WM QRS West Midlands Quality Review Service

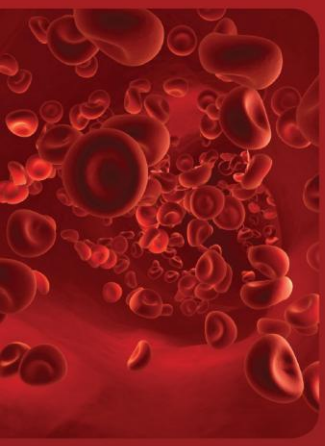
UK Forum on Haemoglobin Disorders

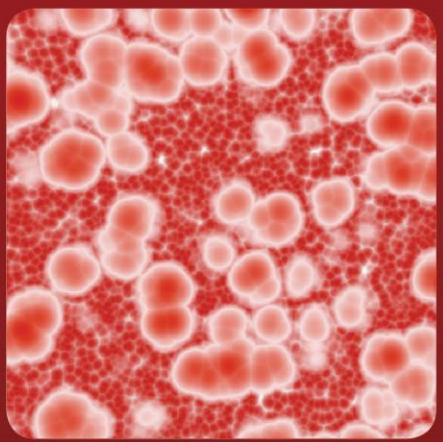
Health Services Caring for Adults with Haemoglobin Disorders

South East London

King's College Hospital NHS Foundation Trust

Visit Date: February 7th 2013 Report Date: July 2013

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INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia in the South East London Network, in particular the King's College Hospital NHS Foundation Trust, which took place on 7th February 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 King's College Hospital NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review.

ADULT HAEMOGLOBIN DISORDERS SERVICES IN SOUTH EAST LONDON SICKLE CELL AND THALASSAEMIA NETWORK

Trust Name	Reviewed as:	Hospital
King's College Hospital NHS Foundation Trust (King's)	Specialist Haemoglobinopathy Team (SHT)	King's College Hospital NHS Foundation Trust
Guy's & St Thomas' NHS Foundation Trust (GSTT)	Specialist Haemoglobinopathy Team (SHT)	St Thomas' Hospital Guy's Hospital
Lewisham Healthcare NHS Trust	Accredited Local Haemoglobinopathy Team (A-LHT)	University Hospital Lewisham
South London Healthcare NHS Trust	Accredited Local Haemoglobinopathy Team (A-LHT)	Queen Elizabeth Hospital, Woolwich
Croydon Health Services NHS Trust	Accredited Local Haemoglobinopathy Team (A-LHT)	Croydon University Hospital
Dartford and Gravesham NHS Trust	Linked Hospital	Darent Valley Hospital
Medway NHS Foundation Trust	Linked Hospital	Medway Maritime Hospital
Brighton and Sussex University Hospitals NHS Trust	Linked Hospital	The Royal Sussex County Hospital

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
King's College Hospital NHS Foundation Trust	SHT	829	12	5 thalassaemia <5 sickle cell top up 33 red cell exchange

NETWORK

King's College Hospital NHS Foundation Trust and Guys' & St Thomas' NHS Foundation Trust were specialist centres in the South East London Haemoglobinopathy Network. The network included University Hospital Lewisham, Queen Elizabeth Hospital, Woolwich and Croydon University Hospital as accredited local haemoglobinopathy teams and Darent Valley Hospital, Medway Maritime Hospital and the Royal Sussex County Hospital, Brighton as linked hospitals.

In addition to the clinical network King's College Hospital NHS Foundation Trust was part of the broader South Thames Sickle Cell and Thalassaemia Network (STSTN), which was formed in 2011 and covered educational, governance and research activities for the whole South Thames area. This Network was a collaboration led by the Consultant Haematologists and Paediatricians at King's College Hospital NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust, but included all the clinicians within both the South East and South West London clinical networks.

A network manager had been in post for two years who coordinated activities of the network. A website had been developed (www.ststn.co.uk) and included information for both professionals and patients. Educational meetings were held three times a year with participation from centres across South London.

SPECIALIST TEAM: KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST

King's College Hospital NHS Foundation Trust is a large teaching hospital situated in the London Borough of Southwark. It is part of King's Health Partners, which is an Academic Health Sciences Centre. As a designated specialist centre for the care of patients with haemoglobinopathies it had 829 adults with sickle cell disease (SCD) on the local register. Since 2006, 620 patients had attended clinics and approximately 550 patients attended regular follow-up. Five patients with thalassaemia major and seven with non-transfusion dependent thalassaemia were also registered with the service. There was a large paediatric haemoglobinopathy service and about twenty patients made the transition to adult services each year.

