WM QRS West Midlands Quality Review Service

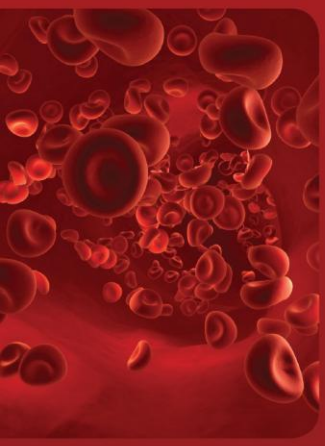
UK Forum on Haemoglobin Disorders

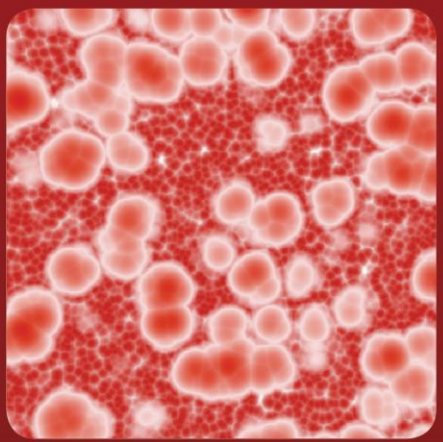
Health Services Caring for Adults with Haemoglobin Disorders

East London

Barts Health NHS Trust

Visit Date: January 9th 2013 Report Date: April 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 Royal London Hospital, part of Barts Health NHS Trust in the East London Network, which took place on January 9th 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 Midlands Quality Review Service and supported by the UK Forum on Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Programme.

ACKNOWLEDGEMENTS

We would like to thank the staff of The Royal London Hospital - Barts Health 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 THE EAST LONDON NETWORK

Trust Name	Reviewed as:	Hospital
Barts Health NHS Trust (RLH)	Specialist Haemoglobinopathy Team (SHT)	The Royal London Hospital
Homerton University Hospital NHS Foundation Trust	Specialist Haemoglobinopathy Team (SHT)	-
Barts Health NHS Trust (RLH)	Accredited Local Haemoglobinopathy Team (A-LHT)	Newham University Hospital
Barts Health NHS Trust (RLH)	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	Chelmsford General Hospital
Colchester Hospital University NHS Foundation Trust	Linked Hospital	Broomfield Hospital
Southend University Hospital NHS Foundation Trust	Linked Hospital	-
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
Bart Health NHS Trust – The Royal London Hospital	SHT	267	60	28 thalassaemia major (16 transfused elsewhere but reviewed at RLH) 42 sickle cell disease (15 Top up, 27 Exchange – manual)

NETWORK

The Royal London Hospital (RLH) had a collaborative relationship with many of the local hospitals as part of the East London Haemoglobinopathy Network and several of the centres in the network were visited. Barts Health NHS Trust was established in April 2012 from a merger of a number of Trusts, including The Royal London Hospital, Newham University Hospital and Whipps Cross University Hospital. The collaborative relationship had been formalised including with Barking, Havering and Redbridge University Hospitals NHS Trust as an accredited local centre and with several 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: BARTS HEALTH NHS TRUST – THE ROYAL LONDON HOSPITAL

Bart's Health NHS Trust was established in April 2012 following a merger of Barts and The London NHS Trust, Tower Hamlets Community Trust, Newham University Hospital NHS Trust and Whipps Cross University Hospital NHS Trust. The Royal London Hospital is situated in Tower Hamlets and near to Newham and Hackney. All of these areas had large numbers of patients with haemoglobinopathies. They provided local hospital services for the majority of patients resident in Tower Hamlets and many of the patients from Newham and Hackney as well as for smaller numbers of patients from further afield (including Waltham Forest and Barking and Dagenham). The PFI project at the The Royal London Hospital, completed in January 2012, provided new A&E, in-patient ward and day unit facilities. The out-patient facilities were located in the original site. There were 267 adults with sickle cell disease known to the centre of whom 42 were transfused and 28 were treated with hydroxycarbamide. The number of adults with thalassaemia known to the service was 60. Of these patients, 28 were transfused locally and 16 were transfused elsewhere but reviewed at RLH. There were over 300 admissions per year and over 2,000 day unit attendances. Over 1,000 follow up and 270 new out-patient attendances were recorded per year. The services consisted of a haematology day unit on-site, an out-patient suite and support by community services in Tower Hamlets, Hackney and Newham.

