WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

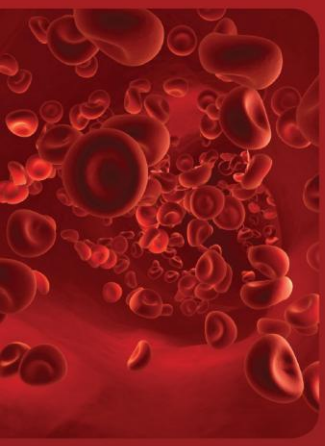
Health Services Caring for Adults with Haemoglobin Disorders

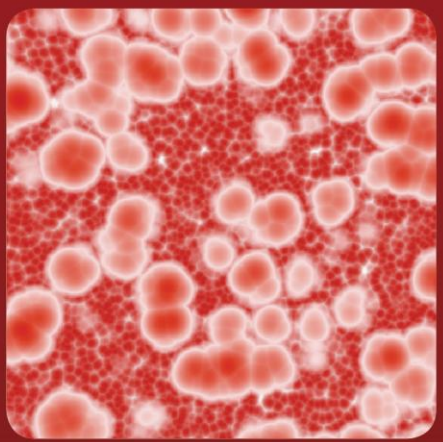
East London

Barts Health NHS Trust

Newham University Hospital

Visit Date: January 24th 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 Newham University Hospital, part of Barts Health Care in the East London Network, which took place on January 24th 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 Newham University 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	Specialist Haemoglobinopathy Team (SHT)	The Royal London Hospital
Homerton University Hospital NHS Foundation Trust	Specialist Haemoglobinopathy Team (SHT)	-
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
Bart Health NHS Trust – Newham University Hospital	A-LHT	530 known to community centre, but only 97 have care plans in the hospital	11	<5 (thalassaemia major and sickle cell disease)

NETWORK

The Royal London Hospital was a specialist haemoglobinopathy team with a collaborative relationship with many local hospitals as part of the East London Haemoglobinopathy Network. Several services 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.

ACCREDITED LOCAL TEAM: NEWHAM UNIVERSITY HOSPITAL

Newham General Hospital was built in 1993, and together with the Gateway Surgical Centre and community services made up Newham University Hospital, part of Bart's Health NHS Trust. Newham University Hospital was a 460 bed hospital covering a fast growing and diverse population, which was the most deprived in London and with the largest population under one year of age. There were two consultant haematologists who covered the entire haematology service. The register of Newham Sickle Cell and Thalassaemia Centre had 530 patients listed (the majority of whom had sickle cell disease) but it was not clear how many of these patients attended the hospital or other centres on a regular basis.

Accident and Emergency

All patients presenting acutely attended the Emergency Department (A&E). The staff aimed to see patients and administer pain relief within 30 minutes of arrival. There was a clear A&E protocol which was available on the intranet. The number of patients who were well known to the department and had patient protocols was 97. These patient protocols were available on the intranet to staff in A&E.

Out-patient and Day Case Facilities

There were two haematology out-patient clinics per week which were held in a generic out-patient area catering for all haematology out-patients. One was a new patient clinic and one was a follow up clinic. Both consultants were in both clinics providing good cross cover. There were no data on haemoglobinopathy out-patient attendances as these data was subsumed within total haematology attendances. A haemoglobinopathy multi-disciplinary team meeting was held prior to clinic on a fortnightly basis and was attended by the community team and (once monthly) by the psychologist. A monthly transition clinic for 12 to 16 year olds was run by one of the adult haematologists and a paediatrician. A nurse-led clinic was run by the clinical nurse specialist (CNS) alongside one of the haematology clinics. This was a dedicated haemoglobinopathy clinic for patients on transfusion programmes, patients on hydroxycarbamide and for those needing an urgent review.

The haematology day unit had been closed a few months before the visit so haematology patients were seen on the oncology day unit. Top-up transfusions were co-ordinated by the clinical nurse specialist. Elective manual exchange transfusions could be carried out on this unit if necessary. There was no facility for acute pain management. There were plans to re-open the haematology day unit, and a space was available, but this was not staffed at the time of the review visit.

In-Patient Facilities

Patients were admitted under the medical team and were usually admitted to the Emergency Medical Unit (EMU) for 24 to 48 hours before being transferred to the medical ward. The haematology consultant reviewed all patients in the EMU and on the medical wards on a daily basis (Monday to Friday). Out of hours cover was provided by the on call medical team with a haematology specialist registrar and consultant on call off-site, provided via a combined rota with the Royal London Hospital. The majority of in-patients were looked after on a single medical ward. There were 193 emergency admissions in 2011-12 with a 3.5 day average length of stay but it was not clear if this was just for sickle cell disease admissions or for all haematology admissions.

Community Services

There was an excellent local community service (Newham Sickle Cell and Thalassaemia Centre) which provided support for adult patients with haemoglobinopathy disorders. It ran a support group and patient educational events. It was staffed both by community nurses, a psychologist who could see patients in hospital if needed, a family liaison officer who provided family support, a social worker and a benefits advisor. Not all of the posts were full-time.

