with thalassaemia. There were no local support groups.	N	Little condition-specific information was available for sickle cell disease and none for patients with thalassaemia. There were no local support groups.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-103 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking f. Where to go for further information, including useful websites and national voluntary organisations	N	Little condition-specific information was available.	N	An information leaflet for patients was available on the day unit. There were plans to use the increased space in the new area to improve access and visibility of information. The letter used for new patients provided a good introduction.
HN-104 All	**Information for Primary Health Care Team** Written information for the patient's primary health care team should be available covering their roles and responsibilities, including: a The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b Information covering side effects of medication, including chelator agents [SC and T] c Guidance for GPs on shared care for hydroxycarbamide and iron chelation therapy (if being prescribed by GPs).	N	'a' was met. There was no evidence of 'b'. 'c' was not applicable.	N	'a' was met. There was no evidence of 'b'. 'c' was not applicable.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-105 All	**Care Plan** All patients should be offered: a An individual care plan or a written summary of their annual review b A permanent record of consultations at which changes to their care are discussed.	N	Reviewers were told that patients were offered a copy of clinic letters. This was apparent in the one set of notes seen by reviewers but could not be confirmed in other notes.	N	No evidence of compliance was available. Care plan or annual review summaries were not in use. Patients were offered the opportunity to receive a copy of their clinic review letter.
HN-106 C SHT A-LHT	**Transition Information** 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	The same consultants followed patients through transition but there was no formal process or specific information for young people.	N	The same consultants followed patients through transition but there was no formal process or specific information for young people.
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	N	The Trust was developing generic paper and electronic patient feedback systems. A haemoglobin disorder questionnaire had started being used. A support group was also being started.	N	There was evidence that patients' views were collected but this was at a general patient satisfaction level rather than specific to haemoglobin disorders. Patients reported that they felt they had received excellent personal care. Essence of care was in place.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-201 All	**Lead Consultant** 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		Y	
HN-202 All	**Cover for Lead Consultant** 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.	Y		Y	
HN-203 All	**Lead Nurse** 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	A nurse was carrying out this role but funding for this post was for children only. Adult services may benefit from specific job-planned time.	Y	A nurse was carrying out this role but funding for this post was for children only. Adult services may benefit from specific job-planned time.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	Y	Cover for absences was available but specialist nurses were employed primarily for children and screening-related work. Although they were caring for adults, this was not formally part of their role.	Y	Cover for absences was available but specialist nurses were employed primarily for children and screening-related work. Although they were caring for adults, this was not formally part of their role.
HN-205 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. 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	The service was considering training staff to achieve appropriate competences but a training plan was not yet in place.	N	The service had begun to work towards delivering training for specific competencies but a comprehensive training plan was not yet in place.
HN-206 All	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-205).	N	As HN-205.	N	Work had begun on a training plan as part of the response to review of staff competence linked to HN-205.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-207 All	**Training Plan – Other Staff** A programme of induction and training covering the care of patients with haemoglobin disorders should be run for: a. Clinical staff in the Emergency Department b. Non-consultant medical staff c. Allied health professionals working with the SHT / LHT (QS HN-301).	N	Training for medical staff in the A&E was in place but there was no evidence of training of A&E nursing staff.	N	Junior Doctors had to go outside the region. The Lead Consultant provided training sessions on an ad hoc basis. Small numbers of patients reduced opportunity for staff to gain experience.
HN-298 All	**Administrative and Clerical Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y		Y	
HN-301 All	**Support Services** Timely access to the following services should be available: a. Dietetics b. Physiotherapy c. Occupational therapy d. Leg ulcer service	Y		Y	

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-302 All	**Specialist Services** Access to the following specialist staff and services should be available: a. Erythrocytopheresis or manual exchange transfusion (24/7) b. Acute and chronic pain team c. Pulmonary hypertension team d. Consultant obstetrician e. Fertility services f. Consultant cardiologist g. Consultant endocrinologist h. Consultant hepatologist i. Consultant ophthalmologist j. Consultant nephrologist k. Consultant urologist with expertise in managing priapism and erectile dysfunction l. Orthopaedic service m. Psychologist with an interest in haemoglobinopathies n. Specialist imaging o. DNA studies	N	There was no evidence for 'f', 'g' and 'h'. Because of the small patient numbers, other services had little specialist expertise in the care of people with haemoglobin disorders (see main report).	N	There was no evidence for 'c','d','e','f' and 'm'. There was some evidence for 'a','b','l','j' and 'k'. Because of the small patient numbers, other services had little specialist expertise in the care of people with haemoglobin disorders (see main report).
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	Y		Y	

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-401 All	**Facilities available** 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.	Y	Compliance is based on self-assessment and discussion with staff as reviewers were not able to visit facilities.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	As HN-401.	Y	
HN-501 SHT A-LHT	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable)	N	Transition guidelines were not available. The same services provided care for children and adults and the view was that transition between services was not needed. Reviewers considered that transition guidelines were needed as young people were transferring to adult facilities and taking responsibility for their own care.	N	Transition guidelines were not available. Paediatric and adult haemoglobinopathy patients were managed by the same consultant haematologists. Communication on transition was given verbally.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First out-patient appointment b. Annual review for both sickle cell disease and thalassaemia	N	An annual review proforma was available for sickle cell disease but there was no evidence relating to first out-patient appointment. The annual review proforma may benefit from review. Only one set of notes was available which had no evidence of an annual review.	N	There was no evidence of annual reviews taking place.
HN-503 All	**Clinical Guidelines: Routine Monitoring** 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.	N	Written guidelines were not available.	N	Draft guidelines were available.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy.	Y		Y	

