WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services Caring for Adults with Haemoglobin Disorders

South East London

Lewisham Healthcare NHS Trust

Visit Date: September 27th 2012 Report Date: January 2013
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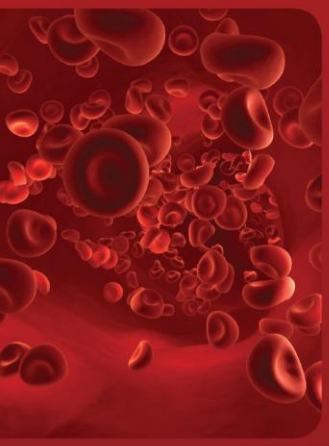


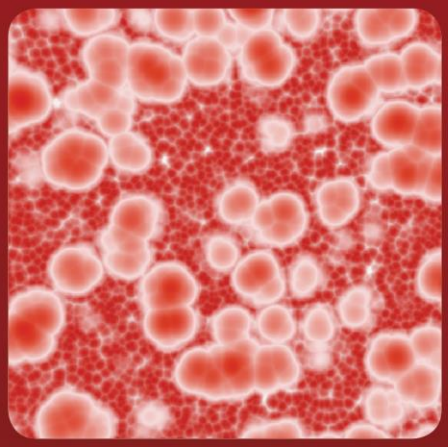


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INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia in South East London Network, in particular the Lewisham Healthcare NHS Trust, which took place on September 27th 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 Lewisham Healthcare NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review.

ADULT HAEMOGLOBIN DISORDERS SERVICES IN 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 (GSST)	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
Lewisham Healthcare NHS Trust	A-LHT	160	19 (7 thal major 12 thal intermedia)	SCD :7 manual (<5 automated at GSST 6 top up thalassaemia) All 7 thalassaemia major patients)

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.

ACCREDITED LOCAL TEAM: LEWISHAM HEALTHCARE NHS TRUST

The adult haemoglobinopathy team was led by a Consultant Haematologist. There was a full time clinical nurse specialist. Junior medical cover for all haematology patients was provided by two registrars on rotation from the London Deanery (South) training programme, a core medical trainee and a Specialty Doctor.

The consultant on-call rota was shared with haematologists from Guy's and St Thomas' hospital (haemato – oncology team). The on-call specialist red cell team at GSTT were able to advise on haemoglobinopathy patients out of hours though no formal arrangements are in place.

The junior medical on-call was non-resident and was provided by the two registrars and Specialty Doctor for weekends and Bank Holidays, when they performed a daily ward round. The registrar on-call at St Thomas'

Hospital provided weekday out of hours junior cover. The medical on-call team was the first port of call for acute emergencies when there was no haematologist on-site.

Accident and Emergency

Patients with acute sickle cell crises attended the Accident and Emergency Department (A&E) where they were initially reviewed by A&E medical and nursing teams. Patients requiring admission were usually admitted by the on-call medical team and handed over to the sickle cell team the following day. The ward registrar (working hours), 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.

Out-Patient and Day Case Facilities

The weekly haemoglobinopathy clinic was held in the main out-patients department. Annual reviews for sickle cell patients were undertaken at Lewisham. Fewer than five of the thalassaemia major patients were also seen at University College London for specialist management and annual review.

Patients with sickle cell disease requiring specialist management of complications were referred either to Guy's Hospital or King's College Hospital, depending on the problem.

Annually there were three to four pregnant patients with sickle cell disease at any one time. They were seen both in the Haematology and Obstetric Clinics, and the consultants worked closely in their management.

The Day Unit component of the David Whitmore Suite (Suite 8) functioned both as a Medical Day Unit for Haematology patients, and as a Chemotherapy Unit. It was open during routine working hours only. If there was no capacity on the Day Unit, patients requiring top-up transfusion who were otherwise stable, were transfused on the Day Surgical Unit.

Exchange transfusion for patients with sickle cell disease was performed manually, usually by the specialist nurse. Emergency or out of hours exchange was undertaken by the junior medical staff. A small number of patients requiring planned automated exchange blood transfusion had them completed at GSTT.

In-Patient Facilities

The majority of haematology patients were treated on Laurel Ward a 26-bedded medical ward with eight side rooms in the Riverside Block, opened in November 2006.

Multi-disciplinary team meetings were held before the twice weekly consultant ward rounds on Mondays and Thursdays. The community haemoglobinopathy clinical nurse specialist (CNS) joined the Thursday session.

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.

