WM QRS West Midlands Quality Review Service

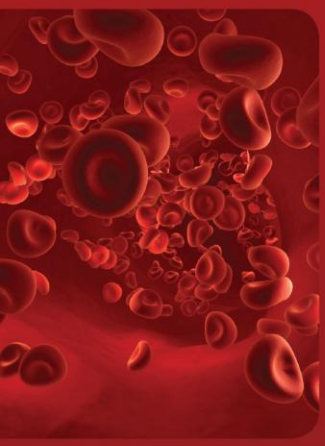
UK Forum on Haemoglobin Disorders

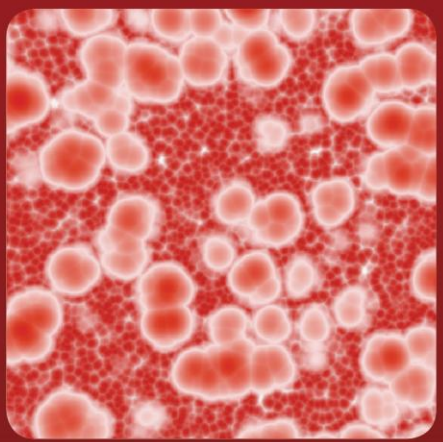
Health Services Caring for Adults with Haemoglobin Disorders

South Yorkshire and North Derbyshire

Sheffield Teaching Hospitals NHS Foundation Trust

Visit Date: March 20th 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 and thalassaemia in Sheffield Teaching Hospitals NHS Foundation Trust. 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.

This was the first visit in the programme of reviews of services for adults with haemoglobin disorders and Sheffield Teaching Hospitals NHS Foundation Trust had relatively little time to prepare for the visit. The Trust would undoubtedly have achieved a higher level of compliance with Quality Standards, especially those relating to clinical guidelines, if the visit had taken place later in the review programme.

ACKNOWLEDGEMENTS

We would like to thank the staff of Sheffield Teaching 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 SOUTH YORKSHIRE AND NORTH DERBYSHIRE

Trust Name	Hospital/s	Abbrev-iation	Reviewed as	Abbrev-iation
Sheffield Teaching Hospitals NHS Foundation Trust	Royal Hallamshire Hospital Northern General Hospital	RHH NGH	Specialist Haemoglobinopathy Team	SHT
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	Doncaster Royal Infirmary	DRI	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
Sheffield Teaching Hospitals NHS Foundation Trust	SHT	70	10	6
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	LHT	<5	<5	<5

NETWORK

Sheffield Teaching Hospitals NHS Foundation Trust provided specialist care for adults with haemoglobin disorders from South Yorkshire and North Derbyshire including patients from Sheffield and a small numbers of patients with sickle cell disease from the surrounding towns of Rotherham, Chesterfield and Barnsley. Doncaster Hospital (Doncaster and Bassetlaw Hospitals NHS Foundation Trust) had a small number of patients with sickle cell disease who were looked after by the local haematology team.

SPECIALIST TEAM: SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST

The Haematology Department at Sheffield Teaching Hospitals NHS Foundation Trust was based at the Royal Hallamshire Hospital. Eighty patients attended the service with 26 admissions in the last 11 months (258 bed days), 94 day cases and 130 follow-up and 10 new attenders in the out-patient clinic. Patients were occasionally admitted to the Northern General Hospital in Sheffield (for example, for orthopaedic surgery) and were reviewed on a daily basis by the haematology team based there who liaised with the Clinical Lead.

Accident and Emergency

The Accident and Emergency (A&E) Department was situated at the Northern General Hospital. Whilst patients were encouraged to present directly to the haematology ward at the Royal Hallamshire Hospital, they may attend A&E and approximately eight patients had been seen in A&E over the last 12 months. Any patients with sickle cell disease needing admission were transferred to the care of the haematologists at Royal Hallamshire Hospital as soon as possible (including night-time transfer). At the Northern General Hospital there was a haematology consultant, an experienced haematology associate specialist, speciality doctor and specialist registrar. They were responsible for the provision of specialist haematology on this site and were available to review patients during working hours.

