WM QRS West Midlands Quality Review Service

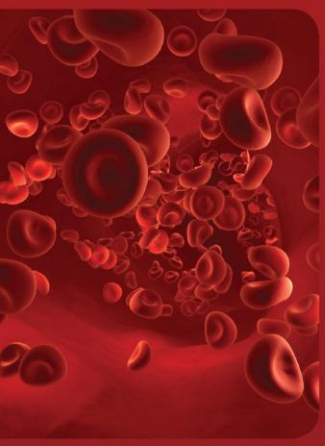
UK Forum on Haemoglobin Disorders

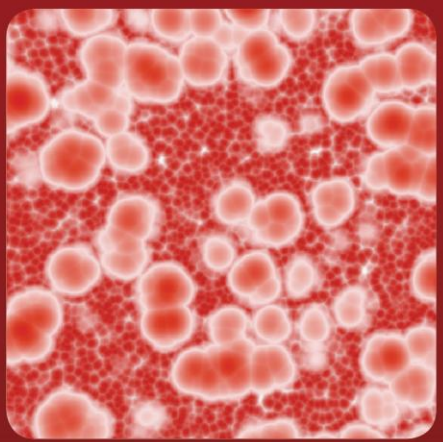
Health Services Caring for Adults with Haemoglobin Disorders

South East London

Croydon Health Services NHS Trust

Visit Date: 2nd October 2012 **Report Date: September 2013**

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INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia in the South Thames Network, in particular the Croydon Health Services NHS Trust, which took place on October 2nd 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 Croydon Health Services 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 THAMES SICKLE AND THALASSAEMIA NETWORK

Trust Name	Abbre-viation	Reviewed as:	Local Team(s) / Linked Hospital(s) LHT
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)	-
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 (CUH)
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	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
Croydon Health Services NHS Trust	A-LHT	584*	9	-

*Data from the Croydon Sickle Cell and Thalassaemia Centre (STC)

NETWORK

At the time of the review 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 (STSCT) Network, which was formed in 2011 and covered educational, governance and research activities for the whole South Thames area. This Network was a collaboration led by the Consultant Haematologists and Paediatricians at King's College Hospital NHS Foundation Trust, and Guy's and St Thomas' NHS Foundation Trust, but included all the clinicians within both the South East and South West London clinical networks.

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

Members of the Croydon team attended the network meetings and educational events. They also had strong formal and informal links and relationships with the services provided by the Specialist Haemoglobinopathy Teams in the Network.

ACCREDITED LOCAL TEAM: CROYDON HEALTH SERVICES NHS TRUST

Croydon Health Services NHS Trust is a combined acute and community Trust. The adult haemoglobinopathy service was provided in the community by the Sickle and Thalassaemia Centre located in its own premises within the local community outside the hospital, a five minute drive from the hospital. Acute care, out-patient and day unit care were provided as part of the haematology service in Croydon University Hospital (CUH).

Croydon University Hospital Haemoglobinopathy Services provided Emergency Department (ED), out-patient, in-patients, High Dependency Unit (HDU), Intensive Treatment Unit (ITU) and haematology day care facilities, allied health services and laboratory and transfusion services. The haematology team comprised four haematology consultants, one of whom was the lead consultant for haemoglobinopathy with another consultant with experience in haemoglobinopathy disorders as deputy lead. In addition there was one haematology specialist registrar and one haematology doctor (registrar level). Three haemoglobinopathy clinical nurse specialist (CNSs) covered the ED, Medical Assessment Unit (MAU), Duppas wards and haematology day unit. The team was supported by two haematology secretaries and haematology laboratory staff.

Emergency Department

Patients with sickle crises or acute complications of sickle cell disease were advised to attend the Emergency Department at Croydon University Hospital. Patients who presented to ED with sickle crisis were triaged and treated in the resuscitation bays. Patients were admitted under the care of the on-call medical team. Once stable, patients requiring admission were transferred to the haematology Duppas Ward or to the Medical Admissions Unit (MAU) where their care was taken over by the haematology team. Patients admitted to MAU were kept there until a bed became available on Duppas Ward. There were 202 ED attendances of adult patients over the age of 16 with sickle cell disease in the twelve month period from April 2011 to March 2012 and 127 admissions of adult patients. Four per cent of all patients were admitted to ITU.

