WM QRS West Midlands Quality Review Service

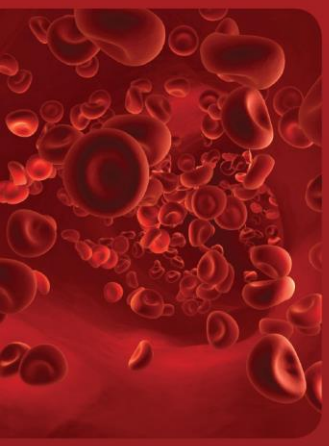
UK Forum on Haemoglobin Disorders

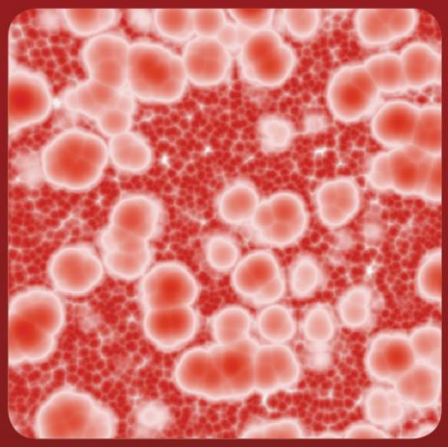
Health Services Caring for Adults with Haemoglobin Disorders

South East London Network

Guy's and St Thomas' NHS Foundation Trust

Visit Date: September 19th 2012 Report Date: January 2013
Version 2: Isseud December 2013 with Network section included

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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 Guys' & St Thomas' NHS Foundation Trust, which took place on September 19th 2012. 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 Guys' & St Thomas' 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
Guy's & St Thomas' NHS Foundation Trust (GSTT)	Specialist Haemoglobinopathy Team (SHT)	St Thomas' Hospital Guy's Hospital
King's College Hospital NHS Foundation Trust (King's)	Specialist Haemoglobinopathy Team (SHT)	King's College Hospital NHS Foundation Trust
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
Guys' & St Thomas' NHS Foundation Trust	SHT	750	9	<5 thalassaemia <5 sickle cell top up 32 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 including 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: GUY'S AND ST THOMAS' NHS FOUNDATION TRUST

Guy's and St Thomas' NHS Foundation Trust was situated in the London Boroughs of Lambeth and Southwark on two sites; St Thomas' Hospital (STH) and Guy's Hospital (GH), which were approximately three kilometres apart. There were approximately 750 adult sickle cell patients known to the service and 670 had been seen in the last twelve to eighteen months. A further nine patients with thalassaemia used the services. Most of the registered sickle cell patients resided in the Boroughs of Southwark, Lambeth, Lewisham and Wandsworth, although patients from all over Greater London attended the service.

The red cell team was part of the Haematology Department. The clinical lead was supported by another consultant with an interest in haemoglobinopathy (at the time of the visit this was a locum appointment), a speciality trainee and foundation year doctor (for care of in-patients).

The sickle cell specialist adult nursing team consisted of one advanced nurse practitioner (ANP) and two clinical nurse specialists (CNS). The transition role was covered by one of the CNSs, who worked part-time in adult and paediatric services looking after 14 to 24 year old patients. The nursing team covered the STH site (in-patients) and Guy's site (Day Unit, out-patients and in-patients).

The psychology service was based in the haematology out-patients at Guy's Hospital and consisted of a clinical psychologist and two health psychologists.

There were laboratory facilities at both sites. One had a large haemoglobinopathy service which carried out high-performance liquid chromatography (HPLC) and genetic testing.

Accident and Emergency

The Accident and Emergency Department (A&E) was situated on the STH site and on average 30 to 50 sickle cell patients attended on a monthly basis. A&E medical and nursing teams initially reviewed patients with sickle cell disease. Patients requiring admission were usually admitted by the on-call medical team and handed over to the sickle cell team the following day. During working hours, the red cell registrar or the on-call haematology registrar were available at all times for advice and reviewed patients with atypical presentations or disease complications if requested, for example, patients with Acute Chest Syndrome.

Patients with uncomplicated sickle cell crisis were transferred to the Clinical Decision Unit (CDU) / Emergency Medical Assessment Unit (EMAU) for management. The patients managed in these clinical areas were reviewed by the in-patient sickle cell team or the on-call haematologist on a daily basis.

Out-patient and Day Case Facilities

The Haematology Day Unit and out-patient clinics were at Guy's Hospital where patients attended for regular and annual reviews. Sickle cell clinics were held twice a week and a number of slots in each clinic were kept for walk-in and urgent patients. Patients were reminded to attend clinic by letter and text. There was a nurse led hydroxycarbamide and annual review clinic on Tuesday afternoon.