The service was supported by two dedicated consultant haematologists who alternated six months in paediatric and adult services and provided cross-cover for absences. A third consultant had just been

appointed to work across Whipps Cross and the Royal London sites. A specialist registrar and a whole time haemoglobinopathy clinical nurse specialist (CNS) were also part of the team.

Accident and Emergency

There were up to three A&E attendances per day and approximately six admissions per week. During working hours patients had the option of attending the haematology day unit for pain management. Patients arriving in A&E were seen within 10 to 20 minutes by a senior doctor (usually a consultant) and the aim was to give pain relief within 30 minutes of arrival. All patients known to the service had an individual health plan on the Electronic Health Record (EHR) which was easily available on-line. Four different pain protocols were in use and staff in A&E were familiar with these. Patients new to the service were treated with the standard pain protocol, but this was not available on-line at the time of the visit. There was regular teaching for the A&E medical staff.

Out-patient and Day Case Facilities

The out-patient clinics were situated a short distance from the main hospital and were in older, but adequate, facilities. A haemoglobinopathy clinic was held twice weekly. Specialist clinics in hepatology, renal and endocrinology were held three to four monthly. In addition, an evening clinic was held bi-monthly situated in the day unit. There was a weekly haematology-obstetric clinic, run by one of the other haematology consultants, but one of the haemoglobinopathy consultants would attend this clinic when a haemoglobinopathy patient attended. Day case facilities were situated adjacent to the hospital in part of the new PFI building. The day unit was not exclusively for haematology but shared with rheumatology and dermatology. Transfusions, both top up and manual exchange, took place here. There were facilities for evening transfusions bi-monthly, simultaneously with the evening clinic. The transfusion service was nurse-led and they carried out the manual exchanges. Facilities for automated exchanges were not available. A nurse-led open access service was available for acute pain management from 9am to 3pm Monday-Friday.

In-Patient Facilities

The patients were admitted from A&E or the day unit to the Acute Admissions Unit (AAU). The acute medical team admitted and reviewed patients who were handed over to the haematology team the morning after admission. Many patients and all those with acute sickle complications were reviewed by the haematology specialist registrar on the day of admission. The AAU was a 78-bedded service which had opened in January 2012, and was of a high standard. It was a consultant-led service where patients under all other specialities except haematology were reviewed on Mondays to Fridays by a speciality consultant within 24 hours of admission. Patients stayed on the AAU for 24 to 48 hours and were then transferred to a medical ward. No in-patient beds were allocated specifically to haematology and patients were often discharged from AAU to home. The haemoglobinopathy patients were reviewed by the haemoglobinopathy consultant who was covering the adult service at least twice a week, and more regularly if necessary. On the other days the patients were reviewed daily by the haematology specialist registrar, except for Wednesday and Friday when they were reviewed routinely by the clinical nurse specialist who would organise for medical review if required. When the

specialist nurse was away, the haematology specialist registrar did a ward round on Wednesday and Friday. Additional junior medical cover was provided by the AAU staff.

Out of hours cover was provided by a haematology specialist registrar, and the general haematology consultants who worked a 1 in 8 rota. The two haemoglobinopathy consultants were on a separate rota for paediatric haematology, but as they worked a 1 in 2 rota, one of them was always on-call and available to provide advice for the adult service.

Community Services

There were links with the community services from Tower Hamlets, Newham and Hackney. Nurses from each of these centres attended the fortnightly multi-disciplinary meetings and saw referrals in the community. Support groups were active in Hackney and Newham but not in Tower Hamlets, although the community nurse had tried to start one there on several occasions. A welfare and benefits advisor worked part-time in Hackney to support patients. Tower Hamlets Community Trust was part of Barts Health NHS Trust since its establishment in April 2012 and there was no SLA with the community sites.

User Feedback

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

REVIEW VISIT FINDINGS

NETWORK

General Comments

The East London Network had met for the first time shortly before the review visit. Further development 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. The specialist haemoglobinopathy team at RLH was not aware of the number of patients in the other centres.

SPECIALIST TEAM: BART HEALTH NHS TRUST: THE ROYAL LONDON HOSPITAL

General Comments / 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. They had produced an excellent annual report, which together with the work plan, gave a good picture of progress so far and further plans for the service. The services had recently moved to a new hospital building and the Trust had merged to become Barts Health NHS Trust.

