WM QRS West Midlands Quality Review Service

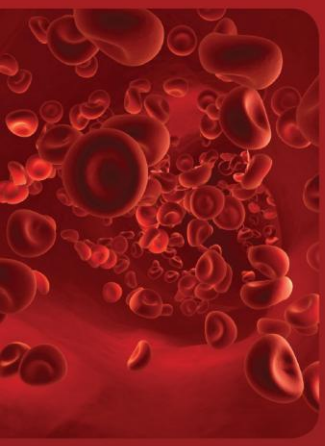
UK Forum on Haemoglobin Disorders

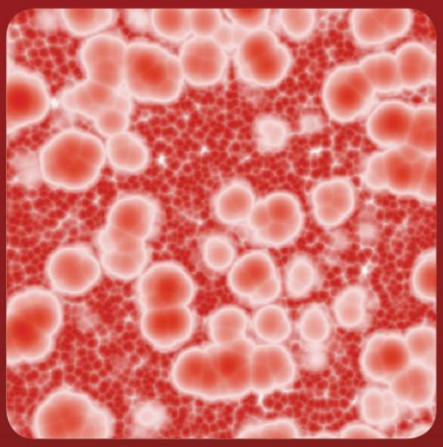
Health Services Caring for Adults with Haemoglobin Disorders

East London

Homerton University Hospital NHS Foundation Trust

Visit Date: January 15th 2013 Report Date: July 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 in the East London Network, in particular Homerton University Hospital NHS Foundation Trust, which took place on January 15th 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 Homerton University Hospital NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review.

ADULT HAEMOGLOBIN DISORDERS SERVICES IN EAST LONDON ADULT NETWORK

Trust Name	Reviewed as:	Hospital
Homerton University Hospital NHS Foundation Trust	Specialist Haemoglobinopathy Team (SHT)	Homerton University Hospital
Barts Health NHS Trust	Specialist Haemoglobinopathy Team (SHT)	The Royal London Hospital
Barts Health NHS Trust	Accredited Local Haemoglobinopathy Team (A-LHT)	Newham University Hospital
Barts Health NHS Trust	Accredited Local Haemoglobinopathy Team (A-LHT)	Whipps Cross University Hospital
Barking, Havering and Redbridge University Hospitals NHS Trust	Accredited Local Haemoglobinopathy Team	Queen's Hospital, Romford King George Hospital
Basildon and Thurrock University Hospitals NHS Foundation Trust	Linked Hospital	-
Mid Essex Hospital Services NHS Trust	Linked Hospital	Broomfield Hospital, Chelmsford
Colchester Hospital University NHS Foundation Trust	Linked Hospital	Colchester General Hospital
Southend University Hospital NHS Foundation Trust	Linked Hospital	-
The Princess Alexandra Hospital NHS Trust	Linked Hospital	-

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
Homerton University Hospital NHS Foundation Trust	SHT	312	21	< 5 thalassaemia major and HbH transfused 31 Sickle Cell Disease (5 Top up, <5 Exchange – manual, 24 Automated exchange)

NETWORK

Homerton University Hospital NHS Foundation Trust was one of two specialist centres within the East London Haemoglobinopathy Network but had separate protocols and pathways. The second specialist centre was at The Royal London Hospital. A collaborative relationship was in place with many of the local hospitals as part of the network and several of the centres in the network were visited. Barts Health NHS Trust was established in April 2012 consisting of six hospital sites: Mile End Hospital, The London Chest Hospital, The Royal London Hospital, Newham University Hospital, St Bartholomew's Hospital and Whipps Cross University Hospital. A collaborative relationship had been formalised with Barking and Havering NHS Trust as an accredited local centre and with several other linked centres in Essex (Basildon, Colchester, Chelmsford, Southend, and Princess Alexandra, Harlow). Homerton University Hospital NHS Foundation Trust was the second specialist centre within the East London Network which had separate protocols and pathways.