Out-patient / Day Case Facilities

Out-patient services were provided in the haematology weekly clinics located in the London Wing out-patient Department. The haematology clinical lead for adult haemoglobinopathy disorders ran the clinics which had an average of 21 appointments for patients with sickle cell disease. Patients were seen by one of the haematology consultants or by the Specialist Registrar/Trust doctor with consultant supervision. Annual reviews took place in these clinics. Entry of the data onto the National Haemoglobinopathy Registry was by a data manager. Phlebotomy was available for all clinics. Fortnightly twilight clinics were run by the sickle cell clinical nurse specialist, on Mondays 5pm to 8pm.

The Haematology Day Unit was open Monday to Friday, 8am to 5pm. Planned top-up and manual exchange transfusion could be carried out there.

In-Patient Facilities

Once admitted, patients were transferred to the direct care of the haematology team. Whilst awaiting transfer from MAU to the Duppas Ward patients remained under the care of the haematology team, but were also seen by the MAU consultants. Twenty-four hour haematology advice was available.

Community Services

The Croydon Sickle Cell and Thalassaemia Centre (STC) was located in its own premises five minutes' drive from Croydon University Hospital (CUH). Each of the three clinical nurse specialists led on a specific area and one was also the centre lead. The CNSs were supported at the centre by one w.t.e. secretary and 0.5 w.t.e. administrative assistant. One CNS was actively involved in the clinical care of adult patients at CUH including attending the weekly haematology multidisciplinary meeting where the care of relevant out-patients and all in-patients was discussed. The CNS provided close liaison between the STC and hospital service. In addition to running community clinics, the CNSs also visited patients at home.

The centre functioned as a drop-in facility where clients received advice and support and the Support Group met there. It also offered events to support adolescents undergoing transition from paediatric to adult services. Education and counselling were also offered.

User Feedback

The review team met a group of service users.

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. The network had a 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 service at Croydon University Hospital planned to increase the use of shared protocols as these became available from the South Thames Sickle Cell and Thalassaemia Network. Thalassaemia patients requiring interventions were also referred to University College London Hospitals NHS Foundation Trust which was outside the Network.

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 service leads 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.

Further Consideration

The findings from review visits at all specialist and accredited local haemoglobinopathy teams within the South East Thames Network (SETN) showed variation 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 SETN. 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 A review of 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.

Good Practice

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.

ACCREDITED LOCAL TEAM: CROYDON HEALTH SERVICES NHS TRUST

General Comments and Achievements

This was a large and rapidly expanding service. Fifty-four new contacts had been made in the twelve months before the review. The haemoglobinopathy team at Croydon was a dedicated, enthusiastic and cohesive team providing a good service overall, with some areas of exemplary practice. The size of the team was small for the number of patients using the service and resources were limited. However, morale within the team was high and the service was particularly patient-centred. The team had a clear understanding of the rapidly changing

demographic composition of the local population and insight into how the service would have to evolve in order to be able to accommodate the anticipated rise in the black and ethnic minority population in the coming years. Although the workload was quite large, the service was flexible enough to care for the needs of the large transient population with haemoglobin disorders who used the service because of the proximity of Croydon University Hospital to Lunar House, the headquarters of the UK Border Agency. The team had strong support from senior management, as evidenced by the enthusiastic participation of the Chief Executive and Chairman of the Trust in the peer review process.

Patient-controlled analgesia had been set up in the Emergency Department (ED) and was monitored effectively. The effectiveness of the team was seen from a recent audit which recorded the achievement of 100% of sickle cell patients receiving analgesia within 30 minutes of arrival in ED. The integration between acute and community services was highly commendable.

