WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services Caring for Adults with Haemoglobin Disorders

North West London

Imperial College Healthcare NHS Trust

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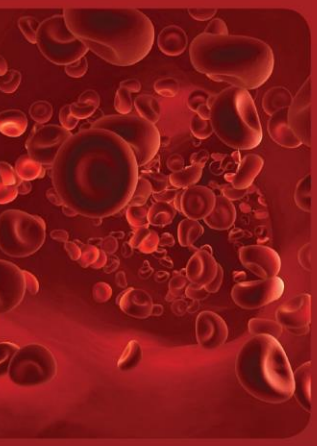


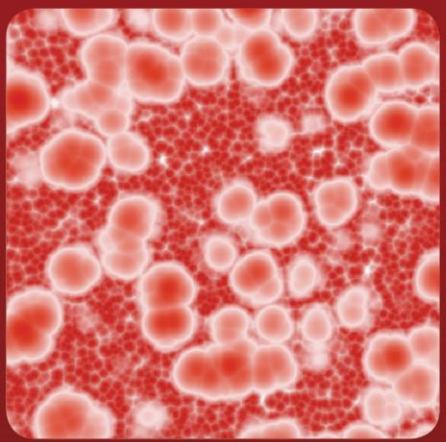


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INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia the North West London Network, in particular the Hammersmith Hospital, Imperial College Healthcare NHS Trust, which took place on January 29th 2013. The purpose of the visit was to review compliance with the '*Quality Standards for Health Services Caring for Adults with Haemoglobinopathies',* 2011. The visit was organised by the West Midland Quality Review Service and supported by the UK Forum on Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Programme.

ACKNOWLEDGEMENTS

We would like to thank the staff of Hammersmith Hospital, Imperial College Healthcare NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review.

ADULT HAEMOGLOBIN DISORDERS SERVICES IN NORTH WEST LONDON NETWORK

Trust Name	Abbrev-iation	Reviewed as:	Hospitals
Imperial College Healthcare NHS Trust	Imperial	Specialist Haemoglobinopathy Team (SHT)	Hammersmith Hospital St Mary's Hospital Charing Cross Hospital
North West London Hospitals NHS Trust	NWLHT	Specialist Haemoglobinopathy Team (SHT)	Central Middlesex Hospital Northwick Park Hospital

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
Imperial College Healthcare NHS Trust	SHT	321	38	46

NETWORK

Imperial College Healthcare NHS Trust (ICHT) was part of a managed clinical network that had been in place since 2004 and was the first in the country for haemoglobinopathies. The network comprised North West London Hospitals NHS Trust (NWLHT), Imperial College Healthcare NHS Trust (ICHT), Chelsea & Westminster Hospital, Ealing Hospital, West Middlesex Hospital and Hillingdon Hospital. A coordinator for the network had been provided through the lead Primary Care Trust until 2011 when funding was withdrawn. This had interrupted the momentum of the network which was undergoing reconfiguration at the time of the visit. Within the network there were established links between both Specialist Haemoglobinopathy Teams and local services with sharing of clinical protocols in some areas though these did not conform to a formal hub and spoke model. Network arrangements in London were dependent on decisions by Specialised Commissioning which had not yet been agreed.

SPECIALIST TEAM: IMPERIAL COLLEGE HEALTHCARE NHS TRUST

Accident and Emergency

Within Imperial College Healthcare NHS Trust, the Emergency Department (ED) at the Hammersmith Hospital was open 24 hours daily as was that of Charing Cross Hospital and St Mary's Hospital. Adult patients with acute sickle crises and thalassaemia were admitted to Hammersmith Hospital and were no longer admitted to Charing Cross or St Mary's Hospitals. At Hammersmith Hospital patients with acute sickle crises and thalassaemia presented to the department at any time. The ED was a relatively small unit run by the medical team. All patients seen at the ED at Hammersmith Hospital were reviewed by a haematology SHO or registrar during working hours and a 'hospital at night' SHO or haematology registrar out of hours. The sickle pain management protocols were available electronically and a hard copy was available in the ED. Hard copy files of individualised patient protocol were also available. At the time of the visit a re-structuring of the emergency departments within North West London was in process and the closure of Central Middlesex ED out of hours had impacted on the team, with an increasing number of patients attending out of hours rather than visiting Northwick Park Hospital ED. The future of the Hammersmith Hospital ED was also under question. In the event of closure there were plans to develop a 24 hour medical speciality assessment unit and therefore 24 hour access and medical care would continue.

Out-patient and Day Case Facilities

In-patient and out-patient areas were co-located and of a uniformly high standard. Clinics were attended by medical staff, specialist nurses and a social worker. The day-case centre offered long-term transfusions (top-up, manual and automated exchange). Day-case pain management was not available at the time of the review but plans were being developed for it at the time of the review.