Outpatient and Day Case Facilities

A monthly red cell clinic was held in medical out-patients by the lead consultant and attended by the Community Haemoglobinopathy Nurse. A specialist registrar sometimes attended this clinic in a supernumerary role. On arrival patients were given blood forms and went to the fifth floor to have blood tests before returning to clinic. No out of hours clinic appointments were available.

A joint obstetric-haematology clinic was run every two weeks. The clinical lead attended this clinic on an ad-hoc basis if there were pregnant patients with haemoglobinopathies.

A large Haematology / Rheumatology Day Unit was located next to the Haematology Ward. This was opened six days a week with examination rooms, recliners and day beds. NHS Blood and Transplant (NHSBT) had a therapeutic apheresis unit within the Day Unit.

In-Patient Facilities

The haematology department comprised a 30-bedded ward with 10 Hepa-filtered rooms. The ward was staffed by trained haematology nurses.

In-patient medical cover for patients with haemoglobin disorders was provided by the Lead Consultant or his Deputy who covered the wards on alternate months. A team of two junior doctors had responsibility for the in-patients with sickle cell disease. Out of hours care was provided by an on-call consultant (1 in 5 rota), a specialist registrar in haematology and the Hospital at Night team. Occasionally the Lead Consultant or his Deputy would be called out of hours by one of the other consultants for advice on specific sickle cell issues.

The palliative care / supportive care team was available at all times and provided an out of hours service if required. Red cell exchange during working hours was performed by the NHSBT team based on the Day Unit. This service had limited availability out of hours and, if not available, a manual exchange would be performed by the junior haematology staff.

Community Services

A Community Haemoglobinopathy Nurse covered paediatrics, adult and antenatal care. Patients were visited at home, if required, although the nurse was primarily based in hospital and saw the patients when they attended the out-patient clinic.

LOCAL TEAM: DONCASTER AND BASSETLAW HOSPITALS NHS FOUNDATION TRUST

The patients with sickle cell disease were offered annual review at Sheffield.

COMMISSIONING

The visiting team met with the Specialist Commissioner who was taking over responsibility for specialist commissioning arrangements. There was a good understanding of the regional prevalence of haemoglobinopathy and how it differed in local populations. There were no data on the number of admissions or use of health care locally by haemoglobinopathy patients. At the time of the visit the service was commissioned by the Primary Care Trust (PCT) / Clinical Commissioning Group and it was thought that the service was funded via a block contract for acute medical services. There were no plans to commission tertiary level services in any different way.

REVIEW VISIT FINDINGS

NETWORK

A formal network was not in place at the time of the visit. Protocols for the management of acute sickle cell disease were not in place in the linked hospitals. In-patient transfer to the Royal Hallamshire Hospital was usually offered but, if this was not possible, the clinical lead phoned the linked hospital on a daily basis to offer advice.

Further Consideration

1 A network of services including voluntary sector organisations and local authorities had not yet been formalised. Peripheral hospitals, although having very small numbers of patients, would benefit from having access to protocols provided from the specialist centre.

2 Service level agreements between provider Trusts may be helpful as part of the development of the formal network of care.

SPECIALIST TEAM: SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST

General Comments and Achievements

A committed, inspirational clinical team was leading the service with limited resources. Dedicated leadership was provided by the Clinical Lead and Community Haemoglobinopathy Nurse. Feedback from patient interviews and surveys was excellent. The in-patient and Day Unit facilities were of a very high standard with an experienced, flexible nursing team. Other achievements included a nurse-led leg ulcer service, nurse prescribing of iron chelation, the registration of all patients on the National Haemoglobinopathy Registry and a recent transition day.

Patients who needed urgent assessment and treatment had 24-hour access to either the Day Unit or the Haematology Ward, accessed by telephoning the ward. This provided flexibility and by-passed the A&E department. There were protocols for the management of pain on the intranet and A&E staff were aware of them. Two audits of the time to first dose of analgesia had been undertaken, but it was not clear if the patients audited were in A&E or on the ward. Only 57% of patients had received analgesia within 30 minutes on the second audit. It was not clear how this was being addressed.