Specialist combined clinics occurred at regular intervals where patients were reviewed by the haematology consultant and a consultant from the designated speciality. These clinics also had clinical nurse specialist and psychology representation. Specialist clinics included renal, orthopaedic, neurology, obstetric and transition. Patients from all over the network and beyond were referred to these clinics. Patients were referred to the pulmonary hypertension clinic at King's when necessary. Thalassaemia patients were also seen at specialist clinics at University College London Hospitals NHS Foundation Trust / Whittington Hospital.

General non-malignant and malignant haematology patients were managed in the Haematology Day Unit. This Unit operated transfusions and automated red cell apheresis as well as a pain service. Care was delivered by trained Day Unit staff supported by the sickle cell CNS and ANP.

The nurse led pain service was also situated within the Haematology Day Unit and was supported by the sickle cell CNS / ANP. This service operated Monday to Friday 9 to 5pm and was open to any registered adult patient with sickle cell disease who had attended clinic within the last 12 months. To attend the service patients phoned the CNS / ANP to ascertain whether they met the inclusion criteria. If a bed was not available or the patient was not suitable they were directed to the A&E department at STH. Frequent attenders or walk-in patients were discussed in the multi-disciplinary meeting (MDM). If a patient required admission they were transported by ambulance to STH.

In-Patient Facilities

The haemoglobinopathy in-patients were seen at the STH site. Initially sickle cell patients were admitted to the medical admission wards (Victoria and Sarah Swift) and then transferred to Albert Ward, which was the designated sickle cell ward. Albert Ward was also the designated clinical area where patient controlled analgesia (PCA) was available.

Sickle cell patients undergoing surgery were admitted to surgical wards at STH and Guy's depending on the procedure and were reviewed daily by the red cell team.

There was a large obstetric unit at STH. A dozen pregnant women a year with haemoglobinopathies were reviewed there by the red cell team daily.

Consultant ward rounds took place three times a week and were multi-disciplinary, they included CNS and psychology representation. Daily ward rounds took place on the other days including weekends and were normally undertaken by the haematology registrar. The general haematology consultant rota was covered by eight consultants, who looked after the haemoglobinopathy out-patients out of hours. A specialist registrar was on call covering the two hospital sites, and they rotated through the red cell post for four months during their training. The review team visited the ward.

Community Services

The community services were based at the South East London Sickle Cell and Thalassaemia Centre. This was a 'three borough service' covering Lambeth, Southwark and Lewisham, which included GSTT, King's College Hospital and University Hospital Lewisham. There was a large nursing team providing neonatal and antenatal screening as well as support for paediatric and adult haemoglobinopathy patients.

User Feedback

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

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: Guy's and St Thomas' NHS Foundation Trust

Accident and Emergency

Individual analgesia care plans were in place for all sickle cell patients and available on the Electronic Patient Record (EPR). When a patient with complex needs was registered on the A&E computer system staff were alerted that they had detailed care plans. These plans were held in the sickle cell folder, which was situated in the department, and were also available to authorised staff on the haematology shared drive. Patients were given a copy of their care plans to carry with them. A folder containing care plans was also kept in the haematology registrar's room and the Haematology Day Unit office.

The team visited the A&E and reported that there was a very good level of haematology support and were particularly impressed by the input of the ANP into teaching.

Out-Patient and Day Case Facilities

There were 32 sickle cell patients on regular red exchange programs. The sickle cell ANP and CNS's were all trained to complete exchanges which they performed on a regular basis within the Unit. Each patient on an exchange program had an individual folder, which set out targets, the indications for exchanges and was used for monitoring results. All patients were reviewed within a multi-disciplinary meeting on a six monthly basis.

If required, it was possible to complete emergency exchanges on both sites. This was carried out by the sickle cell ANP or CNSs. Automated exchanges for acute complications were undertaken by the CNS /ANP during normal office hours (occasionally out of hours emergency exchange was undertaken but this service operated on a goodwill basis). Vascular X ray staff or the haematology registrar inserted femoral lines for these patients. The sickle cell ANP was being trained to insert femoral lines for emergency exchanges. Out of hours, the haematology registrar completed manual exchanges.

A small number of patients were given top up transfusions at the weekend at their request. Plans were in place to provide red cell exchanges at the weekend.

The day care and out-patient facilities were visited by the review team and were good.

