WM QRS West Midlands Quality Review Service

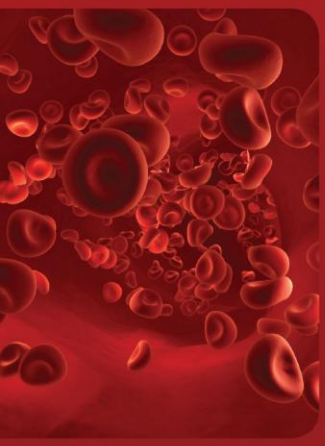
UK Forum on Haemoglobin Disorders

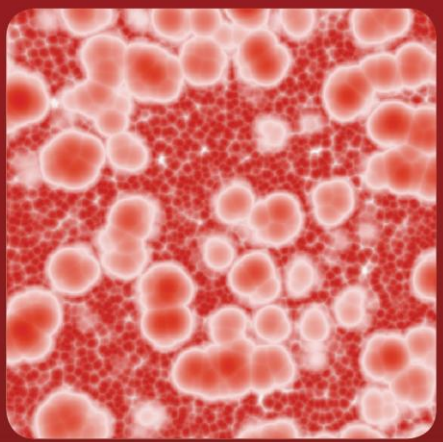
Health Services Caring for Adults with Haemoglobin Disorders

North West England

Central Manchester University Hospitals NHS Foundation Trust

Visit date: May 3rd 2012 Report Date: March 2013

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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 at Central Manchester University Hospitals NHS Foundation Trust. The linked hospitals were the Royal Liverpool and Broadgreen University Hospitals NHS Trust and East Lancashire Hospitals NHS Trust. The visit took place on May 3rd 2012. The purpose of the visit was to review compliance with the '*Quality Requirements for Health Services Caring for Adults with Haemoglobinopathies',* 2011. The visit was organised by the West Midlands Quality Review Service.

ACKNOWLEDGEMENTS

We would like to thank the staff of Central Manchester University Hospitals NHS Foundation Trust (CMFT) the Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUHT) and the East Lancashire Hospitals NHS Trust (ELHT) 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 WEST ENGLAND NETWORK

Trust	Hospitals	Abbrev-iation	Reviewed as:	Abbrev-ation
Central Manchester University Hospitals NHS Foundation Trust	Manchester Royal Infirmary	MRI	Specialist Haemoglobinopathy Team	SHT
Royal Liverpool and Broadgreen University Hospitals NHS Trust		RLBUHT	Accredited Local Haemoglobinopathy Team	A-LHT
East Lancashire Hospitals NHS Trust	Royal Blackburn Hospital Burnley General Hospital	RBH BGH	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
Central Manchester University Hospitals NHS Foundation Trust	SHT	209	52	32
Royal Liverpool and Broadgreen University Hospitals NHS Trust	A-LHT	40		<5
East Lancashire Hospitals NHS Trust and other referring hospitals	LHT		13	15

NETWORK

A network of services had not been formalised so compliance with the network standards was not yet achieved. The network also includes the following; Warrington and Halton Hospitals NHS Foundation Trust, Countess of Chester Hospital NHS Foundation Trust, Aintree University Hospitals NHS Foundation Trust, Wrightington, Wigan and Leigh NHS Foundation Trust, Bolton NHS Foundation Trust, Tameside Hospital NHS Foundation Trust, and The Pennine Acute Hospitals NHS Trust.

SPECIALIST TEAM: CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

Central Manchester University Hospitals NHS Foundation Trust (CMFT) is a teaching hospital with five hospitals: The Manchester Royal Infirmary (MRI), Manchester Royal Eye Hospital, St Mary's Hospital, Royal Manchester Children's Hospital and Trafford General Hospital. The Haematology Department was based at the Manchester Royal Infirmary. There were 264 patients attending the service with 127 admissions in the last 12 months (excluding Accident and Emergency only attendances) with an average length of stay of 2.7 days, and 332 day cases.

Accident and Emergency

Patients with sickle crises or acute complications of sickle cell or thalassaemia were advised to attend the Accident and Emergency Department (A&E) which was situated at the Manchester Royal Infirmary. During working hours patients were seen by the haemoglobinopathy specialist nurse and the red cell registrar.