The outpatient clinic was in a generic medical out-patient facility on the ground floor of the hospital, and although the Community Haemoglobinopathy Nurse said she brought information leaflets with her, one patient did comment on the lack of available patient information. If the Lead consultant was away the date of the clinic was re-scheduled. All patients were sent a text before the clinic and patients who did not attend were phoned by the Community Haemoglobinopathy Nurse.

All patients who were discharged from hospital on opiates were offered an appointment in the Palliative and Supportive Care clinic within two weeks of discharge. The co-location of the Red Cell clinic and the Palliative and Supportive Care clinic meant that patients could be reviewed in both clinics on the same day. Patient feedback was that this was helpful and about 12 patients were followed up on a long-term basis by this service.

All specialist services were available in the Trust and there was a regional pulmonary hypertension service, a joint obstetric clinic, an endocrine clinic (who review the thalassaemic patients at least yearly) and a nurse-led leg ulcer clinic. There was also a joint obstetric-haematology clinic run every two weeks. This was located in the nearby maternity hospital and was run by one of the consultant haematologists.

Formal transition arrangements were not in place but patients were transitioned on an ad-hoc basis with the Community Nurse providing continuity across the services. Reviewers noted that a transition event had recently been held in the Trust for haemoglobinopathy patients undergoing transition.

The Day Unit provided extended hours of opening which allowed availability for out of hours transfusion. Flexible access meant that it also provided an informal day care pain service for patients with sickle cell disease. Patient feedback on the service was very positive.

The Day Unit had recently been refurbished and was of a high standard. The Day Unit had recently extended its opening hours to 8am to 8pm Monday to Friday and 8am to 4pm Saturday and bank holidays. Several patients commented on the flexibility and helpfulness of the Day Unit. Teenage and young person day case facilities were under development and due to be completed shortly after the review. The three Cobe Spectra machines provided stem cell harvesting, leucopheresis, red cell and plasma exchange during working hours with a limited out of hours capacity, although there were no sickle cell patients on long term red cell exchange and only two red cell exchanges had been performed in the last 12 months.

Patients were encouraged to contact the Day Unit directly during working hours and, although there was no official day case pain service, patients were able to attend for review and receive analgesia and fluids as day patients. There was flexibility about whether patients were seen on the Day Unit or whether they were admitted directly to the Ward which seemed to depend on patient need and bed availability.

Age-appropriate facilities (4 beds and a lounge area) for 16 to 25 year olds were of a very high standard and received good patient feedback.

Most patients were reviewed by the palliative care (supportive care and pain) team during their admission, including any patient whose pain was not readily controlled by the usual pain protocol or who had previous problems achieving good analgesia. The palliative care team offered innovative targeted pain control and new agents. In practice this system worked well because patients were regularly reviewed by the palliative care / support care team, although the protocol on the intranet was complicated and out of date. Patients also had access to a massage service whilst in-patient. Patients were encouraged to contact the unit directly if they had problems and would be admitted directly to the ward if a bed was available or the Acute Assessment Unit if not. In

both areas they were looked after by the haematology team during working hours and the Hospital at Night team out of hours.

User Carer Feedback

The visiting team met two users and two carers who gave excellent positive feedback, in particular praising the flexibility of the team, the easy access out of hours and the liaison with the palliative care / supportive care team. Nine patients had completed a survey and were very positive about the care they received and the dedication of the staff.

Immediate Risk

No immediate risks were identified.

Concerns

1 The arrangements for the care by the Specialist Team were of concern for a combination of reasons:-

a. Formalised annual review was not yet undertaken for all patients.

b. Most of the expected guidelines and protocols for care of people with haemoglobin disorders were not yet in place.

c. There was no lead nurse for the care of adults with haemoglobin disorders.

d. Nursing staff on the Day Unit and in-patient ward did not have specific competences in the care of adults with haemoglobin disorders.

e. Only one consultant had a particular interest in care of patients with haemoglobin disorders.

f. Support for linked hospitals and network development was not feasible given the limited specialist staffing available.

