WM QRS West Midlands Quality Review Service

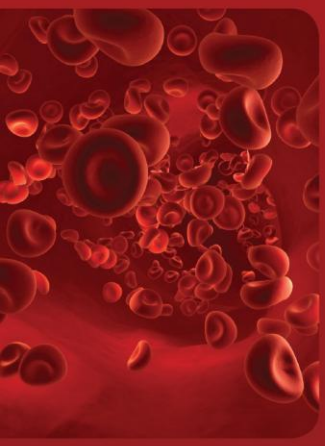
UK Forum on Haemoglobin Disorders

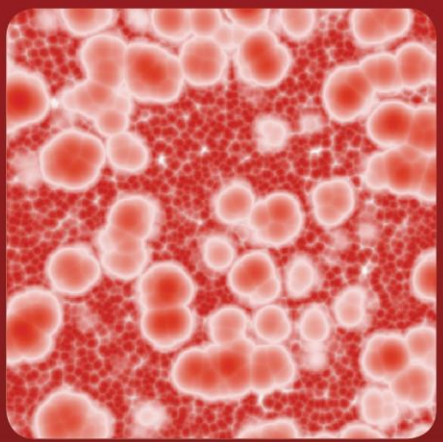
Health Services Caring for Adults with Haemoglobin Disorders

West Yorkshire

Bradford Teaching Hospitals NHS Foundation Trust

Visit date: September 13th 2012 Report Date: April 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 West Yorkshire, in particular the Bradford Teaching Hospitals NHS Foundation Trust, which took place on September 13th 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 Bradford Teaching Hospitals 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 WEST YORKSHIRE

Trust Name	Hospital/s	Abbrev-iation	Reviewed as:	Abbrev-iation
Bradford Teaching Hospitals NHS Foundation Trust	Bradford Royal Infirmary St Luke's Hospital	BRI	Specialist Haemoglobinopathy Team	SHT

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
Bradford Teaching Hospitals NHS Foundation Trust	SHT	20	12	12 Thalassaemia <5 Sickle Cell Disease

COMMISSIONING ARRANGEMENTS

Yorkshire and Humber Specialist Commissioning Group began to commission the service for adults with haemoglobin disorders at Bradford from 1st April 2012. In view of the changes associated with moving to the NHS Commissioning Board from 2013, the network model for Yorkshire and the wider North of England had not yet been decided.

NETWORK

At the time of the visit network arrangements were not in place. The Bradford team was aware of a few patients with haemoglobinopathy who were being seen at other hospitals in the area, especially Airedale NHS Foundation Trust. These patients were not receiving specialist care from the Bradford team and it was not clear whether they were under the care of another specialist centre.

SPECIALIST TEAM: BRADFORD TEACHING HOSPITALS NHS FOUNDATION TRUST

Services for adult patients with haemoglobinopathy were provided at the Bradford Royal Infirmary site (BRI).

Accident and Emergency

The majority of emergency admissions went directly to the Haematology Ward (Ward 7). If a bed or medical staff were not immediately available then patients were asked to report to the Accident and Emergency (A&E) department where they were managed by the A&E staff in conjunction with the on-call haematology team. Occasionally patients presented directly to the A&E.

Out-patient and Day Case Facilities

Out-patient clinics were held by the lead consultant every two weeks. The specialist nurse attended the clinic together with the community haemoglobinopathy counsellors. The out-patient facility was shared with oncology and had recently been refurbished.

In-Patient Facilities

Patients were managed on Ward 7. Patients with acute sickle cell crisis were given priority for admission to the ward. The lead consultant, three other consultants from Bradford and two from Airedale provided 1:6 consultant cover, supported by junior medical staff. Out of hours cover was provided by a haematology specialist registrar and the on-call haematology consultant.

Community Services

Community services were provided by 1.75 whole time equivalent (w.t.e.) haemoglobinopathy counsellors who provided support for paediatric and adult patients as well as counselling for the families of affected newborn babies and the antenatal screening programmes. This service was based in the Manningham Clinic but managed by BTHFT. The counsellors attended the fortnightly haemoglobinopathy clinic and saw patients with sickle cell disease when they were admitted to hospital as well as the thalassaemia patients who attended on a regular basis for blood transfusions.