Outpatient and Day Case Facilities

At Manchester there was a weekly Wednesday clinic (pm) for sickle cell and other general haemoglobinopathy patients. Thalassaemia clinics were held eight times a year (two per quarter). A new initiative was to hold alternate clinics as joint thalassaemia-cardiology clinics where the patients were offered simultaneous haematology and cardiology review. The clinics were held in the purpose built haematology clinic which was adjacent to the Day Unit and the Haematology Ward. The clinic was consultant run with a specialist registrar in attendance but only occasionally seeing patients independently. The clinic was also attended by the acute nurse specialist and one of the community sickle cell nurses. A nurse-run clinic for hydroxycarbamide monitoring was held every Thursday afternoon.

A joint haematology/obstetric clinic was held every Monday morning at St Mary's Hospital and was attended by the sickle cell and thalassaemia specialist midwife, haematologist and an obstetrician.

A formal transition clinic was held every six months.

The Haematology Day Unit was open from 8.30am to 5pm Monday to Friday, for transfusions and apheresis. Automated red cell exchange was available on the Day Unit and by the bedside for acutely unwell patients. Patients with thalassaemia booked into the Day Unit directly and were managed by the Day Unit staff.

Overnight transfusion was available in the Programmed Investigation Unit (PIU) and three to four patients used this facility.

In-patient Facilities

Patients were admitted either directly under the haematology team or by the medical team, according to the clinical problem. Outside normal working hours patients were admitted by the medical team and transferred to the haematology team the next working day. Patients were usually admitted to the general medical wards, and only infrequently admitted to the haematology ward. In-patient medical cover was provided by the lead consultant and team. Out of hours cover was provided by a haematology specialist registrar and on call haematology consultant.

Community Services

Manchester Sickle Cell and Thalassaemia Centre (SCTC) was located near the MRI. This had a Centre Lead, three specialist community nurses (adult) and one specialist midwife. One of the community nurses attended the hospital out-patient clinic. Staff provided community clinics as well as visiting patients at home. The community centre provided access to a social worker. The North England Bone Marrow and Thalassaemia Association (NEBTA) was based at the Manchester SCTC and had members from Leeds and Bradford as well as north west England.

User Feedback

The majority of patients seen by the review team were from Manchester but some were also from Blackburn.

Accredited Local Team: Royal Liverpool and Broadgreen University Hospitals NHS Trust

A team of doctors, nurses and managers from Liverpool (RLBUHT) attended the peer review visit and had partially completed their self-assessment. Some of the evidence was provided as internet links which it was not possible to review during the visit. The team at Liverpool cared for approximately 40 patients with sickle cell disease. Patients included students and some that were on long term transfusion therapy. There were no local patients with thalassaemia. One or two patients per month with sickle cell disease were admitted via A&E, and patients had open access to the Haematology Day Unit 9am to 6pm, Monday to Friday. RLBUHT also provided support to local hospitals. The lead consultant at RLBUHT had one clinic weekly where patients with myeloma and sickle cell disease were seen. About eight patients with sickle cell disease were seen per month.

New sickle patients were seen in a separate new patient clinic. A specialist haematology registrar worked with the lead in clinic and to cover in-patients. The transfusion practitioner organised the exchange transfusions of the small number of sickle patients who were on long-term transfusion via the National Blood Service (NBS) Apheresis Unit where a 24 hour automated exchange transfusion service was offered. A paediatric nurse specialist worked with the young patients through transition and also worked in the acute paediatric services.

Community Services

A part-time community nurse based in Liverpool was in post and covered adult services, paediatric, neonatal and antenatal screening, a 'drop-in' community service in the community centre and co-ordination of a patient support group. She covered Merseyside but not the Wirral. Patients were also offered annual review by the sickle cell community team at the Liverpool Sickle Cell and Thalassaemia Centre.

Local Team: East Lancashire Hospitals NHS Trust

The clinician from Royal Blackburn Hospital (RBH) attended the review and had completed a self-assessment. A thalassaemia clinic was held at RBH every three months and all patients with thalassaemia major and thalassaemia intermedia were seen annually at Manchester (or London), with the local clinician attending the Manchester clinic. A joint paediatric and adult haematology clinic was in place.

Community Services

There were no community services specifically for adults with Haemoglobinopathy Disorders in the Blackburn or Burnley areas.