2 A single Community Haemoglobinopathy Nurse covered paediatrics, adults and antenatal services. There was no cover for the post and arrangements for care of patients during planned or unplanned leave were unclear. A formal service level agreement (SLA) was not in place for the adult work undertaken so the governance arrangements for the post were unclear.

Further Consideration

1 Protocols and guidelines were in place but these were not comprehensive and did not always contain enough detail for someone without specialist expertise in haemoglobin disorders. For example, the protocols for transfusion indications in acute chest syndrome, how to perform a manual exchange and management of heart failure in thalassaemia all needed additional detail.

2 Patient information sheets may benefit from increased detail about the service and disease complications and treatment. Increased visibility of patient information in the ward, Day Unit and out-patient areas may also be helpful.

3 There were no clear links with a user group or support group and the patient feedback described feelings of isolation.

4 Social work and psychology support was difficult to access with long waiting times and, whilst it is recognised that it would not be feasible to supply specific services for this small number of patients, increased access, especially to social work support, would be of benefit for this patient group.

5 There was evidence of training of medical staff, particularly within the haematology unit. Haematology registrars may not, however, be exposed to sufficient patient numbers for adequate training. Consideration should be given to options for enhancing training, for example, through time in services with larger numbers of adults with Haemoglobin Disorders.

6 Expansion of the specialist nursing role to cover developing the competence of Ward and Day Unit staff may be helpful in order to ensure relevant competences to these staff are achieved and maintained.

7 A&E staff reported that they were aware of the acute sickle protocol but did not use it, giving parenteral morphine instead. An audit of A&E management may clarify this issue.

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

Good Practice

1 The palliative care / supportive care team provided an innovative and flexible service, offering a 24-hour acute and chronic pain service for in-patient and an easily accessible out-patient service and very good joint arrangement for pain management.

2 The Young Person's facilities on the Haematology Ward were of a high standard with a well-equipped patient lounge for young people who were admitted to hospital and provision of free televisions and Wi-Fi throughout the unit.

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 people with haemoglobin disorders due to problems counting and coding activity. Future developments towards a clinical network would be in line with the recommendations of the National Clinical Reference Group.

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
Verna Davis	Service Manager - Haemoglobin Disorders	Central Manchester University Hospital NHS Foundation Trust
Lindy Defoe	Specialist Nurse - Haemoglobin Disorders	South Tees Hospitals NHS Foundation Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Elaine Miller	Co-ordinator	UK Thalassaemia Society
Lindsay Randal	Specialist Nurse - Haemoglobin Disorders	Coventry and Warwickshire Partnership NHS Trust
Sharon Ensor	Key Opportunities CIC	Haemoglobin Disorders Review *on behalf of WMQRS*
Pip Maskell	Key Opportunities CIC	Haemoglobin Disorders Review *on behalf of WMQRS*
Sarah Broomhead	Quality Manager	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

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST

Ref	Quality Standard	Met Y/N	Comment SHT
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	It was not clear that the interpreter leaflet was available in other languages.
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 h. Relevant support groups g. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns h. How to get involved in improving services (QS HN-199)	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
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	There was no information for patients with thalassaemia. There was no information on 'e' (i) or (ii) specific to haemoglobin disorders. For (iv) there was some general advice in staying well in the priapism document but not general advice. Sickle Cell Disease: Information on 'a' may benefit from being more explicit. There did not appear to be any National Sickle Cell Society or UK Thalassaemia information available that patients and carers may find useful. Some additional information was available from the community liaison nurse.
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	Some information was covered in the clinic letters that were sent to GPs. 'c' was not applicable as shared care arrangements were not in place.
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	Patients were not routinely offered an individual care plan or a written summary of their annual review but some patients did have comprehensive plans within their clinic letters.
HN-106 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.	Y	A Trust-wide document was in place and the team had started transition meetings. Reviewers considered that further work with this group about the specific information they would require may be beneficial.

