WM QRS West Midlands Quality Review Service

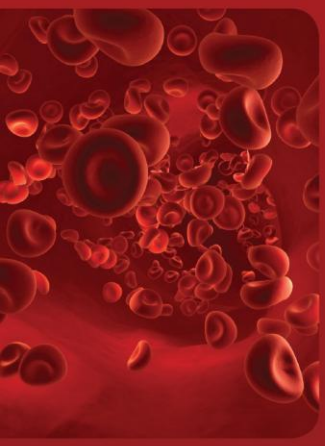
UK Forum on Haemoglobin Disorders

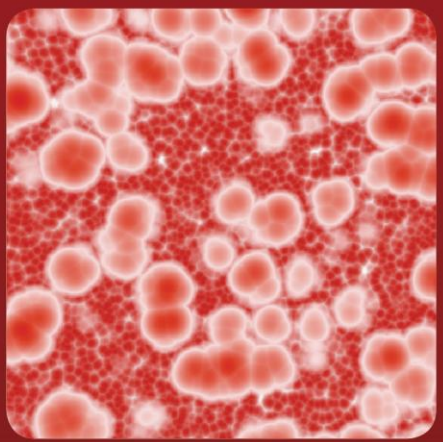
Health Services Caring for Adults with Haemoglobin Disorders

East London

Barking, Havering and Redbridge University Hospitals NHS Trust

Visit Date: February 5th 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 Barking, Havering and Redbridge University Hospitals NHS Trust, Queens Hospital, in the East London Network which took place on February 5th 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 Barking, Havering and Redbridge University Hospitals NHS Trust, Queens 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 NETWORK

Trust Name	Reviewed as:	Hospital
Barking, Havering and Redbridge University Hospitals NHS Trust (BHR)	Accredited Local Haemoglobinopathy Team (A-LHT)	Queen's Hospital (Romford) King George Hospital
Barts Health NHS Trust	Specialist Haemoglobinopathy Team (SHT)	Royal London Hospital (RLH)
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
Homerton University Hospital NHS Foundation Trust	Specialist Haemoglobinopathy Team (SHT)	-
Basildon and Thurrock University Hospitals NHS Foundation Trust	Linked Hospital	-
Mid Essex Hospital Services NHS Trust	Linked Hospital	Broomfield 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
Barking, Havering and Redbridge University Hospitals NHS Trust	A-LHT	377	10	10 thalassaemia major 15 SCD on top up transfusions

Network

As part of the East London Haemoglobinopathy Network, Barking, Havering and Redbridge University Hospitals NHS Trust had a collaborative relationship with Royal London Hospital (RLH) and many of the local hospitals. 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: Barking, Havering and Redbridge University Hospitals NHS Trust

Barking, Havering and Redbridge University NHS Trust (BHR) consists of two acute hospitals: Queen's Hospital and King George Hospital and the former was visited by the peer review team. Queen's Hospital is a new PFI build which opened in 2007. The Trust covered a local population of 750,000 over four PCTs (Havering, Barking and Dagenham, Redbridge and South West Essex). There had been a huge expansion in the service in the past ten years with an increase in patient numbers of over 10% each year due to high levels of migration both directly from overseas and from other areas of London. Barking and Dagenham was one of the highest prevalence areas for haemoglobinopathies in the UK with a carrier rate of 1 in 14 patients and 24 new haemoglobinopathy births per year. There were 377 adult patients with sickle cell disease and 10 transfused thalassaemia major patients known to the service. Acute admissions due to sickle cell disease numbered 189 in the last year.

Within the team there were six full time consultants, of whom one was the haemoglobinopathy lead and two were deputies. There was 0.6 w.t.e clinical nurse specialist at the time of the visit who covered the neonatal, paediatric and adult service in both the acute and community setting. The Clinical Commissioning Group had

just confirmed approval of funding for a nursing team of three to four w.t.e to cover the community and acute aspects of the service and for psychology and benefits support.

Accident and Emergency

Approximately one to three Accident and Emergency Department (A&E) attendances for those with sickle cell and thalassaemia occurred per day. During the daytime patients were signposted to attend the Medical Day Unit instead of A&E. This was a busy A&E with over 350 attendances per day and waiting times were an issue for all patients. Audits showed that the majority of patients did not receive analgesia within 30 minutes of arrival to the department and patient feedback reported long waits (often hours) for analgesia. An easy to use flow chart for emergency care and a comprehensive sickle protocol were available In A&E as both electronic and hard copy. Brief care plans, including analgesia plans, were available as paper copies in a folder in A&E. A comprehensive teaching programme was in place for doctors and nurses working in A&E.

The A&E Department in King George Hospital had low numbers of attendances and the same protocols were in use. Patients admitted at King George Hospital were usually transferred to the in-patient haematology beds at Queen's Hospital.