User Feedback

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

REVIEW VISIT FINDINGS

NETWORK

At the time of the visit network arrangements were not in place.

SPECIALIST TEAM: BRADFORD TEACHING HOSPITALS NHS FOUNDATION TRUST

General Comments and Achievements

This was a committed and enthusiastic team. In particular, the specialist nurse and day unit staff were praised by the users and there were excellent links with the community team who provided good continuity of care between paediatric and adult services. All patients benefited from being managed in the Haematology Ward and from direct access to the haematology team for urgent assessment and care. Day care was responsive to patients' needs. The team acknowledged the difficulties in delivering a comprehensive service for patients with sickle cell disease due to the small numbers of patients.

The facilities in A&E were satisfactory and senior staff were able to demonstrate access to the protocols for the management of acute sickle crisis on the intranet. They reported that they always informed the haematology service when a sickle cell patient was admitted and they found the haematology team most helpful. A teaching programme for A&E medical and nursing staff was not in place.

The Day Case facility was shared with malignant haematology patients and was of a high standard but appeared cramped. Wi-Fi had recently been installed. The design allowed for haematology patients requiring blood tests to be seen in a prompt manner and the unit had its own blood fridge. There were no arrangements

for elective weekend transfusions. Patients reported that their blood was always ready on time and they were not kept waiting for transfusions. Acute and elective automated red cell exchange was performed by the National Blood Transfusion apheresis service at Leeds which was reported to deliver an excellent and responsive service for Bradford patients. Cardiac T2* imaging was available in Leeds.

Patients felt that the day unit was small and cramped and some of the younger patients disliked sharing it with the malignant haematology patients as they found this depressing. They were aware of the number of paediatric thalassaemia patients who would be moving over to adult services and were concerned about the capacity of the unit to respond to this increase.

The in-patient facilities were satisfactory. Management protocols were in place on the intranet. The patients with sickle cell disease appreciated the fact that they had direct access to the ward where they felt safe. They avoided A&E as they felt that the staff there did not know them or their condition and were concerned about delays in the administration of pain relief. Where patients had a copy of their pain plan they commented that A&E staff did not always follow the plan. Some patients were not aware of the existence of these individualized plans.

Most patients had been entered onto the National Haemoglobinopathy Registry (NHR) but some had declined to be registered. Adverse events were not reported on the NHR but there was evidence that a formal mortality review had been undertaken.

The haemoglobinopathy counselors provided training on an ad hoc basis to various clinical staff and had received good support from the Trust for their personal training needs.

Patient Feedback

All the patients reported that they had an excellent relationship with the lead nurse who had provided continuity of care over many years. They also expressed fondness and admiration for the nurses who worked on the day unit; stating that they worked hard and were always cheerful and pleasant. The patients recognised that the day unit had been short-staffed until recently and they were appreciative of the nurses' efforts and the fact that they had worked extra hours trying to avoid inconvenience to the patients. There was similar praise for the nurses on the in-patient ward. The patients felt that the nursing care was of a high standard, the nurses knew them well and they were well looked after in hospital.

Some patients who met the review team were worried about the frequency of medical reviews and about availability locally of some treatments and investigations.

Some of the patients suggested a Facebook page or similar so they could keep in touch with other local patients. They suggested that this would be more convenient than a traditional support group, as many patients were too busy to attend groups. The younger patients reported that they had no problems with transition although the transition plan had only recently been implemented.

Immediate Risk: No immediate risks were identified

Concerns

1 Guidelines and protocols lacked sufficient detail and would be difficult to follow for staff who did not have regular experience caring for people with haemoglobin disorders. Some protocols did not reflect current medical practice. The protocol for iron chelation, in particular, should be reviewed to reflect latest national guidelines.

2 Arrangements for ensuring patients with sickle cell disease had annual reviews were not robust.

3 A competence-based training programme was not yet in place covering all staff involved with the care of adults with haemoglobin disorders, in particular, for a) staff in the Accident and Emergency Department – although A&E was used relatively infrequently, b) medical staff providing cover for the lead clinician. There were no plans for training of nursing staff to meet Royal College of Nursing competences for care of people with haemoglobin disorders.