SPECIALIST TEAM: HOMERTON UNIVERSITY HOSPITAL NHS FOUNDATION TRUST

Homerton University Hospital NHS Foundation Trust was built in the 1980s to replace the Hackney Hospital. Whilst primarily an adult hospital, there was a paediatric Accident and Emergency Department (A&E). Paediatric in-patient and out-patient care took place at The Royal London Hospital. The majority of haemoglobinopathy patients who attended the Homerton University Hospital lived in Hackney, an area of high social deprivation. Young people transitioned for adult care from the Royal London Hospital. There were 312 adults with sickle cell disease known to the centre of whom 31 were transfused and 18 were treated with hydroxycarbamide. The number of adults with thalassaemia known to the service was 21, of whom less than five were transfused (both thalassaemia major and HbH). There were over 450 admissions per year, with over 2,500 day unit attendances and 547 out-patient attendances per year. A haematology day unit and an out-patient suite were on site. The haemoglobinopathy service was supported by community services in Hackney, which had been part of the acute Trust since 2011 and had a shared management team.

The service was supported by two consultant haematologists; a permanent consultant who primarily covered the out-patient service and a locum consultant who primarily covered the in-patients. The locum was working full time but covering a part-time post vacated as a result of retirement. Recruitment to a full time post later in the year was proposed. There was also a specialist registrar, a staff grade who worked primarily in the medical day unit, a F2 junior doctor, an acute clinical nurse specialist (CNS) and a community CNS. A new Lead Nurse and Sickle Cell Centre Manager had just been appointed.

Accident and Emergency

Less than 40% of emergency care was provided in A&E mostly out of normal working hours. During the normal working week patients were sent to the Medical Day Unit. 'Patient profiles' were used for all patients to ensure consistent pain relief. The profiles were a key method of communication, readily available on the local 'S-Drive', and accessed at each attendance.

Out-patient and Day Case Facilities

A general haemoglobinopathy clinic was held on a weekly basis in the general out-patient facility. This was attended by the lead consultant and the staff grade doctor. The clinic was cancelled if the consultant was away. An annual review clinic had been set up in the month preceding the visit. It aimed to review eight patients per week and was held in the MDU. Day case facilities were situated in the Medical Day Unit and haemoglobinopathy patients were the main users of this facility. There were four beds and five chairs reserved for haemoglobinopathy patients. Patients attended for planned appointments, post-discharge clinical reviews, hydroxycarbamide monitoring and blood transfusion. A heavily used drop-in service was available with a small number of patients accessing this on an almost daily basis. The transfusion service was nurse-led and the day unit staff carried out the automated and manual exchanges. The opening hours of the day unit had recently been expanded, following patient feedback, and it was now open from 9am to 7pm five days a week. One of the doctors from the Haemoglobinopathy Team was assigned to the day unit every day. The Acute Specialist Nurse provided haemoglobinopathy training to all nurses on an annual basis.

In-Patient Facilities

The patients were admitted from A&E or the day unit to the Acute Care Unit (ACU), or Lloyd ward, the haematology ward. Patient Controlled Analgesia (PCA) was available on both of these units. Patients admitted from A&E out of normal working hours were admitted and reviewed by the acute medical team and handed back to the haematology team the morning after admission. Patients coming from the Medical Day Unit were admitted directly under the haematology team. On Mondays to Fridays, patients were reviewed by the haematology team. Out of hours cover was provided by the on-call medical team with support from the haematology consultants who worked a 1 in 2 on-call rota.

Community Services

Hackney Community Services had been part of the acute Trust since April 2011 and the haemoglobinopathy service was developing closer working links with the community team. At the time of the visit, the community centre had one adult and one paediatric clinical nurse specialist, a welfare benefits officer, a social care liaison officer and a community development officer. The staff were primarily based in the sickle cell and thalassaemia centre but attended the hospital for a fortnightly multi-disciplinary team meeting. Individual patients were reviewed in hospital if required. A new lead nurse had just been appointed but was not yet in post and one of the responsibilities of the post was to manage both the acute and community nursing staff.

