WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

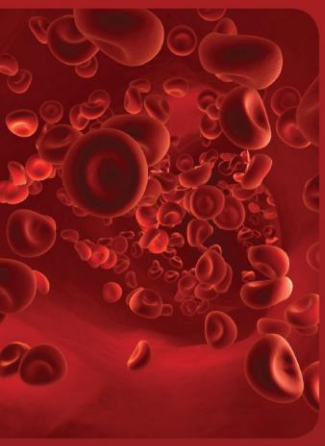
Health Services Caring for Adults with Haemoglobin Disorders

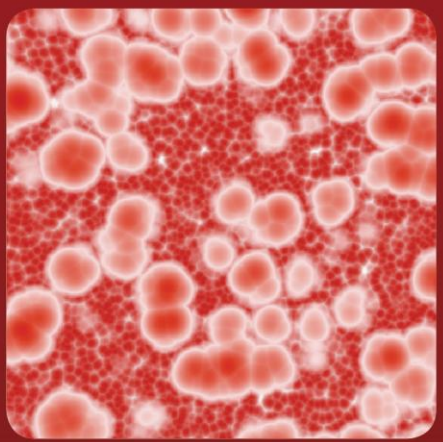
East London

Barts Health NHS Trust

Whipps Cross University Hospital

Visit Date: January 30th 2013 Report Date: August 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 Adult Haemoglobinopathy Network, in particular Barts Health NHS Trust - Whipps Cross University Hospital, which took place on January 30th 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 Barts Health NHS Trust - Whipps Cross University Hospital 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 HAEMOGLOBINOPATHY NETWORK

Trust Name	Reviewed as:	Hospital
Barts Health NHS Trust	Specialist Haemoglobinopathy Team (SHT)	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's Hospital
Basildon and Thurrock University Hospitals NHS Foundation Trust	Linked Hospital	-
Mid Essex Hospital Services NHS Trust	Linked Hospital	Broomfield Hospital

Trust Name	Reviewed as:	Hospital
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
Barts Health NHS Trust - Whipps Cross University Hospital	SHT	180	<5	<5 thalassaemia and sickle cell disease

NETWORK

Whipps Cross Hospital as part of Barts Health NHS Trust, provides local secondary care for Waltham Forest and adjacent boroughs of Redbridge and Epping. As an accredited local centre it collaborated 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 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: WHIPPS CROSS UNIVERSITY HOSPITAL

The haematology department was being re-configured as part of the merger to form Barts Health NHS Trust. The single handed consultant at Whipps Cross University Hospital had been joined by a new consultant a fortnight before the visit and was a joint appointment between Whipps Cross University Hospital and the Royal London Hospitals. The area served by Whipps Cross University Hospital was ethnically diverse with a 40% black and minority ethnic population. Although 180 admissions of patients with sickle cell crisis occurred per annum the majority of out-patient work had been devolved to the community.

Emergency Department

Patients in acute crisis were admitted via the emergency department (ED) which had been refurbished and expanded. An acute care protocol was available in ED and a rapid triage system was in place for patients with sickle cell disease which was meant to ensure that analgesia was given within 30 minutes. An audit concentrating on this aspect of the service was underway at the time of the visit. Junior medical staff were offered regular teaching sessions.

Out-patient / Day Case Facilities

Haematology clinics were held in a generic out-patients suite but the majority of patients with haemoglobin disorders were seen in the GP-led community clinic. At the weekly out-patient clinic, general haematology (non-malignant) and patients with haemoglobin disorders who had just been discharged from the ward, had particular medical problems or who had been referred from the community, were reviewed. Each week between two and five patients with haemoglobinopathy disorders attended. The haematology consultant had attended the paediatric sickle cell disease clinic and worked alongside the paediatric consultant to support

seamless transition from paediatric to adult care but no transitional arrangements were in place at the time of the visit.

The day care facilities were provided in a generic day unit of high quality. The majority of the patients seen on this unit were haemato-oncology patients although less than five haemoglobinopathy patients, including sickle cell disease and thalassaemia patients, received regular top up transfusions there. All these patients were reviewed at least annually at the specialist centre at the Royal London Hospital.

In-Patient Facilities

Patients were usually admitted under the care of the acute physicians to the Emergency Medical Centre, a new facility, and subsequently admitted to general medical wards under the care of the general medical consultants. The haematology team reviewed them on a daily basis Monday to Saturday but day to day care was provided by the medical teams. Out of hours care was by the medical team but there was a haematology specialist registrar and consultant on call 24/7 as part of the Barts Health NHS Trust rotation which also covered Newham University Hospital and the Royal London Hospital.