The Adult Community Nurse for Lewisham attended the out-patient clinics, reviewed in-patients and visited patients in the community as required.

As part of the discharge process, the Adult Community Nurse worked closely with the acute team and was informed when patients were discharged. A follow-up home visit was offered and carried out if required. A weekly nurse-led clinic was held at the Waldron Health Centre in New Cross.

User Feedback

Members of the review team met with a group of patients with sickle cell disease and thalassaemia major.

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.

ACCREDITED LOCAL TEAM: LEWISHAM HEALTHCARE NHS TRUST

General Comments and Achievements

This was a large service with a hardworking team led by a committed lead consultant. The team appeared cohesive and had excellent relationships with the community team. Other clinical teams within the hospital, as well as GP representatives, reported good interactions and had no concerns. Patient feedback for the team was universally positive. Patients gave positive feedback on the consultant who was always accessible and gave excellent support. They were also positive about the staff in the haemoglobinopathy team and respected the team's opinions on their care. The Trust Management and GP commissioners also expressed their support for the work of the team.

Sickle cell protocols for the management of adults were available via the Trust intranet to which all nurses and doctors had their own log in. Clear and comprehensive Individualised care protocols were in place for patients

in the A&E department. The protocols were well laid out and up to date. Individual care plans were available on the Trust intranet for all registered patients with sickle cell disease.

Training of A&E staff was undertaken by the practice development nurse who worked with the haemoglobinopathy specialist nurse. There was a link nurse in A&E for patients with sickle cell disease.

A joint obstetric clinic was planned but was not in place at the time of the visit.

The reviewers were impressed with the model of working of the community nursing team, which was felt to have had an impact on reducing A&E admissions. The team was actively involved in patient care post-discharge from hospital, which included providing general self-care information relating to their condition. The team provided continuity from paediatric to adult care. The community notes were comprehensive. During the weekly clinic the adult community nurse also supported clients by completing Welfare Benefits forms and gave advice about housing although she had received no specific training for this time-consuming task. However the role was to support patients' well-being and maintain their independence by considering their holistic care needs. In addition time was spent supporting the antenatal and genetic counselling clinic sessions by taking partner bloods. The relationship between the Community Specialist Nurse and the acute team, appeared to be good and the links ensured good 'home from hospital' community follow-up for patients. Good care planning added to the seamless service between community and acute providers.

Governance of the service was of a high standard. Data quality and audits were excellent. Over 100 patients had been entered onto the National Haemoglobinopathy Registry in the preceding six months.

The facilities were of a high standard.

Patients who needed other specialist services, such as psychology, were referred to specialist teams. Patients commented that when they interacted with services such as PALS they had not received feedback, which led them to feel that their concerns had not been taken seriously in the Trust.

The treatment in the Day Unit was good. When patients had attended the Riverside Unit, the doctor was sometimes not immediately available which had led to delays in transfusion.

Immediate Risks

No immediate risks were identified.

Concerns

1 Nurses on the Haematology Day Unit and on one of the two medical wards did not have appropriate training in the care of people with haemoglobin disorders. Some nursing staff were unaware of the protocols and had not received any training towards the RCN nursing competences for sickle cell and thalassaemia. Care of people with haemoglobin disorders was not included within their induction programmes.

2 The clinical nurse specialist's workload was excessive in part due to undertaking tasks that may not be the best use of her skills and experience, such as performing manual red cell exchange. This limited her engagement with acutely unwell patients or from more specialist activity or from delivering training. Working arrangements should be reviewed to allow the clinical specialist nurse to focus more time on specialist nursing care. This might include a greater role in nurse education, nurse run clinics and more support for patients in the acute setting.

Further Consideration

1 The weekly haemoglobinopathy clinic was often oversubscribed. To address overcrowded clinics consideration should be given to reviewing capacity, including delivery of care outside haematology areas. Any review should be 'future-proofed' to take into account increasing numbers as paediatric patients move into adult services.

2 Automated apheresis was not available causing pressure on the specialist nurse and junior medical staff. Consideration should be given to ensuring access to this either locally or in conjunction with other specialist providers within the network.

3 A programme of education for nurses and other staff outside of the team in caring for people with adult haemoglobinopathy disorders should be developed to allow staff to increase their knowledge and empower them to actively participate in patient care. This would address issues of patient perception of a lack of knowledge about sickle cell and thalassaemia.