User Feedback

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

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 The Royal London Hospital was not aware of the number of patients in the other centres.

Concerns

1 Whilst the local team was aware of specialist services at the Royal London Hospital clear referral pathways into these specialist services were not yet in place.

2 The local centre had copies of the specialist centre protocols but there was no evidence that these were being implemented or were available beyond the haematology team. Local protocols for both acute and chronic disease management were brief or incomplete. The specialist centre protocols should be urgently implemented.

Accredited Local Team: Newham University Hospital

General Comments / Achievements

This was a small but committed team which faced challenges both in meeting the socio-economic needs of their local population and in responding to the recent merger into Barts Health NHS Trust. An excellent community team provided good patient support and education. They participated in regular multi-disciplinary team meetings and provided psychology and benefits support. There were good facilities, especially in A&E. A clear nursing care plan was in use. Regular nursing teaching sessions took place on the medical ward provided by the clinical nurse specialist (CNS). Users gave positive feedback about the personal service they received from the medical and nursing team and about the transition service. Documentation of regular teaching sessions for junior medical staff in the care of people with haemoglobin disorders was provided but was not available for nursing staff.

Good Practice

1 A multidisciplinary adult/paediatric clinic was held for patients from 12 to16 years of age. A patient passport was in use and an individualised service was provided.

2 The community team had made patient information DVDs for sickle cell disease and had a unique family liaison post.

3 There were clear flow charts for patient pathways and those for A&E care and care of surgical patients were particularly clear.

Immediate Risks

No immediate risks were identified.

Concerns

Services for adults with haemoglobin disorders were of serious concern for a number of reasons:

1 There was no evidence of protocols or guidelines for care of patients with thalassaemia, no access to specialist services and little patient information. There were only small numbers of thalassaemic patients and this concern could be resolved by referral of these patients for review at a specialist centre, at least on an annual basis.

2 Out of hours and weekend cover was not robust and no on-site cover was available. User feedback and review of critical incidents suggested that out of hours cover was inadequate with long waits for analgesia and a lack of recognition of deteriorating patients. Patients reported that they frequently had to wait more than 30 minutes for analgesia and that staff in A&E were not well informed about sickle cell disease. There had been no recent audit about time to analgesia. Protocols covering the management and recognition of acute complications had insufficient detail for non-specialist staff. There should be urgent consideration of implementation of protocols from the specialist centre and development of referral pathways.

3 Good clinical data were not readily available. It was not clear how many patients regularly attended the centre and how many day attenders and out-patient appointments took place. There was no evidence of formal annual reviews of patient care. Patients were not entered on the National Haemoglobinopathy Registry and there were no plans to implement this or adverse event reporting.

4 Mortality and morbidity meetings took place on a local level (within the MDT) but there was no evidence of effective feedback from these meetings or of learning from them.

5 There was no cover for the lead nurse and although the lead nurse undertook a lot of nursing education the RCN competences were not yet being implemented.

Further Consideration

1 There was a strong community service but the communication from the hospital was often sub-optimal. The community service may be able to support the lead nurse.

2 The operational policy had clear flow charts and patient pathways but it was not clear that these were being followed in practice.

3 Access to guidelines should be improved. On the day of the visit not all staff members knew where the protocols could be accessed and others were not yet available. For example, the primary care guidance which had been produced by the specialist centre was included in the evidence folder but was not yet in use.

4 Nursing and medical education was taking place but not always in a systematic way. Attendance was not documented and there was no regular nursing teaching for staff on the Emergency Medical Unit in the care of people with haemoglobin disorders. The lead nurse should be supported in introducing nursing education, including the RCN competences, into A&E, EMU, medical wards and obstetric wards.

5 There was little specific patient information available at the time of visit. Good resources were available in the community centre and at the specialist centre which could be used.

6 There was no haematology day unit facility available at the time of the visit and no availability for exchange transfusion. There were large numbers of transfused children in the service and planning for how this will be managed on transition should take place. Out of hours provision for transfusion was not provided.

7 There was no evidence of liaison with the pain team and patient controlled analgesia was only available on the surgical wards where there was little nursing knowledge about sickle cell disease.

8 One small audit of vaccinations showed a large number of patients without a GP and a large number of unvaccinated patients. Consideration should be given to providing vaccinations for out-patients.

COMMISSIONING

General Comments and Achievements

Barts Health NHS Trust was established in April 2012 from a merger of a number of Trusts, including Barts and the London NHS Trust, Newham University Hospital NHS Trust and Whipps Cross University Hospital NHS Trust. For the purposes of the adult haemoglobin disorders peer review services were visited at each of these Trusts. 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 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.

The service was commissioned at the time of the visit as part of a block contract with Newham Primary Care Trust / Newham Clinical Commissioning Group and from 2013/14 would be incorporated in the Barts Health NHS Trust contract.