Review Visit Findings

Network

General Comments

No formal network was established for the North West due to the relatively low prevalence of haemoglobin disorders. There were no formal contractual links between East Lancashire Hospitals NHS Trust and CMFT. Community services were available in the Greater Manchester, Liverpool and Merseyside areas, but there was no cover in the Wirral or Cheshire and patients there had to attend the Liverpool centre. There was very little community support for patients from the Blackburn area although patients attending clinics in Manchester could see community staff based in the clinic, including counsellors. A joint haematology obstetric clinic was

also run and some pregnant patients from Blackburn were cared for through shared care arrangements. Consideration might be given to the development of community outreach clinics.

Concern

Services provided by the smaller local units had low patient numbers. To achieve consistency in quality, these services would benefit from involvement through formal network arrangements. This would enable sharing of protocols, patient information and training resources. The creation of a formal network covering north west England should ensure access to annual reviews by the specialist team for all patients with haemoglobin disorders in the region.

SPECIALIST TEAM: CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

General Comments and Achievements

At Manchester (MRI) a committed, inspirational clinical team was leading the service with limited resources. Dedicated leadership was provided by the Clinical Lead, Clinical Nurse Specialist and Community Haemoglobinopathy Nurse. The Accident and Emergency Department saw two to four patients with sickle cell disease per week. Patients with acute sickle cell crisis were initially managed using an Emergency Department pathway. The Accident and Emergency pathways were robust and clear. The good working relationships between the haemoglobin disorders team and A&E staff supported the delivery of effective emergency care. The pathway was based on the Trust Protocol for Painful Sickle Cell Crisis. A&E staff were aware of the sickle cell protocols and these were readily available on the intranet. Laminated versions of protocol were apparent in A&E. Patients requiring analgesia not covered by the protocol had individualised care plans which were held by the patient and also available in A&E and the patient's records. There was evidence of repeated audits of analgesia, with action plans that had been implemented, and recently published clinical research. For example, audits of time to analgesia were regularly performed. A thorough staff training programme was in place. A clear protocol for hydroxycarbamide monitoring was used.

Other achievements included a nurse-led hydroxycarbamide service, a newly established thalassaemia cardiology clinic and a joint obstetric clinic. The facilities were good and included an electronic tracking system of observations for in-patients which bleeped when observations reached a level which required action. A clear and high quality transition document was being used which was given to the patients during childhood. They carried this with them until young adults which allowed monitoring of movement through transition. A clear transition protocol was used and highly regarded.

The staff on the Medical Admissions Unit commented that the specialist nursing support was timely and effective. The medical wards were familiar with the Sickle Cell Protocol and the use of patient-controlled

analgesia devices. A business case had been submitted to increase the number of beds on the Haematology Ward to allow admission of the sickle cell patients.

Patients were offered annual reviews in the clinic but this was not routinely recorded on the National Haemoglobin Registry. Assistance with data management might be beneficial.

Ten patients were on long term red cell exchange and these procedures were usually carried out by the clinical nurse specialist. This was time-consuming and not thought to be a best use of her skills and expertise. Femoral line insertion was performed by the junior doctor working on the day unit. There was a plan to train the Day Unit staff so they could take on the apheresis.

Overnight transfusion was available in the Programmed Investigation Unit (PIU) and three to four patients used this facility. One of the patients commented that it was often difficult to book into this unit in a timely fashion.

Community support in Manchester was good and comprehensive patient information was available. Support groups in Manchester were active. Two patient support groups for Sickle Cell Disease and an annual patient conference for children and adult patients and carers were held alternately with Liverpool. The Manchester SCTC was aiming to provide an outreach service into Blackburn, subject to obtaining funding. The feedback from patients was positive and they reported that the specialist team provided good care.

Any further local service developments had been put on hold pending the introduction of new commissioning arrangements from April 2013.

Immediate Risks

No immediate risks were identified.

Concern

1 There was no cover for absences of the nurse specialist in Manchester who had a heavy workload and numerous responsibilities, including providing an apheresis service, hydroxycarbamide monitoring, in-patient care and much of the nurse training.

Further Consideration

1 The annual review proforma used by the community team at Manchester was comprehensive but it was not clear how this information was communicated to the specialist team at MRI. There was duplication with the hospital clinic annual review. A clear communication process and a discussion between the teams might be helpful to ensure efficient annual reviews.