Community Services

The community service was based at Wood Street Health Centre and was staffed by 1.5 w.t.e. community clinical nurse specialists. The out-patient service had been moved to the community service in 2009 and was initially run by a local GP and attended by the haematology consultant who offered support and training. The haematology consultant had stopped attending the clinics in 2011, and the initial GP was on maternity leave. At the time of the visit the clinics were covered by another GP who had received no specific haemoglobinopathy training.

User Feedback

The review team met with a group of users and carers.

Commissioning

Some of the review team met with local commissioners from Waltham Forest Clinical Commissioning Group (CCG).

Review Visit Findings

Network

General Comment

The East London Network had met for the first time shortly before the final review visit from within the network. 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. It was not clear how this would impact on the adult haemoglobinopathy services provided across the Trust or at Whipps Cross University Hospital.

Accredited Local Team: Whipps Cross University Hospital

General Comments

The service was under-resourced and until three weeks before the review, had been managed by a single-handed consultant with little other support. The recent appointment of a new consultant post with responsibility for haemoglobinopathy patients may address some of the issues in the report but the job plan for the newly appointed consultant had not been finalised at the time of the visit. The appointment of this post and the merger into Barts Health NHS Trust offered opportunities for development of the service and the potential for shared learning and education. The community model was innovative, patient centred and engagement with the Clinical Commissioning Group was good. However this model was not currently fit for purpose and considerable investment and development was needed for it to offer an alternative way of providing haemoglobinopathy care in the future. Engagement with the acute pain team for in-patients was good.

The acute care protocol available in the emergency department (ED) lacked detail on many complications, apart from acute pain. A recent audit and patient feedback suggested that the waits in ED could be long and despite the rapid triage system patients with sickle cell disease did not always receive analgesia within 30 minutes. Also, within ED there was no systematic nursing education.

The acute care protocols were brief, especially as the primary care givers were not haematologists, although comprehensive protocols from the Barts Health NHS - Royal London Hospital were available via the intranet. The regular education sessions provided for the junior medical staff were not attended by all staff who had responsibility for these patients and there were no regular teaching sessions for nursing staff.

Protocols on chronic disease monitoring, first visit or annual review follow-up, or criteria for referral to the Whipps Cross University Hospital or to any specialist unit, were not available at the time of the visit. On review of the patient notes systematic monitoring of chronic disease complications was not evident. Letters were sent to the hospital consultant after each patient visit and there were no multi-disciplinary meetings or other regular communication between the community and the hospital team. The Clinical Commissioning Group (CCG) had reviewed the community service six months before the review visit and reported similar findings to the review team. A business case had been developed to increase resources in the community clinic and to increase haematology support but this had not yet been agreed by the CCG.

In addition this service was only available to Waltham Forest residents and the out-patient follow-up for patients' resident outside Waltham Forest but attending Whipps Cross University Hospital was not clear.

Patients who met with the review team commented that they were not clear who was their lead consultant and they did not know who they should contact when ill for urgent care or for routine health problems.

Immediate Risk

The review team had a major concern about the quality and safety of the current provision of out-patient care and chronic disease management in the community setting. The GP running this service had not had any specific training in the care of patients with haemoglobinopathies. There were no protocols for out-patient investigations, no guidelines for when onward referral to specialist services should be made and appropriate systematic annual investigations and reviews were not taking place. In this situation it is likely that chronic disease complications would not be picked up, or would not be investigated or treated in an adequate manner, which could lead to serious patient morbidity or even mortality. This was confirmed in writing to the Chief Executive of the Trust, the Chief Operating Officer of the Clinical Commissioning Group and the Local Specialised Commissioning Group.

This is not a criticism of the community clinic model of care but specialist haemoglobinopathy care should be provided for haemoglobinopathy patients either by haematology consultant attendance in the community service or by referring these patients back to the hospital out-patients clinic. There are several models of how this could be resolved but the community clinic should not continue in its current format.

Concerns

The review team had serious concerns about the service for a number of reasons:

1 The team had no hospital clinical nurse specialist (CNS) and this gap in service was reflected in the lack of nursing training, lack of health promotion and lack of engagement with or use of the RCN competences. The appointment of someone to a CNS post, either as a Trust appointment or as a joint appointment with the community, would address these issues.