Out-patient and Day Case Facilities

The day unit and out-patients unit were in adjacent facilities shared with oncology and of high quality. Blood transfusions were administered on the day unit. The majority of those attending were for top up transfusions but manual exchange transfusions could be performed if necessary. There was a drop in nurse-led acute pain service. The day unit was open 9am to 7pm Monday to Friday and Saturday opening was about to start. A fortnightly adult haemoglobinopathy clinic was run by the haemoglobinopathy lead and one of the deputy lead consultants. On alternate weeks the same consultants ran the paediatric clinic, with a paediatric staff grade. There was no specific transition clinic as the staff were the same in both services. The deputy lead also ran a joint obstetric clinic on a monthly basis. There was access to a nurse-led phone clinic for those patients who required hydroxycarbamide and iron chelation monitoring.

In-Patient Facilities

The patients were admitted from A&E to the haematology ward or, if this was full, to the Medical Admissions Unit. During the day they were admitted directly under the haematology team, but out of hours patients were admitted under the medical team and transferred to the haematology team the next day. The nursing staff on the haematology ward and medical admissions team received regular training. Patient Controlled Analgesia was available and the majority of in-patients were reviewed by the pain team on a daily basis. In-patients were under the care of the attending haematology consultant, who worked on a one in six rota, and a haematology specialist registrar and SHO. Out of hours cover was provided by one of the haematology consultants.

Community Services

There were no formal links with community services but the single clinical nurse specialist, employed by the Trust, provided both acute and community care. There was a community hub at King George Hospital where some services were provided. A plan to expand this service was in place. A welfare and benefits advisor worked part-time in Tower Hamlets and Barking, Havering and Redbridge University Hospitals NHS Trust.

User Feedback

The review team met with a group of patients with sickle cell disease and thalassaemia Although the patients had concerns about the A&E services and the long waits there, they gave positive feedback about the clinical team and the day unit service.

Commissioners

Members of the review team met with a team from the local Clinical Commissioning Group who had submitted a business case for service development based on a community model with emphasis on self-management.

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.

Accredited Local Team: Barking, Havering and Redbridge University Hospitals NHS Trust

General Comments / Achievements

This was a large haemoglobinopathy service led by highly motivated and dedicated medical and nursing staff who were highly valued by the patients. The service faced several challenges including the huge expansion in patient numbers over recent years, a shortage of nursing support and difficulties with A&E services. A realistic

action plan was in place which included agreed funding for a considerable increase in nursing staff and a move to extended hours in the day unit. The hospital facilities were excellent and there was good patient feedback about the service, in particular about the medical and nursing staff. There was a high level of engagement both within the Trust, with the Chief Executive being aware of issues in the service and placing it as a high priority, and with the Clinical Commissioning Group who had listed the haemoglobinopathy service in its commissioning intentions.

Other achievements of the service included extensive and high quality patient information leaflets which were readily available in the day unit and out-patient areas. All patients were admitted to a single ward this enabled the development of highly skilled staff and included close collaboration with the pain team.

Good Practice

1 There were nurse led clinics for hydroxycarbamide monitoring and for iron chelation therapy monitoring.

2 There was an excellent training plan in place for both medical and nursing staff and records of attendance were kept to ensure that all staff were trained.

3 The day unit was a good resource for a number of reasons

   a. It had good facilities and complementary therapists were available

   b. The open access pain service was highly rated by patients and was a good solution to the issue of long waiting times in A&E

4 The pain service provided 'open access' to medical attention and pain management and the pain team stayed involved with the in-patients.

5 There was a welfare and benefits advisor available.

Immediate Risks

No immediate risks were identified.

Concerns

1 Long waits for analgesia in the Accident and Emergency Department were reported. Audits showed that the majority of patients did not receive analgesia within 30 minutes of arrival and patient feedback reported very long waits (often hours) for analgesia. The Trust was aware of this issue and starting to address it.

2 The nursing cover, especially the community support, was inadequate for the number of patients. An action plan was in place to address this.

3 Data on patients adverse events and annual reviews were not being entered on the National Haemoglobinopathy Registry due to the shortage of data management staff.

4 The lead consultant only had three PAs in their job plan for haemoglobinopathy services, which was insufficient given the number of patients in the service.

Further Consideration

1 Provision of an automated exchange programme and local provision of specialist MRI scanning facilities should be considered and would enhance the patient experience and may provide cost benefits

2 Whilst there was a good pathway for transition care, there was a need for further support in this area, which could be achieved with the planned nursing expansion.

3 Referral pathways to the specialist centre should be clarified as it was not always clear when patients should be offered specialist review and this did not seem to be done in a systematic way. Several hospitals were providing tertiary level care which led to patients accessing different hospitals for different parts of their care. Some services were being provided to local centres, without clear guidance. There should be increased liaison with the specialist centre, in particular, to discuss how the referral pathways across the network could be developed

4 The Clinical Commissioning Group (CCG) were aware of the exceptionally high concentrations of patients in some GP clusters. The CCG was highly motivated which should allow the development of integration with the community and the provision of community based clinics. This should be considered in line with the national work stream and be consistent with the model service specification for community haemoglobinopathy care from the National Haemoglobinopathies Project.

5 This was a rapidly expanding service and horizon scanning should be considered to plan for the predicted further rapid growth over the next few years.