2 Psychology support for adults with haemoglobin disorders was not routinely available in the region. This was highlighted by patients following transition from paediatric services where psychology support was available. Arrangement for psychology support would benefit from review.

3 Whilst the majority of the patients were entered on the National Haemoglobinopathy Registry and adverse event reporting was done, annual reviews were not being recorded. Data support would help the service to meet this requirement.

4 The specialist nursing service was very reliant on a small number of individuals and cover for absences by staff with specialist expertise in haemoglobin disorders was usually not available.

5 A recent patient survey had been performed but not yet analysed. Service users indicated that they would like information on the results of this survey and feedback about resulting actions.

Good Practice

1 The patient information was of a very high standard, in particular the adult information pack, the transition information and the student information.

2 The protocols were of high quality and were comprehensive. The pre-operative and post-operative protocol and checklist were identified as being of particular merit.

3 The transition service was of high quality.

Accredited Local Team: Royal Liverpool and Broadgreen University Hospitals NHS Trust

General Comments and Achievements

In the evidence reviewed from RLBUHT the patient information and protocols were brief and generic. Sharing the protocols and information from the Manchester centre may be helpful. There were no formal network arrangements with Manchester, but regular teleconferences had recently been started. There was evidence of active support groups in Liverpool.

The patients had all been entered on the National Haemoglobinopathy Registry but had not undergone formal annual reviews.

It was not clear how often the Haematology Day Unit was used by patients. There was no specific acute clinical nurse specialist. A business plan for a part-time acute specialist nurse was produced in 2011, but not funded. There were no formal multi-disciplinary meetings.

Patients were given copies of their last clinic letter and a chemotherapy alert card if they were on hydroxycarbamide. An Audit/Service evaluation in 2010 revealed concerns about management of 'did not attend's, transition and chronic complications. Several changes had been made to the service as a result of this audit. One of these changes was that clear and thorough transition patient information had been developed and a transition clinic had been established which ran several times a year. All clinic patients were phoned by the consultant's secretary prior to their appointment to decrease the 'did not attend' rate. Patients had a yearly echocardiogram to check for pulmonary hypertension.

Care plans were in place in the community and the community nurse facilitated a support group. The community nurse role did not cover the acute service and only covered part of the local area. Cover for absence was provided by screening link health visitors. The paediatric nurse covered acute services and also provided community monitoring of hydroxycarbamide and iron chelation and visited children at home acutely to help with pain management. These services did not continue after 18 years of age and transition to the adult service.

Immediate Risks

No immediate risks were identified.

Concerns

1 At the time of the visit patients in Liverpool did not have access to specialist care meeting the expected standards for an accredited local team. In particular,

   a. appropriate patient information was not available

   b. patients did not all have annual reviews

   c. there was no lead nurse with specialist expertise in the care of patients with haemoglobin disorders or cover for this role

   d. there was no evidence that ward and day unit staff had appropriate competence in the care of people with haemoglobin disorders, and

   e. guidelines and protocols were brief and lacked the expected level of detail.

2 Community services were not available in Wirral or Cheshire. Patients in these areas were able to visit the community centre in Liverpool and receive support but were not offered support in their homes.

Good Practice

The transition service at Liverpool was of high quality. The team at Liverpool had worked very hard over the last two years to set up transitional care and the relevant patient information was also of high quality.

LOCAL TEAM: EAST LANCASHIRE HOSPITALS NHS TRUST

General Comments and Achievements

Whilst formal network arrangements were not yet in place there was a close working relationship between Manchester and Blackburn. All the Blackburn patients attended the specialist centre for annual review, and these clinics were attended by the local haematologist. Some protocols were shared with Manchester, but local protocols had been developed for thalassaemia monitoring and acute sickle management.

The majority of patients with sickle cell and thalassaemia in Greater Manchester were known to the MRI team and attended clinics at least once a year. Shared care arrangements with local hospitals were in place for patients outside Greater Manchester. These covered routine care and some common protocols and guidelines.