In-Patient Facilities

Nursing staff on the Victoria, Sarah Swift and Albert Wards had considerable experience of managing sickle cell patients and regular training updates were provided.

Patient controlled analgesia (PCA) was introduced in 2012 for adult patients in a sickle cell crisis and an extensive training program was underway for medical and nursing staff. There were plans to extend PCA to the Sarah Swift and Victoria Wards. The anaesthetic team provided out of hours PCA support. PCA was also offered to patients with sickle cell disease undergoing surgery and within medical and obstetric high dependency units using local protocols.

Facilities were satisfactory and a nurse was able to show where protocols and care plans were located. Staff were enthusiastic about the introduction of PCA and could see a positive impact on the quality of pain management as well as their workload.

Community Services

The Adult Community Nurse for GSTT attended the monthly multi-disciplinary meetings with the red cell team and had an active caseload of about 50 patients who were discussed at these meetings. The nurse also attended the out-patient, obstetric and transition clinics. Patients were visited in the community as required, or reviewed as in-patients.

The review team met with the community nurses who said they would welcome more integration with the acute service. However, the communication between the acute and community teams was good. .

User Feedback

The patients gave very positive feedback about the service and praised the medical and nursing staff. They found the Day Unit very friendly and efficient and appreciated the walk-in pain service though they would have liked it to expand availability to include weekends.

Some users would have liked the orthopaedic service to be more widely available.

Achievements

The service for adult haemoglobinopathy patients was excellent and was delivered by committed and enthusiastic multidisciplinary team. The team had strong leadership at medical and nursing levels and was supported by the management of the Trust. Patient feedback was very positive.

The standards of medical care were very good with comprehensive protocols of a high standard and the introduction of highly specialist clinics for complications of sickle cell disease. The patients had benefitted from

an individualised approach to pain management, which included their care plans and the recent introduction of PCA analgesia. The pain service operated from the Day Unit was particularly appreciated by patients.

The sickle cell team provided regular medical and nursing training. The ANP and specialist nurses had developed an extensive training programme for nurses to ensure that standards were maintained in A&E, on the wards and in the Day Unit. Over 70 A&E nurses had received training over the summer in pain management. New members of the A&E department nursing team were required to spend a morning with the sickle cell ANP/ CNS as part of their induction. The sickle cell ANP/CNS also provided education for the emergency care of sickle cell patients for the King's College A&E course.

The ANP and specialist nurses were able to deliver emergency red cell apheresis and the ANP offered nurse-run clinics for annual review and monitoring.

There was clear evidence of patient benefit from a very experienced and long-established team of psychologists who were an integral part of the team. They provided support to the clinical team in their dealings with patients. They reviewed patients during an in-patient stay, or on an out-patient basis in clinic or in the Haematology Day Unit. Members of the psychology team joined the consultant ward rounds and assessed newly referred patients. Alternatively they assessed patients during their annual review. There was a weekly support group for patients / family members and neuropsychological assessment was available if required. The users specifically mentioned how the psychology service was very approachable and had helped them to be self-sufficient.

Immediate Risks

No immediate risks were identified.

Concerns

1 The very large, complex and expanding patient workload was excessive for one consultant. Although there was support from a second consultant who has an interest in haemoglobinopathy and had dedicated sessions, this was a locum appointment at the time of the review. The service would benefit from the substantive appointment of a second consultant.

2 Annual reviews were undertaken but they were not always formally recorded, consideration should be given on how to achieve this Standard.

3 Some patients expressed concerns that some nursing staff on some acute medical wards had little experience in the care of patients with sickle cell disease and were less responsiveness to their pain management. This may be resolved as the PCA service becomes more widely available as planned, supported with appropriate staff training.

Further Consideration

Patient numbers were set to increase as patients moved over from the paediatric service, as the tertiary referrals grew from within the Network and externally, and as more patients were referred to the specialist clinics. It may be beneficial to undertake robust service planning to ensure facilities and staffing are appropriate to meet future requirements. Considerations for service planning include:

a. A data manager to assist with audit, governance and annual review documentation.

b. Extension of Day Unit opening hours to accommodate transfusion and the acute pain service at weekends and out of normal working hours.

c. Although there were no particular concerns expressed about split-site working, the Trust should consider whether transfer of in-patient facilities onto the Guy's site would bring efficiencies in terms of staffing and patient pathways.

d. The service may benefit from better access to advice and help with welfare rights. This would enable to community nurses to concentrate on other aspects of their work.