User Feedback

The review team met with a group of patients with sickle cell disease and carers.

Review Visit Findings

Network

General Comments

The specialist haemoglobinopathy team in Homerton University Hospital NHS Foundation Trust operated a stand-alone service with no linked hospitals and without shared protocols or pathways with the other specialist centre in East London at The Royal London Hospital, (Barts Health NHS Trust). The East London Haemoglobinopathy Network had met for the first time shortly before the review visit and was attended by the staff from Homerton University Hospital. The network was in the early stages of development and further work was needed before the services could work as a single service across the network. Although formal referral pathways were not yet in place there was a willingness to work together and a work plan had been developed that included a plan for joint audits.

Specialist Team: Homerton University Hospital NHS Foundation Trust

General Comments and Achievements

This was a large haemoglobinopathy service with committed medical and nursing staff who were highly valued by the patients and responsive to their needs. Patient consultation had been extensive and had contributed to a great deal of the service improvement in the year prior to the visit. Changes included the appointment of two part-time psychologists, development of an automated exchange programme, several patient workshops and the 'Experience Based Design Project'. Comprehensive information for patients with sickle cell disease and for primary care physicians had been developed which was of high quality, although there was little information for patients with thalassaemia. There were good staffing levels in the community services and

although these were not yet fully utilised by, or integrated with the acute service, plans were in place to do this. An excellent annual report included a thorough detailed work plan.

The A&E facilities were good and staff seemed well informed about how to access the 'patient profiles'. Patients stated they were generally seen promptly in A&E and that this had improved recently. An audit in 2012 showed that over 50% of patients received analgesia within 30 minutes. The Sickle Cell Handbook was available on the intranet and in paper copy but was a large document and not well indexed so staff might find it difficult to access information quickly in an emergency. Staff reported good support from the haematology team.

Patients and carers who met with the review team gave positive feedback about the haemoglobinopathy medical and nursing teams. They felt confident in their care and had good relationships with staff. Patients provided good feedback about the haematology day unit and transfusions were provided in a timely fashion. Patients felt that the care on both the day unit and in A&E had improved recently. Some concerns were raised about the care on the medical wards with several patients stating that the nursing staff did not seem very well informed about haemoglobinopathies and they often had to wait for analgesia. Patient feedback suggested that increased staff education, particularly in regard to sickle cell disease and crisis management, would improve the care received on the wards.

Good Practice

1 The individual 'patient profiles' were an excellent communication aid and their use was well demonstrated in all clinical areas.

2 A thorough planned programme of teaching, in particular for all nurses on the day unit and in A&E, was delivered by the acute nurse specialist on an annual basis.

3 The medical day unit had extended opening hours from 9am to 7pm, five days a week.

4 A welfare and benefits advisor was available in the local community, with time specifically allocated for people with haemoglobin disorders.

Immediate Risks

No immediate risks were identified.

Concerns

The arrangements for the care by the specialist team were of serious concern for a number of reasons:

1 Protocols for the management of thalassaemic patients were not available and, although this was a small part of the workload, there were some transfusion dependent thalassaemic patients. Information about monitoring and treatment of iron overload was inadequate and endocrine or cardiac monitoring were not mentioned. Whilst there was clinical evidence that iron overload was being monitored, this

was entirely dependent on the haematology consultant. There was no access to specialist services, for example endocrine, hepatology or cardiac services, which may be required for patients with thalassaemia. There was no routine access to cardiac MRI scans. These issues should be addressed urgently. Several centres in London with large numbers of patients with thalassaemia have clear guidelines and specialist clinics. Links with one of these teams may be helpful.

2 Transition clinics were not provided and the transition of care from paediatric to adult services was not clear. A pathway for the transfer of care from paediatric services was not in place.