COMMISSIONING

General Comments and Achievements

Barts Health NHS Trust was established in April 2012 from a merger of a number of Trusts, including the 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 hospitals. The priority identified by the Trust was to review services across the merged organisations.

The commissioners had agreed the configuration of the clinical networks, within the description of the East London Network which included BHR. 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 for patients were expected to be undertaken.

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	Guys & St Thomas' NHS Foundation Trust
Dr Baba Inusa	Paediatric Haematologist	Guys & St Thomas' NHS Foundation Trust
Dr Elizabeth Rhodes	Haematology Consultant	St Georges Healthcare NHS Trust
Rhonda Foster	Specialist Nurse	Croydon Health Services NHS Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
George Constantinou	UK Thalassaemia Society Trustee	UK Thalassaemia Society
Patrick O'Jeer	Patient 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
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	Additional patient leaflets were available.
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	Information was available and offered to patients. However, it had been revised and the final draft was also provided to the review team.

Ref	Quality Standard	Met Y/N	Comment
HN-103 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	Y	
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	Information on chelation therapy was well-presented in the clinic area. Written information was provided in clinic letters but a standard letter or a letter with a standard footnote may be helpful.
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	Although a permanent record of consultations was provided and a comprehensive clinical review was undertaken, a written summary of the annual review was not offered to patients.
HN-106 C SHT A-LHT	**Transition Information** Information should be available for young people covering arrangements for transition to adult care. This information should cover all aspects of QS HN-501.	Y	Information was generic but a review was included in the comprehensive plans for service development.

Ref	Quality Standard	Met Y/N	Comment
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	Y	Feedback was through the community nurses and a recent patient survey had been undertaken. Awareness days were planned but had not started yet. Involvement of patients and carers was also part of the plans for the development of an individualised care plan.
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	However the numbers of PAs in the job plan was too few for the likely growth in the numbers of patients with haemoglobin disorders indicated by the local demography.
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	Although the clinical nurse specialist was only for 22.5 hours per week.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	At the time of the visit there was only 0.6 wte nursing time to cover the whole service, however funding had been agreed to increase the numbers of nurses in the team to four.

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	At the time of the visit nurse specialist support provision was limited, however funding had been agreed to increase the numbers of nurses in the team to four.
HN-206 All	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-205).	Y	The training records were comprehensive.
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	
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	An administrator provided support but the temporary data manager was on sick leave and arrangements for cover had not been made.
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	The tissue viability nurse had a special interest in haemoglobinopathy.

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	At the time of the visit 'e' and 'm' were not provided and there was concern that patients were attending multiple centres in London for these services.
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	Y	
HN-401 All	**Facilities available** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	However this was included in the comprehensive plans for service development for which funding had been agreed. This included a Saturday transfusion service.

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	Although 'a' and 'c' were covered the guidelines did not include other aspects of transition. The consultant team was the same for children and adults but there was no community service to support transition arrangements. However this was included in the comprehensive plans for service development.
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	Although the clinical review was thorough it was not formally identified as an Annual Review or recorded as such.
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	The specification of when patients should be referred to specialist centres would benefit from more detail.
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	However more clarity was needed on the actual practice of exchange.

Ref	Quality Standard	Met Y/N	Comment
HN-505 All	**Chelation Therapy** Clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT / SHT.	Y	More information on chelating agents was needed and although there was information on regular monitoring it did not cover the frequency required.
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:** a. Fever, infection and overwhelming sepsis b. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	Y	Although 'k' and 'l' were brief.
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	

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	Additional information on specialist review was needed also 'e' and 'f' were not covered.
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	Queens Hospital had an ITU on site that had experience of providing services to patients with haemoglobin disorders.
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	Y	
HN-511 All	**Thalassaemia Intermedia** Clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy.	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	N	The operational policy did not address 'c', 'd' or 'f'.
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	Reference to multi-disciplinary meetings was made in the evidence which included a list of attendees however there were no minutes.
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.	Y	All community services were provided by the Trust haemoglobinopathy team so there was no need for a service level agreement.
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	At the time of the visit, the data manager was on sick leave which had led to delays in entering patients onto the NHR. Annual updates were not being entered.

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	Monitoring for 'a', 'b' and 'f' was not undertaken routinely.
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	Data for 'd' and 'e' were collected in an electronic spread sheet for all of the adults who were on a transfusion programme which detailed their Hb, U&E, LFTs, ferritin, PCRs and transfusion volume every 4 weeks, as well as their virology, R2 and T2* MRI results annually.
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	There was no rolling programme for auditing guidelines though this was included in the comprehensive plans for service development. Painful crisis and incentive spirometry were audited annually.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	A current research programme had just closed and research was included in the comprehensive plans for service development.

Ref	Quality Standard	Met Y/N	Comment
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months	Y	Clearer documentation of the review and learning undertaken was needed.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Limited network arrangements were in place but areas were covered in the proposed 2013-14 work programme.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	N	Limited network arrangements were in place, 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	The review team met with the clinical commissioning groups at this visit, who were actively involved in planning service configuration for the future. 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 as the drivers for improving equity across the network were 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.