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
Dr Sara Trompeter	Consultant Haematologist and Paediatric Haematologist	University College London Hospitals NHS Foundation Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Jon Currington	Senior Strategy & Planning Manager	East Midlands Specialised Commissioning Group
Katie Read	Volunteer representative	UK Thalassaemia Society
Kalpna Patel	Service User	London
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 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	
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)	N	There was information from the Sickle Cell Society and the Thalassaemia Society, some of which was out of date. No local information was available. The community service had a Facebook page which increased its accessibility. There was a proposal to develop a patient information leaflet for Barts Health, with specific information about Newham University Hospital.

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	However, they had a good DVD that covered 'a'. There was also some information for 'f'. Verbal information was given to cover some of these aspects and there were plans to develop a Barts Health leaflet.
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 had been generated by the Royal London Hospital and they had plans to roll this out across Barts Health but this had not been done at the time of the visit. Guidance for GPs was not provided as they do not prescribe these medications for Newham patients.
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	There was no formal annual review and no evidence of care plans, however, all patients were offered a copy of their clinic letters.
HN-106 SHT A-LHT	**Transition Information** Information should be available for young people covering arrangements for transition to adult care. This information should cover all aspects of QS HN-501.	N	However, a transition passport was provided to patients. Patients gave positive feedback on transition arrangements.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	N	However, speakers attended annual community-led patient conferences. Coffee mornings and workshops were also arranged for patients and carers. A patient survey was planned for 2013.
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	There was no written evidence of CPD. Reviewers were assured that CPD had been undertaken.
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	
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	Nursing cover was not provided.

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	However, there was evidence of appropriate training for 'c' and a rollout of national competences was planned for 2013. The designated ward that cared for patients with sickle cell disease had nursing staff with a sickle cell link nurse.
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	However, the training plan did not cover all staff or the RCN competences.
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	Not all nurses in A&E had up to date training covering the care of patients with haemoglobin disorders. (See main report).
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 evidence of dedicated administrative or clerical 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	

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	Most of these services were available off site but the referral pathways were not clear. There were plans to implement clear referral pathways as part of the merger with Barts Health.
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	Space on the day unit facility was limited. However, there were plans to open a new haematology day unit in Spring 2013.
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.	N	No routine out of hours care was available.

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 were in the Operational Policy but would benefit from being available separately.
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	However, there was evidence of 'a'. Royal London guidelines (Barts Health) were available for 'b' but were not yet in use.
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.	N	Adult Sickle Cell and Thalassaemia Royal London guidelines were available and there were plans to use these in the future. Indications for early referral were not clear.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	N	There was information for 'b' and 'c' only. There were plans to implement these guidelines as part of the Bart's Health merger.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-505 All	**Chelation Therapy** Clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT / SHT.	N	Adult Sickle Cell and Thalassaemia Royal London guidelines were available and there were plans to use these in the future.
HN-506 All	**Clinical Guidelines: Acute Complications** Clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision **For patients with thalassaemia:** k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	N	The available local information was incomplete and brief. Adult Sickle Cell and Thalassaemia Royal London guidelines were available and there were plans to use these in the future.
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	A comprehensive, user friendly flow chart was used.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-508 All	**Clinical Guidelines: Chronic complications** Clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team.	N	Guidelines for 'a' and 'b; were brief and there was no evidence for 'c', 'd', 'e', 'f', 'g' and 'h'.
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	Adult Sickle Cell and Thalassaemia Royal London guidelines were available and there were plans to use these in the future but they were not currently in use.
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	N	There were guidelines for 'a' and 'b' but nothing for 'c'.
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	Adult Sickle Cell and Thalassaemia Royal London guidelines were available and there were plans to use these in the future but they were not currently in use.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	N	There was insufficient evidence in the Operational Policy to cover areas 'b' and'd'. 'c' was not applicable.
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	However, no minutes or Terms of Reference were available.
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	However, there were plans for this in the work programme to be agreed by 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	There was no data manager post and no plan in place for managing data collection.

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	No monitoring for 'b' and 'f' and there were doubts around the accuracy of the data for 'e'.
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 was no audit information for 'b', 'c', 'd' and 'e'. There was a brief audit of 15 patients for 'a' but no action plan resulting from this.
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 were plans to audit compliance when final guidelines have been agreed.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N	No current research.

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	N	Some reviews had taken place but there was no evidence regarding outcome implementation and learning.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	There were plans to implement document control procedures when Barts Health NHS Trust documents had been validated.

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 only established in April 2012 and the priority was to look at how the Royal London merged services with Newham Hospital and Whipps Cross Hospital. There was early evidence of partnership working. However, it is unclear at present 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	Specialised Commissioners were working with providers in mapping networked hospitals and there was an initial map of the six proposed networks within London.

Ref	Quality Standard	Met Y/N	Comments
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by each network, in particular, achievement of QS HY-702 and HY-798.	N	London Specialised Commissioners held bi-monthly clinical quality review meetings with all providers of haemoglobinopathy services within London. At the time of the visit information from Newham Hospital haemoglobinopathy service was not submitted to this meeting.