3 The service's role as a specialist team was a concern for a number of reasons:

a) There were no specialist clinics on site and no clear guidelines about when patients should be referred to specialist clinics.

b) Access to specialist services was fragmented and patients were referred to several hospitals which had varying amounts of expertise. These referral pathways could be clarified to utilize local specialist clinics within the geographical region.

c) Some emergency specialist services for example, urology, were not available out of hours and there was no guidance on out of hours referral or management.

d) Despite large numbers of patients with challenging pain behaviour, liaison with an acute or chronic pain team was not in place.

4 Large numbers of day attendances were recorded, many of which were multiple attendees, and 16 patients accounted for 60% of emergency admissions. Small numbers of patients had very frequent and long hospital attendances. It appeared that some patients may be using the day service daily for injectable opiates for the management of chronic pain. Reviewers did not consider this an appropriate use of the day service and suggested that such patients may be better managed in conjunction with a chronic pain team and with community input. This problem had been recognised and a work plan was in place. It may be useful to review the data for multiple attenders separately from those who used the day unit appropriately for the management of acute pain since for the latter group of patients it was a highly effective service.

5 There was little evidence of network working and many of the concerns could be addressed by the development of a network with shared specialist services.

Further Consideration

1 When the consultant haematologist was absent the out-patient clinics were cancelled due to the lack of cover.

2 There was no data support and the 'patient profiles' (see Good Practice) were maintained by the consultant. Data on patients were being entered on the National Haemoglobinopathy Registry. Although the initial patient cohort had been entered by an administrator, ongoing data support was not available.

3 Cover for the lead nurse's absence was not available at the time of the visit

4 Opening the day unit at weekends may help to increase the responsiveness of the service to patients' needs.

5 Joint sickle/obstetric clinics were not offered so patients were reviewed by a specialist midwife in the obstetric clinic and were reviewed separately in the haemoglobinopathy clinic, often on a different day. Multi-disciplinary clinics might improve the patient experience.

COMMISSIONING

General Comments

Although commissioners had agreed the configuration of the clinical networks, the organisation and delivery of services within the East London network for people with haemoglobin disorders may benefit from further consideration.

Further Consideration

1 Network arrangements needed further consideration and formalising to clarify services for adult haemoglobinopathy across the network.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Jo Howard	Consultant Haematologist/Joint Clinical Lead for Peer Review Programme	Guy's & St Thomas' NHS Foundation Trust
Brigid Offley-Shore	Specialist Nurse	Ealing Hospital NHS Trust
Sekayi Tangayi	Service Manager/Nurse Lead and Specialist Nurse	East London NHS Foundation Trust
Natasha Lewis	Specialist Nurse	East London NHS Foundation Trust
Dawn Collier	Day Care Sister	University College London Hospitals NHS Foundation Trust
Kalpna Patel	Sickle Cell Society Staff Member and Service User	Sickle Cell Society
Chris Sotirelis	UK Thalassaemia Society Trustee	UK Thalassaemia Society
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	N	Evidence was available for 'c', 'd', 'e' and 'f'. Patients had not seen the 'light blue booklet'.
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	Although information had been available since March 2012, patients were unaware of the 'Patient Information Booklet' and it was not seen at the facilities visited.

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	N	Comprehensive information was available for sickle cell disease only and the information on chelation in the handbook was out of date.
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	Information on sickle cell disease was available in the Primary Care Handbook but not for thalassaemia.
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	However, there was evidence of records of consultations where changes to care had been discussed. The 'Patient Profile' was reviewed with the patient at each clinic attendance but patients were not offered a copy and were unclear who owned the profile.
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.	N	Paediatric care was based at The Royal London Hospital. The responsibility for making the arrangements for transition to adult care belonged with The Royal London Hospital.

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	
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.	Y	Cover was robust for acute episodes although the weekly clinic was cancelled in the absence of the lead consultant.
HN-203 All	**Lead Nurse** A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders.	N	However, a lead nurse had been appointed to commence in February 2013.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	There was no evidence of cover for absences of the lead nurse.

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.	Y	The RCN competences were not used.
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).	Y	
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	Training for A&E nurses in haemoglobinopathy was mandatory.
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	There was no specific administration support.
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	Fitness sessions were run for patients with sickle cell disease.