In addition to providing care for patients who resided locally in the boroughs of Lambeth, Southwark and Lewisham, patients attended from other parts of Greater London and south east England and also from outside these boundaries. King's was a tertiary referral centre for a number of other specialities including liver and neurosciences and patients with sickle cell disease who required these services urgently were transferred.

The red cell team was part of the Haematology Department. At the time of the visit the clinical lead was employed by the Trust with another consultant who held an academic chair. They were supported by a clinical lecturer undertaking a higher degree, a speciality trainee and a foundation year doctor.

The sickle cell specialist adult nursing team consisted of one clinical nurse specialist (CNS).

Emergency Department

The emergency department saw 30 to 50 patients with sickle cell disease per month. All patients arriving by ambulance were taken to the emergency department. During normal working hours, patients were reviewed by the red cell team and were admitted, if necessary, directly under haematology. Patients arriving after 5pm and at weekends were initially admitted under the on-call medical team.

Regular attendees were provided with individual analgesic care plans. These were available on the electronic patient record system and could be accessed from anywhere in the hospital. The care plans were updated annually with the patient. Patients were triaged as high priority with a view to administering initial analgesia within 30 minutes of arrival. There was a named linked nurse responsible for sickle cell disease in the emergency department.

Out-patient and Day Case Facilities

The Haematology Day Unit managed patients with both non-malignant and malignant haematological disorders (excluding chemotherapy). The unit was open on weekdays from 9am to 5pm and provided a walk in service for patients with haemoglobinopathies including those with acute painful episodes. Transfusions were also undertaken on the day unit. There were no arrangements for out of hours transfusions.

Red cell exchange was performed within the apheresis service in the haematology department with an average of four automated exchange transfusion procedures being carried out every week. Emergency exchange transfusions were also undertaken on the unit, depending on availability, or performed manually by haematology medical staff.

Patients on the automated transfusion programme numbered 33 including less than five children. Seven patients with sickle cell disease and thalassaemia required regular top up transfusions. The haemoglobinopathy CNS liaised closely with staff on the unit and maintained a blood transfusion care plan. A bi-monthly multidisciplinary team meeting was in place to discuss patients on long-term transfusions.

There was a weekly sickle cell disease and a separate weekly thalassaemia clinic. New and follow-up patients were seen in these clinics and annual reviews were undertaken. A multidisciplinary pre-clinic meeting took place before the sickle cell clinic. Immunisations were offered to patients in the clinic.

In addition to patients who attend regularly, other patients with sickle cell disease, thalassaemia major and intermedia were seen on a shared care basis with their local hospitals.

Reminders by text were sent out prior to clinic appointments. There was a policy in place to follow up patients who did not attend clinic.

Specialist combined clinics were held at regular intervals where patients were seen by the haematology consultant and a consultant from the designated speciality. Specialist clinics included renal, orthopaedic, obstetric, pulmonary hypertension, liver and transition. Patients from all over the network and beyond were referred to these clinics. Thalassaemia patients were also seen at specialist clinics for their cardiac problems at University College London Hospitals NHS Foundation Trust and Whittington Hospital.

Patients requiring psychological services were referred to the team of psychologists with a specialist interest in sickle cell disease based at Guy's and St Thomas' Hospital .

In-Patient Facilities

During normal working hours patients were admitted via the day unit under the haematology team. Out of hours and at weekends, admissions were via the emergency department under the medical team and then care was transferred to the red cell team on the next working day. The on-call haematology registrar was always available for advice and to review patients. The RD Lawrence ward was the designated ward for patients with haemoglobinopathies but patients were occasionally admitted to other medical wards. Consultant ward rounds took place twice a week and included the CNS. Daily ward rounds took place on the other days including weekends and were normally undertaken by the haematology registrar. The non-malignant haematology consultant rota was covered by eight consultants who looked after the haemoglobinopathy out-patients out of hours.

Patient controlled analgesia (PCA) was available on the haematology ward only.

Sickle cell disease patients undergoing surgery were admitted to surgical wards depending on the procedure and were reviewed daily by the red cell team.

Pregnant in-patients were reviewed daily and there was a weekly joint haemoglobinopathy/obstetric clinic.