Ref	Quality Standard	Met Y/N	Comment SHT
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	'c' was not met.
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	
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.	N	Although there was cover this was not provided by a named deputy with regular experience caring for people with haemoglobin disorders.
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.	N	There was no lead nurse with overall responsibility. See main report.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	As HN-203
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	Mandatory training was in place but there was no evidence that nursing staff had specific competences for their role in the care of people with haemoglobin disorders. Medical and ward staffing appeared sufficient for the number of patients cared for by the service.
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	There was no training plan covering all staff for developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders. The training plan seen by reviewers was not haemoglobinopathy specific but did cover mandatory training and haematology disorders in general
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	'a' and 'c' were not met. There were plans to train staff in A&E.
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.	N	Some secretarial support for the consultant was available but not for collating data or for entering data into the National Haemoglobinopathy Register.
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	Nurse consultant support to those with leg ulcers was very good.

Ref	Quality Standard	Met Y/N	Comment SHT
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	Y	General psychology support was available but not by a psychologist with an interest in haemoglobinopathies.
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	
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	The facilities on the Day Unit were particularly good. See main report.
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	The Day Unit provided extended working hours and was able to provide out of hours access for blood transfusions.

Ref	Quality Standard	Met Y/N	Comment SHT
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	There were general Trust transition guidelines but these were not specific to haemoglobinopathies. In practice, processes were in place to address these issues.
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	The guidelines were very general. Little guidance was included for care of patients with thalassaemia. In practice, community liaison haemoglobinopathy nursing support and counselling was available. There was no evidence that annual reviews were 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.	Y	
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	N	The guidelines were general and did not include sufficient information for junior staff. The process for manual exchange would benefit from being more explicit.

Ref	Quality Standard	Met Y/N	Comment SHT
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	The North Trent Network guidelines had been adopted but these had limited detail about dosage and dosage adjustment and the guidelines did not cover trigger levels for the management and monitoring of iron overload. Monitoring of haemoglobin levels prior to transfusion was also not included. 'f' was not applicable as prescribing was not undertaken by GPs.
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	The guidelines did not cover all the requirements of the QS. For patients with thalassaemia the guidelines did not cover cardiac failure. For Sickle Cell Disease: 'd' only covered mesenteric pain and 'j' was not included.
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	Guidelines were in place in A&E but the pain management protocol written at Royal Hallamshire Hospital was not followed.

Ref	Quality Standard	Met Y/N	Comment SHT
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	The guidelines for chronic complications did not cover 'c', 'e' or 'f'.
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	
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	
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 for Thalassaemia Intermedia were not yet in place.

Ref	Quality Standard	Met Y/N	Comment SHT
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	An operational policy covering the requirements of the standard was not yet in place.
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	There were no formal MDTs but informal arrangements were in place.
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	An SLA was not in place since the transfer of community services to the Children's Hospital. Informal support was still available from the Community Liaison Nurse.

Ref	Quality Standard	Met Y/N	Comment SHT
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	Details of annual reviews and adverse events were not yet entered. Demographic data were included for all patients.
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	Monitoring of data on an ongoing basis was not yet in place.
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	The list for 'a' and 'b' was provided as evidence but it was not clear how this related to the proportion of patients. 'c' had been undertaken (80% 2009/2010 and 57% 2010/20112). Evidence of any action to improve compliance was not clear. For patients with thalassaemia an audit covering 'd' and 'e' had not been undertaken because of the small patient numbers.

Ref	Quality Standard	Met Y/N	Comment SHT
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	Relevant guidelines were not yet in place aand so several implementation could not be reviewed.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N	The lack of a research infrastructure meant that involvement was not possible. A non-malignant haematology research network had recently been set up.
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	Three monthly clinical meetings were in place. The mechanism for feedback to patient comments, including complaints, was not clear.
HN-799 All	**Document Control** 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** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	A formal clinical network was not yet in place.
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
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

Ref	Quality Standard	Met Y/N	Comments
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
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	As HY-199

Ref	Quality Standard	Met Y/N	Comments
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	A network of services including voluntary sector organisations and local authorities had not yet been formalised. There was evidence of some linked providers. Specialist commissioning arrangements were not in place at the time of the visit.

Ref	Quality Standard	Met Y/N	Comments
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 HY-798.	N	Clinical Quality Review meetings covering the relevant QSs were not yet in place.