4 Clinical nurse specialist staffing was insufficient because her main role related to care of patients with haemophilia and she had no time scheduled in her job plan for care of patients with haemoglobin disorders. Although the day unit Sister was identified as covering absences, in practice it was difficult for the full range of duties to be covered during the clinical nurse specialist's holidays and other leave.

Further Consideration

1 Consideration should be given to whether patient numbers cared for by Bradford Teaching Hospitals NHS Foundation Trust are large enough for the Trust to be able to provide the expected standards of care and for staff to develop and maintain specialist expertise in the care of people with haemoglobin disorders. As part of new network arrangements, collaboration with a Specialist Team with a larger number of patients and ensuring local access through an 'Accredited Local Team' in Bradford may be a better alternative.

2 While recognising that the views expressed by individual patients about their care may not be representative of all patients and may be informed by a particular encounter or experience, some patients did raise concerns about the care they received. A patient focus group was planned and reviewers hoped that this would be used to discuss these issues in more detail.

3 The expertise of the specialist nursing counsellors could be utilised to develop in-house training in the care of patients with haemoglobin disorders.

4 Whilst the majority of the patients were entered onto the National Haemoglobinopathy Registry, data on adverse events and annual reviews were not yet being entered.

5 Although there was good patient information, much of it was directed at children and carers and was not specific for an adult audience.

6 Service-level multi-disciplinary arrangements for review and learning were not yet in place, in particular, the mechanism for learning from reviews of near misses and incidents was unclear.

7 The hospital had a relatively large population of transfusion dependent thalassaemia major patients and patient numbers were expected to grow as patients moved over from paediatric care. This should be taken into consideration when planning day care capacity, staffing and out-patient care. Involving patients in service planning for the future may also be helpful.

8 In taking forward the development of this service, consideration should be given to looking at and learning from guidelines and protocols in use in other centres.

Good Practice

1 Transition arrangements were good and the community team had received a `Roald Dahl' grant to develop the service. This was particularly important because of the large paediatric population in Bradford.

2 All patients had individualised care plans for pain and transfusion management.

COMMISSIONING

Concern

1 Arrangements for access to specialist care for patients from Airedale were not clear.

Further Consideration

1 Consideration should be given to whether patient numbers cared for by Bradford Teaching Hospitals NHS Foundation Trust are large enough for the Trust to be able to provide the expected standards of care and for staff to develop and maintain specialist expertise in the care of people with haemoglobin disorders. As part of new network arrangements, commissioning specialist care from a specialist team with a larger number of patients and ensuring local access through an 'Accredited Local Team' in Bradford may be a better alternative.

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 Jenny Welsh	Consultant Paediatric Haematologist	Sheffield Children's NHS Foundation Trust
Neill Westerdale	Advanced Nurse Practitioner Haemoglobinopathies	Guy's and St Thomas' NHS Foundation Trust
Louise Smith	Paediatric Specialist Nurse	Alder Hey Children's NHS Foundation Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Elaine Miller	Voluntary Sector Representative	Thalassaemia Society
Dr Asa'ah Nkohkwo	Advisor	Sickle Cell Society
Sharon Ensor	Quality Manager	Director KeyOpps Ltd.- On behalf of West Midlands Quality Review Service

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	The information on accessing benefits and job seeking was excellent.
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	N	Information for children and community literature were strengths but there were gaps in health promotion information on travel and vaccination. Information did not cover problems, symptoms and signs for which emergency advice should be sought.
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	Written information covering side effects of medication was not available. Point 'c' was not applicable.
HN-105 All	**Care Plan** All patients should be offered: a. An individual care plan or a written summary of their annual review b. A permanent record of consultations at which changes to their care are discussed	Y	Care plans were in notes but these were not routinely shared with patients.
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	Recently introduced arrangements were praised.

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.	N	Although there were no mechanisms to involve patients there were plans to do so in the future.
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	
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	Y	The day unit Sister was identified as covering absences but, in practice it was difficult for the full range of duties to be covered during holidays and other leave.