A transition clinic was held monthly at St Mary's Hospital. Some types of elective surgery on haemoglobinopathy patients took place at Charing Cross Hospital under the supervision of the local haematology team. The review team did not visit these facilities. There was a joint haematology and obstetric clinic and good interaction with the other specialty medical teams, particularly the pulmonary hypertension service.

In-Patient Facilities

These were of high standard and provided on a 24 hour basis. Patients were always admitted into a haematology bed, usually on ward D7. The haematology team was available 24 hours a day and there was good cover from specialist haemoglobinopathy consultants.

Community Services

Unfortunately the peer review team was unable to meet the community nurses. Historically there had been minimal interaction with community services, although this was believed to be improving. Some patients were able to attend the Brent Sickle Cell and Thalassaemia Centre (SCT) but in general, local community services appeared to be relatively under-developed at the time of the visit.

User Feedback

The review team met several patients both as in-patients and in scheduled meetings.

REVIEW VISIT FINDINGS

NETWORK

General Comments

The configuration of the North West London Network was undergoing change at the time of the visit. Network arrangements in London were awaiting decisions by commissioners. At the time of the visit the structure and operation of the network did not conform to the requirements of the quality standards. There was a recognized need to reinstate the role of coordinator on which the previous successful functioning of the network had relied.

SPECIALIST TEAM: IMPERIAL COLLEGE HEALTHCARE NHS TRUST

General Comments and Achievements

This was a long established and excellent service with a nationally recognised clinical lead. The service was well organised and supported by a specialist nurse. There was a high level of patient satisfaction with in-patient care. A dedicated social worker had made significant impact to the holistic care of the patients and there were strong links with specialised services, including pulmonary hypertension, renal and obstetrics. The day case unit was open for extended hours on Saturday mornings, allowing flexibility for transfusions. There were plans to extend these opening hours further to include access to ambulatory pain management. There was good recruitment to clinical trials and basic science research was also ongoing. Of particular note was that the team had recently appointed a 0.4 w.t.e quality manager who had already had a significant impact on the governance of the service. Junior staff interviewed commented on the comprehensive induction programme that they had been through and the team also ran primary care training sessions. The Trust had an interpreter policy in place. Some of the patients had transferred their care from Charing Cross Hospital and were unaware of the mechanisms of contact, processes and structure of the services available to them at Hammersmith Hospital. In general, however, the feedback regarding the quality and care received from the specialist team was good. The 'iTrack' system was used to compile patient satisfaction surveys.

Immediate Risks

No immediate risks were identified.

Concerns

1 Only about half of the patients with haemoglobin disorders had been entered onto the National Haemoglobinopathy Registry (NHR). The updating of the NHR had been done by the specialist nurse and the team had no data management support.

2 One locum was in place as the deputy haemoglobinopathy consultant but the future of the post had not been secured. The peer review team considered that a substantive appointment of a second haemoglobinopathy consultant was essential to the sustainability of this high quality service.

3 There was little evidence of effective interaction with the community teams.

Further Consideration

1 Limited psychological support was available for this large population of patients and was provided through the Brent Sickle Cell and Thalassaemia Centre. The team had applied for funding for a psychologist but had not been successful. The provision of additional psychological support for this large population of patients should be considered.

2 At the time of the visit individualised pain protocols were only available in hard copy to staff in the emergency department and consideration should be given to making these available in electronic form.

3 There is a requirement within the Quality Standards for good document control and although the quality manager had already made significant in-roads, further work was needed.

COMMISSIONING

General Comments

Future challenges were linked to the changes in commissioning and network arrangements. The challenge was to ensure that the transition was managed in such a way that the knowledge of the commissioning arrangements for the adult haemoglobinopathy disorders service was communicated and that expertise was, where possible, retained within the new arrangements. There were some concerns from the patient's point of view regarding the regional configuration of emergency departments.

Good Practice

The specialist commissioner had developed a significant level of expertise and there was effective coordination across the network.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Josh Wright	Consultant Haematologist (Lead)	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Tullie Yeghen	Consultant Haematologist	Lewisham Healthcare NHS Trust
Dr Paul Telfer	Senior Lecturer (Honorary Consultant) in Haematology	The Royal London Hospital
Joanne Bloomfield	Specialist Nurse & Manager	Nottingham City Hospital NHS Trust
Kalpna Patel	Service User	Sickle Cell Society
Teresa Warr	Head of Service Development	South Central Specialised Services Commissioning Group
Pip Maskell	Quality Manager	Haemoglobin Disorders Review *on behalf of WMQRS*

APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

The Quality Standards are in the following sections:

HN - Services for Adults with Haemoglobin Disorders

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

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

Each section covers the following topics:

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

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

SERVICES FOR ADULTS WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Met Y/N	Comment
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	The supporting evidence was excellent and included an Interpreter Services Policy.
HN-102 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carerscovering at least: a. Brief description of the service, including times of phlebotomy and transfusion services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. How to contact the service for help and advice, including out of hours e. Staff of the service f. Community services and their contact numbers g. Relevant support groups h. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns i. How to get involved in improving services (QS HN-199)	Y	'Nutshell' booklets were issued to patients and carers and they contained specific information for sickle cell and thalassaemia. However, the patients seen were unaware of the service information.