Community Services

The community services were based at the South East London Sickle Cell and Thalassaemia Centre. The nursing team provided genetic counselling, antenatal screening and support for adults and children with

haemoglobinopathies. This service covered three boroughs (Lambeth, Southwark and Lewisham) and served patients attending King's College, Guy's and St Thomas', and Lewisham Hospitals. The community specialist haemoglobinopathy nurse responsible for patients registered at King's attended the multidisciplinary ward rounds once a week and the monthly multidisciplinary team meetings. She undertook case management of complex cases and provided regular feedback. The nurse was involved in the transition process for patients aged 13 to 15 years and she attended the paediatric clinic on Tuesdays.

User Feedback

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

REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

The South Thames Sickle Cell and Thalassaemia Network was under development and had established regular education and patient meetings. They had a committed network administrator and data coordinator. The network had a website and was working towards common protocols and governance objectives. The service had produced patient newsletters. There was also evidence of review and learning from adverse events.

The South East London Haemoglobinopathy Network was functioning, but not fully operational. However there had been progress against the network standards in a number of areas:

- Final policies had been agreed for hydroxycarbamide, manual exchange transfusion and some acute complications.
- The consultants (adult and paediatric physicians) for King's and GSTT met monthly and had also held meetings with the commissioner to review service configuration, including provision of red cell apheresis.

Good Practice

1 The network had a strong interest and track record of participating in research in the two lead centres with an agreed network policy and trials list thus enabling all patients in the network to access clinical trials.

Further Consideration

The findings from review visits at all specialist and accredited local haemoglobinopathy teams within the South East Thames Network (STSTN) showed a degree of inequality between centres in the provision of care particularly in relation to specialist nursing support, transition arrangements and specialist psychology services. Whilst the findings from each review visit need to be considered by the individual Trusts, further development of the network and engagement with commissioners should help to identify the needs and the resources required to meet them within STSTN. Further consideration should be given to:

1 Identifying clinical leads for service improvement and audit.

2 Continuing development of network guidelines for the management of acute complications of sickle cell and thalassaemia. It is suggested that pain management be reviewed in particular as there were differences in the protocols of the lead centres which may be confusing for patients if they access more than one centre for care.

3 Implementing network-wide audit to inform protocols.

4 Reviewing transition arrangements across the network.

5 Ensuring that lessons learnt from review of adverse events are disseminated across the network.

6 Encouraging participation of primary care to develop protocols of shared care and promote knowledge about haemoglobinopathies amongst community-based health care professionals.

7 The network administrator was a short term appointment through external charitable funding. Recurrent funding for this role should be explored.

SPECIALIST TEAM: KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST

General Comments and Achievements

This was a large service with committed and hard working medical and nursing staff. The team had strong medical leadership and was supported by the management of the Trust. Patient feedback was very positive concerning members of the multidisciplinary team.

The standards of medical care were good with comprehensive protocols of a high standard. Highly specialist clinics for complications of sickle cell disease had been introduced. MRI imaging for iron overload was available on site. The patients had benefitted from an individualised approach to pain management, which included their

care plans. Patients particularly appreciated the walk-in pain service that operated from the day unit which managed the majority of acute painful episodes.

The community nursing service was good and there were effective links with the acute CNS.

The in-patient ward was satisfactory although the team noted that there appeared to be little in the way of patient amenities. The apheresis and day care facilities were cramped, though they ran efficiently.

Clinical governance arrangements were effective. Multidisciplinary meetings and review of mortality and adverse events took place regularly. There was active participation in the National Haemoglobinopathy Registry (NHR) with adverse event reporting. At the time of the review over 380 patients were registered.

There was evidence of patient involvement in the service. A patient forum took place twice a year and staff contributed to patient education. Topics were chosen that helped patients improve their understanding and the self-management of their illness. It also provided a mechanism for patients and carers to give feedback which contributed to developing services. The patient support group met every three months.

Good Practice

1 The team had developed a comprehensive database which was integrated into the hospital electronic patient record and which recorded routine visits and annual reviews. This database was able to produce reports and letters and was a valuable resource for audit and research. This database could be adopted for use by other centres.

2 Research into haemoglobin disorders was strong with an academic Chair and a strategy which included laboratory and translational research together with clinical trials. The latter were available to other centres in the network and beyond. There was an impressive track record of peer-reviewed publications.

3 Education was also strong including an internationally recognised annual conference on sickle cell disease.

4 The service level agreement with the community service was detailed and comprehensive.

5 Patient information was good with a series of leaflets for patients detailing the services provided and describing complications.