Good Practice

There were many examples of innovative practice ranging from psychological interventions, specialist clinics through to nursing. Publication of outcomes and experience from this practice would be beneficial to the wider sickle cell disease community. Those that could be considered as a beacon for introduction into sickle cell services in other parts of England included:

e. The range of combined specialist clinics.

f. Information leaflets for patients were of a very high standard. The reviewers singled out information on pain management, the role of cognitive behaviour therapy and psychology as particularly good.

g. Transition pathways and the role of the adolescent transition nurse.

h. Individualised care plans for patients.

i. Comprehensive training programme for nurses.

j. Access to INPUT, a residential course for patients for chronic disease management.

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 Marie Donohue	Consultant Haematologist	Nottingham University Hospitals NHS Trust
Dr Paul Telfer	Consultant Haematologist	Barts Health NHS Trust
Lindy Defoe	Haemoglobinopathy Specialist Nurse	South Tees Hospital NHS Foundation Trust
Louise Smith	Paediatric Specialist Nurse	Alder Hey Children's NHS Foundation Trust
Teresa Warr	Head of Service Development	South Central Specialised Services Commissioning Group
Pip Maskell	Quality Manager	Haemoglobin Disorders Review *on behalf of WMQRS*

APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

The Quality Standards are in the following sections:

HN - Services for Adults with Haemoglobin Disorders

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

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

Each section covers the following topics:

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

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

SERVICES FOR ADULTS WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Met Y/N	Comment SHT
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y	
HN-102 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy and transfusion services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. How to contact the service for help and advice, including out of hours e. Staff of the service f. Community services and their contact numbers h. Relevant support groups g. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns h. How to get involved in improving services (QS HN-199)	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
HN-103 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	Y	However, 'e' 'iv' was very general and could have included more detail relevant to adult haemoglobin disorders. The 'Managing Pain' leaflet was very good.
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	GP advice on chelation therapy was not available as there were so few patients that this Standard 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	
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	The Information leaflet was comprehensive.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	Y	
HN-201 All	**Lead Consultant** A nominated lead consultant haematologist with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	Y	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHTs this should be a named deputy within the SHT with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHT. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHT advice and support.	Y	However, the locum consultant had a draft job plan and was not a permanent post.
HN-203 All	**Lead Nurse** A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders.	Y	
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
HN-205 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available.	Y	
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	
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.	Y	However, there was insufficient administrative support for the patient numbers.
HN-301 All	**Support Services** Timely access to the following services should be available: a. Dietetics b. Physiotherapy c. Occupational therapy d. Leg ulcer service	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
HN-302 All	**Specialist Services** Access to the following specialist staff and services should be available: a. Erythrocytopheresis or manual exchange transfusion (24/7) b. Acute and chronic pain team c. Pulmonary hypertension team d. Consultant obstetrician e. Fertility services f. Consultant cardiologist g. Consultant endocrinologist h. Consultant hepatologist i. Consultant ophthalmologist j. Consultant nephrologist k. Consultant urologist with expertise in managing priapism and erectile dysfunction l. Orthopaedic service m. Psychologist with an interest in haemoglobinopathies n. Specialist imaging o. DNA studies	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	
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	Top up transfusion could be provided out of hours but nothing was in place for exchange transfusions, however, there were plans for development of out of hours provision.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-501 SHT A-LHT	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable)	Y	
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First out-patient appointment b. Annual review for both sickle cell disease and thalassaemia	Y	
HN-503 All	**Clinical Guidelines: Routine Monitoring** Clinical guidelines on routine out-patient monitoring and management between annual reviews should be in use. Local Haemoglobinopathy Team guidelines should specify the indications for early referral to the Specialist Haemoglobinopathy Team.	Y	
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	Y	

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

Ref	Quality Standard	Met Y/N	Comment SHT
HN-508 All	**Clinical Guidelines: Chronic complications** Clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team.	Y	
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	N/A	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	Y	However, some review dates were listed as 2007.
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	However, it was not explicit who authorised transfusions.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	Y	
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community (QS HN-205) and representatives of support services (QS HN-301).	Y	
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	
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	Approximately two thirds of patients were registered on the National Haemoglobinopathy Registry (NHR). Responsibility for entering further information onto the database was not clear.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-702 All	**Ongoing Monitoring** The service should monitor on an ongoing basis: a. Number of patients having acute admission, day unit admission or A&E attendances b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year c. Length of in-patient stays d. Re-admission rate e. DNA rate f. Waiting times for transfusion	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	
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	
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months	Y	However, there was no evidence of follow up actions taken.
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	'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.