Ref	Quality Standard	Met Y/N	Comment
HN-205 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available.	N	Clinical nurse specialist staffing was insufficient because her main role related to care of patients with haemophilia and she had no time scheduled in her job plan for care of patients 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	There was no evidence of a training plan. A more formal programme for training in line with the RCN competences for ward, day unit and A&E staff could be considered.
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	Some community training was evident.
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	This was difficult to achieve due to the relatively low numbers of patients. T2* access was available but not ferriscan.
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, clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	The day unit was cramped with little capacity for additional numbers. Patients were concerned about the future due to the high numbers of children with thalassaemia under treatment.
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hours transfusion, phlebotomy and clinics appropriate to the needs of the local population.	N	No out of hours elective transfusion was available.

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	Although there were guidelines they would benefit from more details specific to the care of people with haemoglobin disorders.
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First appointment b. Annual review for both sickle cell disease and thalassaemia	N	Proformas were not reflected in guidelines. There were no annual review records for sickle cell patients.
HN-503 All	**Clinical Guidelines: Routine Monitoring** Clinical guidelines on routine 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.	N	Clinical guidelines on routine monitoring were not in use.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	N	A transfusion policy was in use but points 'a' and 'b' were not met as the protocols were not specific enough about these areas.

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.	N	There was no evidence of chelation therapy guidelines being used.
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	The guidelines did not contain specific detail for use by staff in A&E and haematology staff who were non-haemoglobinopathy specialists but may be involved in the management of acute complications. The guidelines were not easy to follow, did not cover all aspects expected by the QS and contained some errors.
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 guidelines would benefit from being more detailed.

Ref	Quality Standard	Met Y/N	Comment
HN-508 All	**Clinical Guidelines: Chronic complications** Clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team.	N	The guidelines for chronic complications did not contain sufficient detail.
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	N	There were no guidelines for specialist management though there was evidence of a pre-operative checklist in the notes reviewed.
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.	N	Guidelines contained insufficient details.

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 clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	N	There was follow up of patients who did not attend however the operational policy did not cover all aspects of the QS.
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	These meetings were not yet established and no minutes were seen by the review team.
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.	N	A service specification was provided but it was not clear which organisations were included. A robust service specification of community services was not available.
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	Evidence was provided for 20 patients entered into the NHR. Adverse events appeared not to be recorded but plans were in place to do this in the future.

Ref	Quality Standard	Met Y/N	Comment
HN-702 All	**Ongoing Monitoring** The service should monitor on an ongoing basis: a. Number of patients having acute admission, day unit admission or A&E attendances b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year c. Length of in-patient stays d. Re-admission rate e. DNA rate f. Waiting times for transfusion	N	Ongoing monitoring was not in place.
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	Although there was an audit for acute pain and analgesia, no evidence was seen for 'a', 'b', 'd' or 'e'.
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 evidence of a rolling programme of audit.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N	There was no evidence of research relating to the care of patients with haemoglobin disorders.

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	N	A presentation of a review for a death was provided but the mechanism for learning from outcomes of reviews of near misses and incidents was unclear.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	Trust guidelines were used.

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Invitations to a focus group had been sent but the group had not met at the time of the visit.
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	A network of services had not been formalised so compliance with the network standards was not yet achieved.
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-205 and HN-206.	N	A network of services had not been formalised so compliance with the network standards was not yet achieved.

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	A network of services had not been formalised so compliance with the network standards was not yet achieved.
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	A network of services had not been formalised so compliance with the network standards was not yet achieved. However, an informal approach to other specialist centres would be particularly beneficial.
HY-701	**Annual Meeting** The network should hold a meeting at least annually involving network leads (QS HY-201) and lead consultants and lead nurses for each LHT / SHT in the network (QSs HN-201 and HN-203) to review the network's progress towards achievement of Quality Standards and its implementation of agreed service development plans.	N	A network of services had not been formalised so compliance with the network standards was not yet achieved.

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	A network of services had not been formalised so compliance with the network standards was not yet achieved.
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 network of services had not been formalised so compliance with the network standards was not yet achieved.
HY-704	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	A network of services had not been formalised so compliance with the network standards was not yet achieved.
HY-798	**Review and Learning** The network should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses', especially those involving more than one service within the network.	N	A network of services had not been formalised so compliance with the network standards was not yet achieved.

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	The model for Yorkshire and the wider North of England had not yet been decided although a number of options were under consideration.

Ref	Quality Standard	Met Y/N	Comments
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	The service had been taken into specialist commissioning from April 2012 but was not yet fully commissioned by the SCG.