Immediate Risk

No immediate risks were identified.

Concerns

1 The number of agency nursing staff in MAU was high so it was difficult to ensure that all staff had appropriate competences in the care of people with haemoglobin disorders. The Trust was undertaking a drive to recruit more permanent nursing staff. Consideration should be given to ensuring that those appointed had relevant competences or received appropriate training.

Further Consideration

1 Cover for absences of the CNS working in the acute service was provided from the team based in the STC. It may be helpful to consider succession planning within the acute team because of the rapid growth in patient numbers.

2 Access to a psychologist with expertise in haemoglobinopathies was not available. Consideration should be given to providing this through dedicated sessions for haemoglobinopathy patients.

3 A formal training programme specifically for adult haemoglobinopathy disorders for nurses was not in place and evidence of nurse competence documentation was not available. The general nurses were also unaware of the RCN competence framework for healthcare professionals caring for people with sickle cell disease and thalassaemia. The service may benefit from a more structured approach to continuing professional development. Nurses in the Trust should be made aware of the Royal College of Nursing competence framework.

4 The transfusion guideline was not up to date and did not reflect new data on perioperative transfusion practice in sickle cell disease. This would benefit from review.

Good Practice

1 The *'Just a minute'* card for users to comment of the service was commendable

2 The proforma summarising the patients' details and analgesia requirements in ED was comprehensive.

3 Multi-disciplinary team (MDT)meetings occurred at three levels each with a different purpose: weekly team meetings to discuss individual patient management, four to six weekly meetings between the lead clinician and the CNSs to review operational issues, and quarterly meetings with a wider membership for a strategic emphasis. These multi-layered, multi-level, MDT meetings were highly commendable. They allowed the entire team to be well informed about individual patients' needs, provided a means for troubleshooting problems related to service provision, and involved relevant stakeholders in service development.

4 The protocol for hydroxycarbamide and iron chelation was good.

5 The community service was of a high quality. Rapport between staff and service users was excellent. Service users received strong support. The review team met users of the service who gave very positive feedback about the service in general and, in particular, the quality of support from the STC staff. The commissioner also reported that they regularly received very good feedback about the STC as a model of good practice. In the judgment of the reviewers, the community provision was a model service. It was patient-centred with a high level of service user involvement and engagement in service development. The staff gave every possible support to service users. As a result, the members of staff enjoyed a very positive relationship with the service users. The STC was fully integrated with the acute service. All in-patients were reviewed by the CNS. The CNS also attended the weekly multi-disciplinary meetings where the care of in-patients and out-patients were discussed. She would then follow up any issues in the community including visiting the patients in their homes as required. The CNS also ran a fortnightly twilight clinic, 5pm to 7pm. Phlebotomy was available in this clinic. This allowed her to review patients who might find it difficult to attend clinic in normal hours or resolve problems in-between reviews in the consultant-led clinics.

COMMISSIONING

General Comments and Achievements

Regular contract review meetings took place between commissioners and providers. This included a clinical quality review group that oversaw clinical governance of all services. 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 Bernard Davis	Consultant Haematologist – Clinical Lead for Peer Review Programme	Whittington Health NHS
Patrick Ojeer	User representative	London
Julie Nicholson	Haematology & Oncology Matron	St George's Healthcare NHS Trust
Christine Williams	Service Manager	Homerton University Hospital NHS Foundation Trust
Dr Asa'ah Nkohkwo	Adviser	Sickle Cell Society
Pip Maskell	Quality Manager	Haemoglobin Disorders Review on behalf of WMQRS

APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

The Quality Standards are in the following sections:

HN - Services for Adults with Haemoglobin Disorders

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

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

Each section covers the following topics:

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

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

SERVICES FOR ADULTS WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Met Y/N	Comment
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y	
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
HN-103 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	Y	
HN-104 All	**Information for Primary Health Care Team** Written information for the patient's primary health care team should be available covering their roles and responsibilities, including: a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Information covering side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on shared care for hydroxycarbamide and iron chelation therapy (if being prescribed by GPs).	Y	The information presented for hydroxycarbamide and Iron chelation was very good. The '*Just a minute*' card for users to comment on the service was also commendable, (see main report).
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	Although annual summaries were present, the annual review proforma was completed manually by the consultant without a signature or date.
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	However, more detail was suggested as necessary to cover all aspects of QS HN-501 in detail.