Ref	Quality Standard	Met Y/N	Comment
HN-302 All	**Specialist Services** Access to the following specialist staff and services should be available: a. Erythrocytopheresis or manual exchange transfusion (24/7) b. Acute and chronic pain team c. Pulmonary hypertension team d. Consultant obstetrician e. Fertility services f. Consultant cardiologist g. Consultant endocrinologist h. Consultant hepatologist i. Consultant ophthalmologist j. Consultant nephrologist k. Consultant urologist with expertise in managing priapism and erectile dysfunction l. Orthopaedic service m. Psychologist with an interest in haemoglobinopathies n. Specialist imaging o. DNA studies	N	There was no evidence for 'e', 'f', 'g', 'h' and 'i'.
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	
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, a weekend out of hours service was not available.

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)	N	There was no evidence of Transition Guidelines.
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First out-patient appointment b. Annual review for both sickle cell disease and thalassaemia	N	There was some evidence of clinical guidelines for annual reviews, however, these were incomplete.
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, early referral guidelines for thalassaemia patients were not seen.
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	The transfusion guidelines were comprehensive and easy to follow. However, there were no guidelines for thalassaemia.

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.	N	The information was brief and there was no evidence for 'e'.
HN-506 All	**Clinical Guidelines: Acute Complications** Clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision **For patients with thalassaemia:** k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	N	There was no evidence of guidelines for patients with thalassaemia. The information in the handbook was out of date for chelation.
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	The samples of patient profiles were very good.

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.	N	Local team guidelines made no reference to specialist services and there was no evidence for thalassaemia for 'b' and nothing covering 'd' and 'f'.
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	N/A	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	Y	However, thalassaemia was omitted.
HN-511 All	**Thalassaemia Intermedia** Clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy.	N	There was a small number of patients with beta thalassaemia major and thalassaemia intermedia.

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.	Y	There was a comprehensive 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	The multi-disciplinary team meetings were well established.
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	The community service was part of the team.
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	However, 68% of the patients were registered on the National Haemoglobinopathy Registry.

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	Formal data were not available, however, patients seen confirmed that the service was monitored on an ongoing basis and that there was no issue with waiting times for transfusions.
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	No audits were evident for patients with thalassaemia. However good information was available for patients with sickle cell disease.
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 participation in network-wide audits and the guidelines had not been amended following audit.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N	No evidence of participation in randomised, controlled trials was presented. However, there was an excellent, recent publication record of local initiatives.

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	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Limited network arrangements were in place but areas were covered in the proposed 2013-14 work programme.
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	Limited network arrangements were in place, with only one formal meeting having taken place, but areas were covered in the proposed 2013-14 work programme.
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	Limited network arrangements were in place but areas were covered in the proposed 2013-14 work programme.

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	Limited network arrangements were in place but areas were covered in the proposed 2013-14 work programme.
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	There was early evidence of partnership working. However, it is unclear at present where the annual reviews were undertaken. Barts Health NHS Trust was only established in April 2012 and the priority for the new Trust was to look at how The Royal London Hospital merged services with Newham University Hospital and Whipps Cross University Hospital.
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 had met on one occasion and had agreed an audit programme for 2013.

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	Limited network arrangements were in place but areas were covered in the proposed 2013-14 work programme.
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	Limited network arrangements were in place but areas were covered in the proposed 2013-14 work programme.
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	Limited network arrangements were in place but areas were covered in the proposed 2013-14 work programme.
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	Limited network arrangements were in place but areas were covered in the proposed 2013-14 work programme.

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	Y	Specialised Commissioners were working with providers in mapping networked hospitals and there was an initial map of the six proposed networks within London. Service developments should be agreed with local and specialised commissioners and should be consistent with national policy and reflect the guidance in the National Haemoglobinopathy Project.
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.	Y	London Specialised Commissioners held bi-monthly clinical quality review meetings with all providers of haemoglobinopathy services within London.