The clinician from the Royal Blackburn Hospital (RBH) had completed a self-assessment and attended the review for a discussion with the lead clinician. Seven adults at RBH with thalassaemia major were receiving regular transfusion and less than five patients with thalassaemia intermedia received intermittent transfusion. Patients received their transfusions at another hospital; in a ward at Burnley General Hospital (BGH). No sickle cell patients attended regularly. There were approximately three acute sickle admissions per year. Emergency care was provided through the Accident and Emergency Department using locally adapted protocols, based on protocols from MRI.

There was no acute or community nurse support for patients in Blackburn.

The Manchester SCTC saw newborn babies from the Blackburn area on a single occasion but provided no other routine support. Blackburn patients were able to attend the Manchester community centre and support groups on an informal basis, but there was no formal arrangement for this.

Some patient dissatisfaction and unease about the arrangements for transfusion at Burnley General Hospital was reported with particular concern that out-patient care took place at one hospital and transfusions at another. The patients also raised issues about communication between the two sites, for example, blood was not always ready for them. The facilities were not reviewed, reviewers did not meet managers from Burnley and it was not possible, due to timing issues, to discuss with the Lead Consultant at Blackburn on the day of the visit. However the Lead Consultant from the review team subsequently discussed this with the Trust and they clarified some of the issues. East Lancashire Hospitals NHS Trust operated over two sites: Blackburn site for

acute in-patient care and Burnley site for elective procedures. Both paediatric and adult patients were assessed clinically on the Blackburn site and had transfusions on the Burnley site with paediatric patients receiving their transfusions on Ward 27 and adult patients on Ward 16. There was a dedicated nurse for this role on Ward 27 but, in view of the small numbers of patients, this was not possible on Ward 16. Medical staff were always present on the Burnley site to review patients if needed and there was a robust policy for the transfer of unwell patients from Burnley to Blackburn if necessary. Any transfusion delays were documented and investigated, and the Trust was developing a schedule for adult patients to make the laboratory and clinical areas aware of transfusion dates for these patients. The Trust was planning to conduct a patient survey.

Immediate Risks

No immediate risks were identified.

Concerns

1 Patient feedback on the service provided between the Burnley General Hospital and Royal Blackburn Hospital was of concern and would benefit from a more detailed review against the Quality Standards.

2 There were no nurse specialists at Blackburn and development of local specialist nurses, or outreach nursing support from Manchester, should be considered.

COMMISSIONING ARRANGEMENTS

Despite being in the 'Minimum Take for Specialised Services' for 2012/13, the service was not commissioned through the Specialised Commissioning Group but through the PCT clusters.

Commissioners did not review quality of care as defined by data submission to the National Haemoglobinopathy Registry or learning from events.

Concern

The relationship between Central Manchester University Hospitals NHS Foundation Trust (CMFT) and any linked or local centre was not clearly defined. As the only provider in the North West with sufficient numbers of patients it is important that a formal arrangement is established by CMFT to provide specialist level input and support to other Trusts in the north west. This could be by means of provider to provider service level agreements (SLAs) and could take the form of shared care, outreach or in-reach with annual reviews being conducted by the Manchester team. This would require formal commissioning of specialist care for all patients from the CMFT service.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Jo Howard	Consultant Haematologist – Clinical Lead for Peer Review Programme	Guy's & St Thomas' NHS Foundation Trust
Dr Bernard Davis	Consultant Haematologist	Whittington Hospital NHS Trust
Dr Sara Trompeter	Consultant Haematologist	UCL Hospitals NHS Foundation Trust
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Sekayi Tangayi	Service Manager/Nurse Lead & Specialist Nurse	East London NHS Foundation Trust
Lindsay Randall	Specialist Nurse	Coventry & Warwick PCT
Rosena Geoghegan	Advanced Nurse Practitioner	Our Lady's Children's Hospital, Dublin
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Sherill Gregory	MHC-TR Manager (Nurse)	Croydon Health
Evelyn Schiller	Service User	Bristol
Jacqueline Simpson	Service User	Croydon
Elaine Miller	Voluntary Sector Representative	Thalassaemia Society
Pip Maskell	Quality Manager	Haemoglobin Disorders Review *on behalf of WMQRS*
Sue McIldowie	Observer	WMQRS

APPENDIX 2: COMPLIANCE WITH QUALITY REQUIREMENTS

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 but Specialist Haemoglobinopathy Teams may wish to take the opportunity to discuss them with the commissioner responsible for the service.