Ref	Quality Standard	Met Y/N	Comment
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	Y	This was a 'model' type service. Excellent feedback was provided from service users and the commissioner.
HN-201 All	**Lead Consultant** A nominated lead consultant haematologist with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	Y	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHTs this should be a named deputy within the SHT with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHT. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHT advice and support.	Y	
HN-203 All	**Lead Nurse** A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders.	Y	However, the excellent service was dependent upon one individual.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	Y	The service planned to train another nurse with an interest in this area to meet the expected growth in patient numbers.

Ref	Quality Standard	Met Y/N	Comment
HN-205 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available.	Y	Formal arrangement should be considered for documenting competences of the nursing staff on the haematology and general wards.
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	There was no evidence to demonstrate the maintenance of appropriate competences.
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 general nurses were unaware of the nurse competences covering the care of patients with haemoglobin disorders.
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	
HN-301 All	**Support Services** Timely access to the following services should be available: a. Dietetics b. Physiotherapy c. Occupational therapy d. Leg ulcer service	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-302 All	**Specialist Services** Access to the following specialist staff and services should be available: a. Erythrocytopheresis or manual exchange transfusion (24/7) b. Acute and chronic pain team c. Pulmonary hypertension team d. Consultant obstetrician e. Fertility services f. Consultant cardiologist g. Consultant endocrinologist h. Consultant hepatologist i. Consultant ophthalmologist j. Consultant nephrologist k. Consultant urologist with expertise in managing priapism and erectile dysfunction l. Orthopaedic service m. Psychologist with an interest in haemoglobinopathies n. Specialist imaging o. DNA studies	N	Access to psychology services (point 'm') was not available.
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	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.	Y	

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

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

Ref	Quality Standard	Met Y/N	Comment
HN-508 All	**Clinical Guidelines: Chronic complications** Clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team.	Y	
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	Y	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	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	However, the guidelines would benefit from further detail such as what to do when the clinical lead was unavailable.

Ref	Quality Standard	Met Y/N	Comment
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	Y	
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	The three-tiered system for the multi-disciplinary meetings was considered good practice (see main report).
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	Annual reviews were undertaken but data were not always entered onto the National Haemoglobinopathy Registry.

Ref	Quality Standard	Met Y/N	Comment
HN-702 All	**Ongoing Monitoring** The service should monitor on an ongoing basis: a. Number of patients having acute admission, day unit admission or A&E attendances b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year c. Length of in-patient stays d. Re-admission rate e. DNA rate f. Waiting times for transfusion	Y	
HN-703 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **For patients with sickle cell disease:** a. Proportion of patients with recommended immunisations up to date b. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required c. Proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival. This audit should cover all hospitals where patients with sickle cell disease may attend. **For patients with thalassaemia:** d. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) e. Proportion of patients who have developed new iron-related complications in the preceding 12 months	N	Audits were being undertaken but had not been completed at the time of the visit.
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	The service did not yet have a rolling programme of audit but there were plans to implement this.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N/A	

Ref	Quality Standard	Met Y/N	Comment
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months	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	Leads for service improvement and audit (points 'e' and 'f') were not yet in place.
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.

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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 point '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 across the network such as the Gene bank study. 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	N	Croydon Clinical Commissioning Group planned to lead on the commissioning of the service in the future to ensure compliance with relevant clinical standards and guidance. Where relevant, reference to London specialised commissioning was planned.
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.	N	It was suggested by the commissioning representative that local commissioners ensured funding through acute and community contract arrangements. Addressing activity and finance performance was planned for discussion through the monthly monitoring meetings.