6 A pre-conception service was available.

Immediate Risks

No immediate risks were identified.

Concerns

1 A serious concern for the service related to the low levels of staffing for such a large patient caseload. This may not be sustainable in the long-term, particularly as young adults transition from the paediatric service or when research staff leave:

a) There were insufficient consultant programmed activities and the service relied on a fixed term clinical research fellow. In addition the academic haematologist was regularly spending more time on clinical duties than allotted in their job plan.

b) A single CNS was working over and above her job plan. This lack of specialist nursing support had restricted training in haemoglobinopathy for other nurses in the Trust (see below).

c) There was no psychologist with an interest in haemoglobin disorders and patients were referred to St Thomas's, which restricted access for the majority of them.

2 Evidence in audits showed that 52% of the patients had received analgesia within the appropriate timeframe. Patients said they would avoid the emergency department and wait for the day unit to open even if they were in pain.

Further Consideration

1 It may be beneficial to undertake robust service planning to ensure facilities and staffing are appropriate for present and future caseload. Considerations for service planning include:

a) Ensuring medical and nursing numbers are adequate for the numbers of patients.

b) A review of nurse training to ensure that it is delivered in a systematic manner and is linked to the RCN competences. Consideration should be given to allocating additional CNS time to support this.

c) A review of the transition service, although there was a protocol for nursing support, young patients did not meet the adult haematologist until after they transferred to adult services.

d) Ensuring all patients have access to expert psychology services.

e) Ensuring adequate administrative support for ongoing data entry into the local database and National Haemoglobinopathy Registry (NHR).

f) Extension of day unit opening hours to accommodate transfusion and the acute pain service at weekends and out of normal working hours.

2 The clinic policy should be reviewed to ensure that copies of clinic letters and care plans are offered to patients.

3 The pain management protocol was noted to be different from that offered in most other centres and outwith current NICE guidelines. PCA (patient controlled analgesia) was not universally available and depended on the in-patient ward. The team should review management of acute sickle painful crisis within the Trust and evaluate the effectiveness of the local protocol.

4 The patients interviewed stated that they perceived that they were given less priority than other haematology patients, who they felt had better facilities and nursing support. Some patients did not have access to their care plans and felt that these were not always followed in the emergency department. They reported delays in pain management in the emergency department and negative attitudes from some of the staff there. Consideration might be given to training for emergency department staff on haemoglobin disorders.

5 Although the guidelines were of a high standard they lacked the detail needed for non-specialist staff and it was difficult to pick out key practice points. Some guidelines did not refer to thalassaemia patients.

6 There were relatively few patients with thalassaemia. Consideration should be given to collaborating with other centres for the management of this group of patients.

COMMISSIONING

General Comments

Commissioners had agreed the configuration of the clinical network but further development was needed to clarify the relationships and contractual arrangements between members of the network.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Kate Ryan	Consultant Haematologist/Joint Clinical Lead for Peer Review Programme	Central Manchester University Hospital NHS Foundation Trust
Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust
Dr Corrina McMahon	Consultant Haematologist	Our Lady's Children's Hospital, Dublin
Christine Williams	Service Manager Representative	Homerton University Hospital NHS Foundation Trust
Julie Nicholson	Haematology & Oncology Matron	St Georges Healthcare NHS Trust
Sia Nyandemo	Patient Representative and CEO	Sickle Carers Awareness Network(SCCAN)Founder/CEO
Chris Sotirelis	UK Thalassaemia Society Trustee Advisor	UK Thalassaemia Society
Pip Maskell	Quality Manager	Haemoglobin Disorders Review on behalf of WMQRS

APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

The Quality Standards are in the following sections:

HN - Services for Adults with Haemoglobin Disorders

HY - Haemoglobin Disorders Network (Adults):
Quality Standards for Haemoglobin Disorders Clinical Networks are given separately from those for Specialist Haemoglobinopathy Teams. These Standards are the responsibility of Specialist Haemoglobinopathy Teams but, by agreement, the functions may be delegated to other organisations or coordinating groups.

HZ - Haemoglobin Disorders – Commissioning
These Quality Standards are the responsibility of commissioners.