Further changes in the service were expected. There was good evidence of previous and ongoing research. Transition had been highlighted as an area needing further work, and there was evidence of transition focus groups and a booklet about transition was in preparation. Staff reported good support from the haematology team. Regular teaching of medical staff in A&E was in place but not of nursing staff.

Feedback from the patients who met with the review team was positive about the haemoglobinopathy medical and nursing teams and patients stated that they felt confident in their care and had good relationships with staff. Feedback about the haematology day unit was good and patients said that transfusions were provided in a timely fashion. The patients raised some concerns about A&E care and care on the medical wards. Several patients stated that nursing staff other than from the haemoglobinopathy team did not seem very well informed about haemoglobinopathies. They suggested that their analgesic needs were not met in a timely fashion particularly for those who needed pain relief more frequently, and that sometimes their description of their level of pain was not believed. However the patients did feel that this had improved. Despite a high number of thalassaemia patients the review team only met with patients with sickle cell disease.

Good Practice

1 An excellent database was used and all out-patient consultations were entered on this in real time and patient letters were drawn directly from the database. This was a very useful tool both for clinical practice and for audit and research.

2 Supra-specialist clinics were run with renal, hepatology and endocrine input, which offered excellent specialist advice.

3 The team had worked closely with the pain team in the past and had an innovative approach to analgesia with four main protocols in use and each patient having an individual pain protocol.

4 Bi-monthly evening clinics were held with opportunities for patients to have evening transfusions.

5 A welfare and benefits advisor was available in the local community.

Immediate Risk: No immediate risks were identified.

Concerns

1 Nursing support was of concern for a number of reasons:

   a. Cover for the specialist nurse was not in place which was a particular problem on Wednesday and Fridays when she led a ward round. In her absence the ward round was covered by the haematology registrar, but they then did not attend clinic.

b. There was little evidence of nurse training or development of competences in the care of people with haemoglobin disorders in either the ward areas or in A&E and patients felt that nurses did not seem well informed about their condition.

c. Patient feedback included concerns that they often had to wait for pain relief whilst on the ward. An audit in December 2012 had shown that only 50% to 60% of patients received first dose analgesia within 30 minutes and it was not clear how this was being addressed.

2 Since the loss of the data manager post in summer 2012 the service had not had the resource to enter patient or annual review data onto the National Haemoglobinopathy Registry. It also limited their ability to collect data about patients in the wider network.

3 There was no designated in-patient area for care of haemoglobinopathy patients. This led to problems both on the Acute Admissions Unit (AAU) and when patients were moved from there to medical beds. The development of a specific haematology in-patient area and 'cohorting' of patients on the AAU would enable concentration of nursing education in one area and should lead to improved in-patient care.

4 Automated exchange transfusion was not available. In view of the large numbers of patients receiving manual exchange transfusion the provision of an automated service would have significant clinical and cost benefits.

Further Consideration

1 Access to community services with psychology services, benefits advice and support groups depended on patients' district of residence. These services were not available to over half the patients and provision of these services within the hospital setting may help to provide more equitable access. There were no SLAs with two of the three community centres.

2 Protocols and information leaflets were available but had not all been through document control and were not all available on the intranet. Reviewers were told this was due to the change in governance procedure with the formation of the new Trust.

3 Whilst out of hours transfusions were available, this was only twice a month and may benefit from expansion.

4 Developing common pathways across Barts Health NHS Trust would be beneficial and should be considered.

COMMISSIONING

General Comments

Barts Health NHS Trust was established in April 2012 from a merger of a number of Trusts, including the Royal London Hospital, Newham University Hospital and Whipps Cross University Hospital. For the purposes of the adult haemoglobin disorders peer review, services were visited at each of these hospitals. The priority identified by the Trust was to review services across the merged organisations.

Within the description of the East London Network several other small hospitals appeared to have a relationship with The Royal London Hospital as a Specialist Haemoglobinopathy Centre. The level of local and specialist care provision to those hospitals outside London was not clear. Although early partnership was evident it was unclear where the annual reviews were expected to be undertaken.

Commissioners of community services were not represented at the review meeting and therefore commissioning arrangements for these services were not discussed in detail.