4 Patients' information was not comprehensive and some appeared to be directed more to children or carers. Consideration should be given to using information and resources that are already available from other Trusts within the South East London Network. Patients reported a lack of interaction with other service users which left them feeling isolated from one another. They would like more access to services such as psychology, although they were referred to GSTT for psychology this remained an informal process. Consideration should be given to involving patients more in the design of services and local support.

5 Patients felt that waiting times in the A&E were sometimes too long and that the experience of haemoglobin disorders amongst the A&E staff was variable. Care plans were not always followed and the lack of understanding of the conditions sometimes resulted in inappropriate analgesia. Patients rarely saw the specialist nurse when they attended the A&E department. However, audits results were available which showed that the majority of patients received pain relief within the recommended target timeframe. The induction, awareness of protocols and training of A&E staff may benefit from review.

6 Arrangements for clinical advice from the red cell team at GSTT should be formalised.

Good Practice

The transition pathway documents were comprehensive.

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.

Further Consideration

Two GP commissioners and an acute commissioner met the visiting team and they were aware of the importance of the service and considered the care given to be both holistic and thorough. The GPs would like more integration of aspects of the service with primary care and the local team should explore this. They had well-established training links with the hospital, which could include training in haemoglobin disorders.

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
Natasha Lewis	Senior Nurse	East London NHS Foundation Trust
Neill Westerdale	Advanced Nurse Practitioner Haemoglobinopathies	Guy's and St Thomas' NHS Foundation Trust
Christine Williams	Service Manager	Homerton University Hospital NHS Foundation Trust
Jacqueline Simpson	Service User	London
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Sharon Ensor	Quality Manager	Haemoglobin Disorders Review *on behalf of WMQRS*

APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

The Quality Standards are in the following sections:

HN - Services for Adults with Haemoglobin Disorders

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

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

Each section covers the following topics:

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

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

SERVICES FOR ADULTS WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Met Y/N	Comment 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	N	HealthWatch was not yet 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)	N	Written information for service users and their carers on how to get involved in improving services was not available.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-103 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	N	Although there was a very good booklet available on the wards covering 'a' – 'e', it did not contain enough detail. Information on 'd' and 'e' was available on the wards.
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, '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	Clinical letters were copied to patients, including the Annual Reviews that had been undertaken.
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	Transition information was also available from the community services team.

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	Patient feedback 'pods' were available throughout the hospital.
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	Evidence was contained in the job description with time dedicated to haemoglobinopathies, as well as certificates and an Honorary contract with Kings University. There was also an attending rota between consultants for in patient / day case review.
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	Advice from the red cell team at GSST was available at all hours though no formal arrangements were in place.
HN-203 All	**Lead Nurse** A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders.	Y	Although the lead nurse had adequate training on sickle cell and thalassaemia there was no indication that the RCN competences were being used.
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.	N	Although staff appeared to be experienced there was no evidence of specific training or continuing professional development in the care of people with haemoglobin disorders.
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	Training was evident for the lead consultant but there was no plan for the development of haemoglobinopathy competences fornursing staff.
HN-207 All	**Training Plan – Other Staff** A programme of induction and training covering the care of patients with haemoglobin disorders should be run for: a. Clinical staff in the Emergency Department b. Non-consultant medical staff c. Allied health professionals working with the SHT / LHT (QS HN-301).	N	The lead consultant had been involved in teaching however this was not extended to Allied Health Professionals or Emergency Department staff. There were plans for induction but no evidence that this had happened.
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	Administrative support was available but no separate data analyst.
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	A policy demonstrated the availability of support services and although psychology was included it was unclear if services were part of the MDT.

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	There were no 'out of hours' facilities.

Ref	Quality Standard	Met Y/N	Comment SHT
HN-501 SHT A-LHT	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable)	Y	The transition plan was good.
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	Guidelines were available but the Indications for referral to specialist services were not clear particularly for thalassaemia.
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	The protocol for exchange transfusion for sickle cell disease was good although they were more generic for thalassaemia.

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	
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 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.	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	Y	
HN-511 All	**Thalassaemia Intermedia** Clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy.	Y	

Ref	Quality Standard	Met Y/N	Comment 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	The Operational Policy was comprehensive.
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community (QS HN-205) and representatives of support services (QS HN-301).	N	Minutes were not available or other evidence that multi-disciplinary meetings were held.
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.	Y	

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	Data summary was excellent.
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	Clinical audits had taken place although more clarity was needed for'd'.
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	There was no rolling programme of audit of implementation of evidence based guidelines
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	
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.

Ref	Quality Standard	Met Y/N	Comments
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.
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.