Each section covers the following topics:

100 - Support for Service Users and their Carers
200 - Staffing
300 - Support Services
400 - Facilities and Equipment
500 - Guidelines and Protocols
600 - Service Organisation and Liaison with Other Services
700 - Governance

NOTE. Different Quality Standards (QSs) are not comparable in terms of their importance or likely impact on the quality or outcomes of the service, and a figure summarising the number of QS's met cannot be used to assess the overall standard of the services provided or to compare this Trust's services with others.

SERVICES FOR ADULTS WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Met Y/N	Comment
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y	However, the information on these services was not easily 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	The information for community services and their contact numbers was particularly good.

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	No evidence was seen for 'f' during the review visit. However, the evidence for 'a' to 'e' was good. Leaflets from the sickle cell and thalassaemia societies were available from the service.
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	However, the patients who met with the review team had not seen this information. Point 'c' was not applicable.
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	Y	A care plan for thalassaemia was not seen, however, they were present on the IT system. The patients who met with the review team had not seen copies.
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.	Y	

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	However, there was little evidence for thalassaemia.
HN-201 All	**Lead Consultant** A nominated lead consultant haematologist with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	Y	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHTs this should be a named deputy within the SHT with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHT. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHT advice and support.	Y	
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 there was a lead nurse identified, there was no evidence of a job plan and RCN competences were viewed but not signed off.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	There was no cover for absences of the lead nurse.

Ref	Quality Standard	Met Y/N	Comment
HN-205 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available.	N	There was no evidence of signed off competences for 'b' and 'c'. Staffing levels were not appropriate for the number of patients cared for by the service.
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	Local training was carried out in haematology.
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	The administration support was not appropriate for the number of patients cared for by this service.
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
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	Y	
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	Y	
HN-401 All	**Facilities available** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	However, the wards lacked some patient facilities and the day unit was likely to be cramped if all the apheresis machines were operated simultaneously.
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	There was no out of hours 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)	Y	
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First out-patient appointment b. Annual review for both sickle cell disease and thalassaemia	Y	
HN-503 All	**Clinical Guidelines: Routine Monitoring** Clinical guidelines on routine out-patient monitoring and management between annual reviews should be in use. Local Haemoglobinopathy Team guidelines should specify the indications for early referral to the Specialist Haemoglobinopathy Team.	Y	
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	N	There was not enough evidence for 'b', no algorithm for transfusion targets or triggers were demonstrated.

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	
HN-506 All	**Clinical Guidelines: Acute Complications** Clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision **For patients with thalassaemia:** k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	Y	However, reference was not included for patients who attended this service but were not known to the Trust. The pain management protocol was unusual, a review should be considered and evaluation of outcomes. There was no reference to choice of antibiotics for 'b'.
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.	Y	
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	Y	
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 was no specific reference to thalassaemia.
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.	Y	There was a good operational policy in place.
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	
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	There was a robust service level agreement with community services.
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.	Y	

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	Y	
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	The 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 in 2012, was 52%.
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.	Y	Point 'b' was not applicable.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	

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

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	Y	
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	Points 'e' and 'f' were not in place yet.
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.	Y	An annual sickle cell disease conference was held at King's. Regular adult and paediatric network meetings were in place.

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	King's had local guidelines and network guidelines were under development.
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	Network policies were available for hydroxycarbamide, manual exchange transfusion, renal disease and acute chest syndrome.
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.	Y	An annual sickle cell disease conference was held at King's. Regular adult and paediatric network meetings were in place. The Service Leads at GSTT and King's met monthly.

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	Evidence was provided for 'a' but 'b' was not yet collected.
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	A programme of audit and review had not been agreed.
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.	Y	A good range of trials were available, for example the Gene Bank Study was available across the network. It was possible for patients to be referred to King's or GSTT to take part in ongoing clinical studies. Information about trials was in the South Thames Sickle Cell and Thalassaemia (STSTN) patient newsletter, red cell news and more information was planned to be made available on the website.
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.	Y	Network arrangements for review and learning were integrated within the network meetings.

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 lead specialist commissioner for London provided the configuration for London. See page 3 for the Trusts within the SE London Network. GSTT and King's were designated as SHTs. University Hospital Lewisham and Queen Elizabeth Hospital, Woolwich were designated Accredited-LHTs. Darent Valley Hospital, Dartford, Medway Hospital, Brighton and Sussex University Hospital were designated as LHTs. Community Services South East London Sickle Cell and Thalassaemia Centre (Wooden Spoon House) covered Lambeth, Southwark and Lewisham boroughs.
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	Minutes were available for the monthly meetings and for the sub-group on transfusion.