2 Few protocols were available and those that were seen by the review team were brief, sometimes out of date and without quality control. The merger with Barts Health NHS Trust provided access to the comprehensive protocols from other teams but these would still need to be localised. Referral guidelines to the specialist centre were not available and these should be developed.

3 Although the thalassaemia population was small, no patient information leaflets available were available. Management protocols were not available. Again this could be resolved by liaison with the Royal London Hospital. Although the regularly transfused patients had regular review at the specialist centre, their interim review arrangements were not clear and the management of non-transfused iron loaded patients was not clear.

4 The haemoglobinopathy out-patient and day unit data was not available and ongoing data collection was not in place. Patients were not being entered onto the National Haemoglobinopathy Registry, adverse events were not reported and annual reviews were not performed or recorded.

5 Both medical and nurse training was not systematically provided which is especially important as patients were looked after on general medical wards by general medical teams.

6 Robust transition arrangements were not yet in place although a recent meeting had been held with the consultant paediatrician to address this issue.

7 Access to a high risk obstetrician was no longer available and haematology/obstetric multi-disciplinary meetings were not taking place. It was not clear how pregnant haemoglobinopathy patients were offered care and a plan was not in place to address this gap in service provision.

Further Consideration

1 Little patient information was available. Patient information could be made available locally from the Royal London Hospital or from Newham Community Centre so this issue could be easily addressed.

2 A support group was not available for patients.

3 Few recent audits had taken place and no audit plan was available.

4 There were no out of hours facilities for transfusion or out-patient review.

5 There was no access to specialist psychology, social work support or benefits advice

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COMMISSIONING

General Comments

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 haemoglobinopathy peer review services were visited at each of these Trusts. The priority identified by the Trust was to review all services across the merged organisations. Although early partnership working was evident across adult haemoglobinopathy services it was unclear where the annual reviews were undertaken.

Although the commissioners had agreed the configuration of the clinical networks, 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 of London was not clear. Although early partnership was evident it was unclear where the annual reviews were expected to be undertaken.

The Clinical Commissioning Group was represented at the review meeting but it was unclear how patients accessed specialist care or annual review within the community model that was operating.

Further Consideration

1 Network arrangements needed further consideration and formalising to clarify services for adult haemoglobinopathy across the network and in particular, within the community model used at Whipps Cross University Hospital.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Jo Howard	Consultant Haematologist/Joint Clinical Lead for Peer Review Programme	Guys & St Thomas' NHS Foundation Trust
Dr Sara Trompeter	Consultant Haematologist and Paediatric Haematologist	University College London NHS Foundation Trust
Rosena Geoghegan	Advanced Nurse Practitioner Candidate in Haemoglobinopathy	Our Lady's Children's Hospital, Dublin
Brigid Offley-Shore	Specialist Nurse	Ealing Hospital NHS Trust
George Constantinou	UK Thalassaemia Society Trustee Adviser	UK Thalassaemia Society
Jon Currington	Senior Strategy & Planning Manager	NHS East Midlands Specialised Commissioning Group
Rita Protopapa	Quality Assurance Programme Manager, Haematology	St George's Healthcare NHS Trust
Nicola Howe (Observer)	Senior Commissioning Manager	London Specialised Commissioning Group
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
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	Service information was not easily accessible for service users and their carers. The information available was brief and generalised.
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	Written information was not available for thalassaemia and was only available for 'b','e' and 'f' for sickle cell disease. It was supplemented with general information provided by the Sickle Cell Society and Thalassaemia UK. The patients who met the review team did not know who their primary doctor was or who they should contact when they had an issue. They were unclear whether to contact their own GP or the doctor at the Wood Street Health Centre.

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	There was no information about haemoglobin disorders other than signposting of where to find further information for sickle cell disease.
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	Plans were in place to roll out the Information generated by the Royal London Hospital across all the local units of Barts Health.
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	Patients did not have a care plan except in the emergency department and the Emergency Medical Centre. Letters were copied to patients after consultation and the information was shared between community and hospital.
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	Information was provided about the joint clinic which had allowed seamless transition. The clinic had stopped at the time of the visit but an initial meeting had taken place with the newly appointed dedicated red cell consultant to begin to discuss transition arrangements.