Ref	Quality Standard	Met Y/N	Comment
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	There was good written information available for patients with sickle cell disease. Thalassaemia information required further detail.
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	There were plans to roll out the North West London Haemoglobinopathy Network guidelines for hydroxycarbamide therapy.
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	Y	
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	There were good leaflets and checklists in use.

Ref	Quality Standard	Met Y/N	Comment
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.	Y	There was evidence of robust statistical information regarding staff and patient knowledge about the condition. The patient feedback service '*iTrack*' was also utilised and a service user group had recently been established
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	Cover at the time of the visit was provided by a locum. Plans were in place for a substantive post.
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	
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	Cover for the Lead Nurse was provided by named linked nurses only.

Ref	Quality Standard	Met Y/N	Comment
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	There was no evidence for 'b' and 'c'.
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	Some documentation for nurse training was available. Ongoing training was under discussion.
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 comprehensive junior doctor induction programme was provided.
HN-298 All	**Administrative and Clerical Support** Administrative, clerical and data collection supportshould be appropriate for the number of patients cared for by the service.	N	A 0.4 w.t.e. quality manager was in post but support was not appropriate for the number of patients cared for by the service.
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	

Ref	Quality Standard	Met Y/N	Comment
HN-302 All	**Specialist Services** Access to the following specialiststaff 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	There was little evidence of interaction with the pain team for management of acute pain and reviewers considered that the psychology cover was limited for a service of this size.
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	Facilities were universally of a high standard.
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	

Ref	Quality Standard	Met Y/N	Comment
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	The transition guidelines were comprehensive.
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	
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	Y	

Ref	Quality Standard	Met Y/N	Comment
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	There were separate guidelines for sickle cell disease and thalassaemia, but 'f' was not fully in place.
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	
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	Electronic sickle cell disease guidelines were available in the ED but individualised pain protocols were only available in hard copy.

Ref	Quality Standard	Met Y/N	Comment
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.	Y	Evidence of strong links with respiratory, renal and obstetric departments was provided.
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	The service planned to use the North West London Haemoglobinopathy Network guidelines.
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.	Y	

Ref	Quality Standard	Met Y/N	Comment
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	There was no evidence for 'b', 'c', 'd' and 'f', however, there was a draft Operational Policy.
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).	Y	
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N	A draft service level agreement was in place.
HN-701 SHT A-LHT	**Data Collection** Data on all patients should be entered intothe National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	N	There was no data manager. Some data had been entered on to the NHR by the specialist nurse.

Ref	Quality Standard	Met Y/N	Comment
HN-702 All	**Ongoing Monitoring** The service should monitor on an ongoing basis: a. Number of patients having acute admission, day unit admission or A&E attendances b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year c. Length of in-patient stays d. Re-admission rate e. DNA rate f. Waiting times for transfusion	N	There was no information for 'd' and 'f'.
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	There were plans for an audit in February 2013 for both sickle cell disease and thalassaemia. Audits of pain control and immunisations had been undertaken.
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	There was no evidence for point 'b'. However, there was evidence for point 'a'.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	

Ref	Quality Standard	Met Y/N	Comment
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	There was a 'Red Cell' complaints log and evidence of quality meetings.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	See further consideration 3

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.	Y	
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	The network was not formalised at the time of the visit, so compliance with the network standards was not yet achieved.
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	The network was not formalised at the time of the visit, so compliance with the network standards was not yet achieved.

Ref	Quality Standard	Met Y/N	Comments
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	Transition guidelines were in the process of being approved.
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	Network guidelines for all the areas required by the QS had not yet been agreed. Guidelines for'd' and 'e' were in place.
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	The network was not formalised at the time of the visit, so compliance with the network standards was not yet achieved.

Ref	Quality Standard	Met Y/N	Comments
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	The network was not formalised at the time of the visit, so compliance with the network standards was not yet achieved.
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	The network was not formalised at the time of the visit, so compliance with the network standards was not yet achieved.
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	The network was not formalised at the time of the visit, so compliance with the network standards was not yet achieved.
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	The network was not formalised at the time of the visit, so compliance with the network standards was not yet achieved.

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	The network was not formalised at the time of the visit, so compliance with the network standards was not yet achieved.
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	There were shared protocol meetings but no clinical network quality meetings.