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

SERVICES FOR ADULTS WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	Information was excellent, especially within the adult and teen booklets.	N	'a' and 'b' only were met.	N	Evidence was not available for 'g'.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	Information was of a very good standard.	N	There was no specific haemoglobin disorder specific information. Some generic information was available that covered 'f' and 'g'. Reviewers were told that some information was provided via local internet links.	Y	Compliance was based on self-assessment information.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	Y		N	Information for patients with thalassaemia did not include problems, symptoms and signs for which emergency advice should be sought. Travel advice was not available. For 'b' and'e ii.' Information only related to sickle disease.	Y	Compliance was based on self-assessment information.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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).	Y		N	The community team provided information about 'a'.	Y	Provided by MRI.
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	Individual care plans were available in A&E and with the patient. However, they contained a variable range of information for some patients. There were plans in place to send clinical letters to patients in the future.	N	There was no summary of the annual reviews but clinic letters were sent to patients.	N	There were plans in place to send clinical letters to patients in the future.
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	Excellent transition information was available.	Y	Good transition information was available.	Y	Compliance was based on self-assessment information.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	A rolling programme of audit of patients' and carers experience was not in place. Some staff who met the review team did not know about / understand the complaints procedure. A recent survey had been undertaken but this had not yet been analysed.	N	There was no evidence on involvement of patients and carers.	N	There was no evidence on involvement of patients and carers.
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	The lead consultant had 4 PAs allocated for haemoglobinopathy work.	N	CPD information was not supplied relevant to the role and it was not in the job plan.	Y	

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	24 hour cover was available from the Haematology Consultant on call, and informal arrangements with a named colleague to cover annual leave of the lead consultant.	Y	24 hour cover was available from the Haematology Consultant on call, and informal arrangements with a named colleague to cover annual leave of the lead consultant.	N	However, there was general haematology cover.
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	The lead nurse knew the patients well and was functioning at a high level of competence and responsibility in caring for people with haemoglobin disorders.	N	However, a Transfusion Practitioner covered the small number of patients on long-term transfusion.	N	There was no lead nurse.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	There was no cover for the lead nurse.	N	There was no lead nurse and no cover for this role.	N	There was no lead nurse and no cover for this role.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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 had sufficient medical staffing with appropriate competence. However, whilst the support for lead nurse development was exceptional there was insufficient nursing staff for the number of patients cared for by the service. Community service provision was available except for patients living outside the Greater Manchester area.	N	There was no competence framework covering skill mix, staffing levels and competences expected. Evidence was available about training in the community but not in the acute trust.	N	No staff were specifically allocated to the care of adults with haemoglobin disorders.
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	Significant medical staff training was taking place. However the implementation of the training plan around pain management for nurses had not taken place due to lack of resources.	N	Although there was some evidence of some training there was no training plan in place.	N	There was no training plan in place.
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).	Y	The Lead Consultant taught Specialist Registrars from Merseyside and NW rotations. Teaching was also provided for A&E, pain nurses, medical students and a wide range of allied health professionals.	N	There was no programme of induction and training covering the care of patients with haemoglobin disorders. Some training had been undertaken for A&E staff.	N	No training on care of patients with haemoglobin disorders was undertaken.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	No support for data management was available.	N	Plans were in place to develop a data collection office and a dedicated Quality Manager to provide information and support within the Directorate. Data collection was a Trust-wide service.	N	No administrative, clerical or data collection support was available.
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	Contact details were in operational plans.	N	Evidence of timely access to support services was not available.	Y	

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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 access to named specialists except for 'b' and 'm'. A joint cardiology / thalassaemia clinic had been set up.	N	The self-assessment information stated that all services were available locally apart from psychology. There were no named specialists and no evidence of specialist interest in haemoglobinopathy.	N	However, some evidence was provided for 'b','d','f','g','i','j','k' and 'l'. Specialist support for other services were provided by MRI.
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		Y	