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

Jo Howard	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Guy's & St Thomas' NHS Foundation Trust
Corrina McMahon	Consultant Haematologist	Our Lady's Children's Hospital, Dublin
Rhonda Foster	Specialist Nurse	Croydon NHS Trust
Dawn Collier	Day Care Sister	University College London Hospitals NHS Foundation Trust
Teresa Warr	Head of Service Development	South Central Specialised Services Commissioning Group,
Dr Chris Sotirelis	UK Thalassaemia Society Trustee Adviser	UK Thalassaemia Society
Patrick Ojeer	User / Carer Representative	London
Sharon Ensor	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 SHT
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y	The leaflets were in draft, of a general nature and lacked detail for specialist contacts.
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 the leaflets were in draft, patients had not seen them.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-103 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	N	The leaflets and information did not cover the range indicated in the Quality Standard. Leaflets for 'b' referred to sickle cell disease but not thalassaemia. Information on health promotion ('e') was not available, nor signposting for 'f'.
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	
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	A written summary of their annual review was not available to patients.
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	Transition information was available for sickle cell disease but not for thalassaemia.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	Y	However, not all patients were aware of how they could be involved and how patients were selected for participation. The mechanism for focus groups was in place but it needed more development.
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	However, the arrangement was reliant on the working practice of the incumbents and would need to be enhanced if the service expanded or started to provide support for other services in the network.
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 was not in place for the lead nurse.

Ref	Quality Standard	Met Y/N	Comment SHT
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	Staffing levels of nurses with appropriate competences in the care of people with haemoglobin disorders on the wards was not sufficient. Patients could be admitted to any available bed. There was no nurse specialist support for patients in the community.
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	Although a plan was in place it was aspirational and there was no evidence that it was part of ongoing maintenance of competence for the staff roles in caring for patients with haemoglobin disorders.
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	However, there was a minimal programme for ‘c’.
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 a vacancy and no data management.
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 SHT
HN-302 All	**Specialist Services** Access to the following specialist staff and services should be available: a. Erythrocytopheresis or manual exchange transfusion (24/7) b. Acute and chronic pain team c. Pulmonary hypertension team d. Consultant obstetrician e. Fertility services f. Consultant cardiologist g. Consultant endocrinologist h. Consultant hepatologist i. Consultant ophthalmologist j. Consultant nephrologist k. Consultant urologist with expertise in managing priapism and erectile dysfunction l. Orthopaedic service m. Psychologist with an interest in haemoglobinopathies n. Specialist imaging o. DNA studies	N	Whilst manual exchange transfusion was offered it was a cause for concern due to the numbers of patients. Access to a psychologist with an interest in haemoglobinopathies was not available.
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	However, the service had no specialty beds available for in-patients and consideration of 'cohorting' could benefit patients.
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, the out of hours transfusion was not adequate except in an emergency.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-501 SHT A-LHT	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable)	Y	The guidelines would benefit from more structure and removal of the confusion between the hospital and other partners. Transition 'passports' may also be beneficial.
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 SHT
HN-505 All	**Chelation Therapy** Clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT / SHT.	Y	
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	However, the guidelines were not available in A&E and pain expertise was only involved on request. Psychological support was not easily accessible.
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	However at the time of the visit the guidelines were not available on the intranet.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-508 All	**Clinical Guidelines: Chronic complications** Clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team.	Y	
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	N/A	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	Y	
HN-511 All	**Thalassaemia Intermedia** Clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy.	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	Y	
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	Multi-disciplinary meetings had full representation.
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	There was no SLA or honorary contract but it was planned for September 2013.
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	The main data were collected on the local database although there was no mechanism for automatically updating the National Haemoglobinopathy Registry.

Ref	Quality Standard	Met Y/N	Comment SHT
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	Ongoing monitoring was not in place for 'a', 'b' 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	Y	However, audit information was not available for other hospitals nor for 'e'.
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	However it was planned in the work programme.
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 SHT
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.	N	There were no dates on the documents.

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, only one formal meeting had 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	Barts Health NHS Trust was established in April 2012 and the priority was to look at integration of The Royal London services with Newham Hospital and Whipps Cross Hospital. There was early evidence of partnership working. At the time of the visit it was unclear where the annual reviews were undertaken.
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	The review team met with commissioners of specialised services only. Commissioners of community services were not represented. Specialised Commissioners were working with providers in mapping networked hospitals and there was an initial map of the six proposed networks within London. However the SHT as the driver for improving equity across the network was at an embryonic stage and it was unclear where Annual Reviews were to be undertaken.
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.