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-505 All	**Chelation Therapy** Clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT / SHT.	N	Guidelines were in draft form. The draft was comprehensive.	N	Guidelines were in draft form. The draft was comprehensive.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-506 All	**Clinical Guidelines: Acute Complications** Clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision **For patients with thalassaemia:** k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	N	Guidelines for the management of acute complication of sickle cell disease were available but did not cover 'h', 'I', or 'j'. No specific thalassaemia guidelines were available but UKTS Standards 2008 were used.	N	Guidelines for the management of acute complication of sickle cell diseases were available on the Trust intranet site but did not cover 'h', 'I', or 'j'. No specific thalassaemia guidelines were available but UKTS Standards 2008 were used. Use of guidelines was not clear in the patient notes that were reviewed.
HN-507 All	**Emergency Department Guidelines** Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department.	Y	Compliance is based on self-assessment and discussion with staff as reviewers were not able to meet staff from the Emergency Department.	Y	

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-508 All	**Clinical Guidelines: Chronic complications** Clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain 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.	N	Guidelines were not available for all complications. Some were covered in general guidelines but not easily accessible and patient notes did not show evidence of these being used.	N	Guidelines were not available for all complications. Some were covered in general guidelines but not easily accessible and patient notes did not show evidence of these being used.
HN-509 LHT	**Transfer for Critical Care** 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		N/A	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy.	Y		Y	

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-511 All	**Thalassaemia Intermedia** Clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy.	N	Guidelines were not available.	N	Guidelines were not available.
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) 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). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend 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	No operational policy was available.	N	There was a general policy but this was not condition-specific. 'c' was covered but there was no evidence for 'a' or 'e'. Triage was mentioned.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-602 All	**Multi-Disciplinary Meetings** 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	MDT meetings were not in place due to the small numbers.	N	MDT meetings were not in place due to the small numbers.
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A	No community services were available because of the small numbers involved.	N/A	No community services were available because of the small numbers involved.
HN-701 SHT A-LHT	**Data Collection** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	N	Patients were not registered on the National Haemoglobinopathy Register.	N	All patients were entered on the NHR but there was no evidence of annual reviews or adverse event reporting.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-702 All	**Ongoing Monitoring** The service should monitor on an ongoing basis: a. Number of patients having acute admission, day unit admission or A&E attendances b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year c. Length of in-patient stays d. Re-admission rate e. DNA rate f. Waiting times for transfusion.	N	There was no evidence of compliance with this QS.	N	There was evidence for a and c but not other aspects of the QS.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-703 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **For patients with sickle cell disease:** a. Proportion of patients with recommended immunisations up to date b. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required 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. **For patients with thalassaemia:** d. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) e. Proportion of patients who have developed new iron-related complications in the preceding 12 months.	N	An audit had been undertaken in 2007 but there was no evidence of more recent audit or of re-audit as recommended in 2007.	N	There was no evidence of audits as expected by the QS.
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	There was no evidence of audit of evidence-based guidelines. Network-wide audits had not yet been agreed.	N	There was no evidence of a rolling programme of audit. Network-wide audits had not yet been agreed.

Ref	Quality Standard	Met Y/N	Comment NUTH	Met Y/N	Comment STH
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N	There was no evidence of participation in research.	N	There was no evidence of participation in research.
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months.	Y		Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	This was met for the Trust-wide Transfusion policy but not for other policies.	N	Some policies were document controlled but not all.

NORTHERN HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comments
HY-199	**Involving Patients and Carers** 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 yet been formalised so compliance with the network standard was not yet achieved.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner.	N	As HY-199
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-205 and HN-206.	N	As HY-199

Ref	Quality Standard	Met Y/N	Comments
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	As HY-199
HY-502	**Clinical Guidelines** Network guidelines should have been agreed covering: a. Annual review (QS HN-502) b. Routine monitoring (QS HN-503) c. Transfusion (QS HN-504) d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-302) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-302) g. Transfer for critical care (QS HN-509) h. Specialist management (QS HN-510) i. Thalassaemia intermedia (QS HN-511) 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	As HY-199

Ref	Quality Standard	Met Y/N	Comments
HY-701	**Annual Meeting** 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	As HY-199
HY-702	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Register (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	N	All patients had been asked permission and had given consent to registering on the National Haemoglobinopathy Register.
HY-703	**Audit** 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	As HY-199
HY-704	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	As HY-199
HY-798	**Review and Learning** 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	As HY-199

COMMISSIONING

Ref	Quality Standard	Met Y/N	Comments
HZ-601	**Commissioning of Services** 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: a. Designated SHT/s for the care of adults with sickle cell disease b. Designated SHT/s for the care of adults with thalassaemia c. Accredited LHTs for care of adults with sickle cell disease or thalassaemia d. Other LHTs/ Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	N	Commissioning was through PCTs / CCGs. There were no plans for specialised commissioning and the algorithm was not appropriate to identify and commission specialised activity.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by each network, in particular, achievement of QS HY-702 and QS HY-798	N	Regular review was not in place due to small numbers. Joint commissioning with another centre, such as Leeds, was possible. (See main report).