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	There were good protocols in place in A&E. MAU, Day Unit & Clinical facilities were good. An Electronic Patient Monitoring System was also in place.	Y	Compliance was based on self-assessment and discussion with staff as reviewers were not able to visit facilities.	N	Patients were seen in general outpatient clinics and transfused on the elective ward. The review team did not visit the facilities and compliance is based on self assessment.
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	However, for some patients it was sometimes difficult to be transfused overnight and to get a bed. Weekend service and out of hours phlebotomy had been offered but had not been taken up.	N	No phlebotomy out of hours service was available.	N	However, patients that required 'out of hours' care were admitted via the Emergency Department.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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)	Y	However, patient feedback indicated that in previous years there was insufficient communication in some areas. Although comprehensive transition guidelines had been implemented in recent years.	N	Evidence not clear for 'c' and 'e'. 'f' was not applicable.	N/A	
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	Y		N	There was no evidence of compliance with this QS.	Y	Compliance was based on self-assessment information.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	However, this was in general documentation.	N	There was no evidence of guidelines for routine monitoring.	Y	Compliance was based on self-assessment information.
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		N	There was no evidence of transfusion guidelines.	Y	Compliance was based on self-assessment information.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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.	Y		N	Clinical guidelines incomplete. For 'c', 'e' and 'f' there was no evidence and 'a', 'b' and 'd' were incomplete.	Y	Provided by MRI.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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).	Y	Although there were clinical guidelines on the management of acute complications the focus was on pain management and would benefit from more detail. There was a relevant pre and post operation checklist.	N	Clinical guidelines were available for 'a' to 'h' but they were very brief There were no guidelines for thalassaemia.	Y	Provided by MRI.
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	Good practice evidenced here.	N	There was no evidence of compliance with this QS.	Y	

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	There were no guidelines for 'f' and 'h'.	N	There was no evidence of compliance with this QS.	N	Provided by MRI.
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		Y		Y	Provided by MRI.
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	Good practice was identified within the monitoring sheets for care of patients with haemoglobin disorder during anaesthesia and surgery.	N	However, there were good clinical guidelines for care of patients during anaesthesia and surgery. 'c' was not applicable as there were no patients receiving hydroxycarbamide therapy.	Y	Provided by MRI.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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.	Y		N/A	There were no thalassaemia intermedia patients.	Y	Provided by MRI.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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.	Y		N	No evidence was provided.	N	There was no evidence for 'a'. Some evidence was provided to 'b' to 'f'.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	Some informal meetings were taking place however formal meetings had been planned.	N	There was no evidence of compliance with this QS.	N	There were no MDT meetings.
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.	Y		N	There was no specific SLA with community service but there was close liaison with specialists in Liverpool Community Health Care. A SLA may be reached through the national commissioning process.	N	There was no formal SLA for community services.
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	Patient data was available but annual updates were not entered into the National Haemoglobinopathy Registry.	N	Evidence was available that data had been entered but no adverse events or annual reviews were entered.	N/A	

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	A&E attendances data were not collected. Annual review data were incompletely recorded. Transfusion waiting times were not recorded.	N	Evidence of ongoing monitoring was not in place.	N	Evidence of ongoing monitoring was not in place.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	Clinical audit for 'a' and 'b' had not been undertaken. A comprehensive programme of rolling pain audits was in place. Although there was a protocol, no audit had been undertaken for patients with thalassaemia for monitoring iron overload.	N	Clinical audits had not been undertaken within the last two years.	N	Clinical audits had not been undertaken within the last two years.

Ref	Quality Standard	Met Y/N	Comment (MRI)	Met Y/N	Comment (RLBUHT)	Met Y/N	Comment (RBH/BGH)
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	Although there was regular audit of the acute sickle pain protocol it was not in place for all guidelines and protocols.	N	The service did not have a programme of audit but there was a plan to begin this soon after the visit.	N	The service did not have a programme of audit.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	Evidence of previous participation in research activity was available.	N/A		N/A	
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		N	Arrangements were not in place for review and learning but this was planned from 2012/2013.	N	There was no evidence of arrangements for review and learning.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	An excellent intranet site with easily accessible information was available.	N	A document control procedure was in development.	N	There was no evidence of document control procedures.

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	No formal network was established, however, work was in progress.
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	No formal network was established, however, work was in progress.
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	No formal network was established, however, work was in progress.
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	

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	
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	
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	
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	
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	

Ref	Quality Standard	Met Y/N	Comments
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	

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	There were informal arrangements with specialised commissioners but no formal commissioning of services for people with haemoglobin disorders.
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	Commissioners did not review quality of care as defined by data submission to the National data registry or learning from events.