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.	N	No formal mechanism existed for involving patients and carers. However a recent survey had taken place using a new patient questionnaire in the community.
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.	N	A lead consultant had been appointed three weeks before the visit. There was no job description and the job plan was vague and it was unclear how the lead consultant would undertake Continuing Professional Development of relevance to this role.
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.	N	The team did not have a lead nurse working with the lead consultant, responsible for guidelines, protocols, training and audit relating to haemoglobin disorders, including responsibility for liaison with other services within the network. The RCN competences in caring for people with haemoglobin disorders were not being used.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	The two community clinical nurse specialists provided cover for each other.

Ref	Quality Standard	Met Y/N	Comment
HN-205 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available.	N	The service had insufficient staff. There was not designated consultant to lead/develop/improve service (point 'a') and specific staff were not designated for haemoglobin disorders (point 'b').
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	A training plan had not been produced.
HN-207 All	**Training Plan – Other Staff** A programme of induction and training covering the care of patients with haemoglobin disorders should be run for: a. Clinical staff in the Emergency Department b. Non-consultant medical staff c. Allied health professionals working with the SHT / LHT (QS HN-301).	N	A programme of induction and training covering the care of patients with haemoglobin disorders was available but only for some of the cohorts of medical staff in the emergency department.
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	Administrative support was limited.
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	However it was not clear how patients outside the Waltham Forest area accessed services.

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	Specialist services were available from the SHT at the Royal London Hospital. 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.	N	The review team did not see the certificate.
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.	N	Facilities were available until 6pm twice weekly.

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	Transition guidelines were not available although it was possible to access the guidelines from the Royal London Hospital through the Barts Health NHS Trust intranet.
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	Guidelines were available but were out of date, there was no document control and were not used. It was possible to access the guidelines from the Royal London Hospital through the Barts Health NHS Trust intranet.
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	Guidelines were not available although it was possible to access the guidelines from the Royal London Hospital through the Barts Health NHS Trust intranet. Guidelines for routine monitoring in the community were not being used.
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	Guidelines only covered the hospital transfusion policy.

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	Patients on regular transfusions were all referred to the SHT. Although there was access to the guidelines from the Royal London Hospital they were not localised or being used.
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	Clinical guidelines were inadequate because of their brevity. A referral form or description of the clinical pathway for patients needing emergency department review was not available from Wood Street Health Centre.
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	Guidelines on the management of acute complications were in use in the emergency department but they were in need of revision and were out of date.

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	In particular the reference to 'pain cocktail' was considered inappropriate and no referral pathway guidelines were available.
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	Guidelines were not in place for transfer to critical care.
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	Guidelines were not available but it was possible to access the guidelines from the Royal London Hospital through the Barts Health NHS Trust intranet although these were not used.
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	Clinical guidelines for the management of thalassaemia intermedia were not available.

Ref	Quality Standard	Met Y/N	Comment
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	N	Although points 'e' and 'f' were covered within the operational policy, information was brief and would benefit from expansion.
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community (QS HN-205) and representatives of support services (QS HN-301).	N	Patients were discussed at the haematology multi-disciplinary meeting but this was not documented.
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 agreement in place that described the arrangement.
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	Data were not collected.

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	The service was not monitored on an ongoing basis.
HN-703 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **For patients with sickle cell disease:** a. Proportion of patients with recommended immunisations up to date b. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required c. Proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival. This audit should cover all hospitals where patients with sickle cell disease may attend. **For patients with thalassaemia:** d. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) e. Proportion of patients who have developed new iron-related complications in the preceding 12 months	N	Clinical audit was ad hoc and did not cover the expected range. The Royal London Hospital reviewed thalassaemia audits (points 'd' and '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	An audit programme had not been agreed.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N/A	

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	N	Patients were reviewed and discussed informally at the departmental meeting but discussions were not recorded in minutes.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Documents were out of date.

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comment
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	Comment
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 Hospital merged services with Newham University Hospital and Whipps Cross University Hospital. There was early evidence of partnership working. However, it is unclear at present where 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	Comment
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 Clinical Commissioning Group (CCG) had drawn up a proposal but there were concerns regarding the funding of the model and whether this was consistent with national guidance. The review team met with commissioners of specialised services at the Royal London Hospital visit. 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 specialist haemoglobinopathy teams were in the early development stages and it was unclear where annual reviews would take place.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by each network, in particular, achievement of 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. A business plan was under development within the CCG to describe the activity of the services and the quality review process.