WM QRS West Midlands Quality Review Service

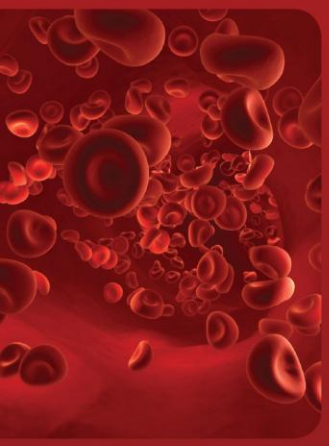
UK Forum on Haemoglobin Disorders

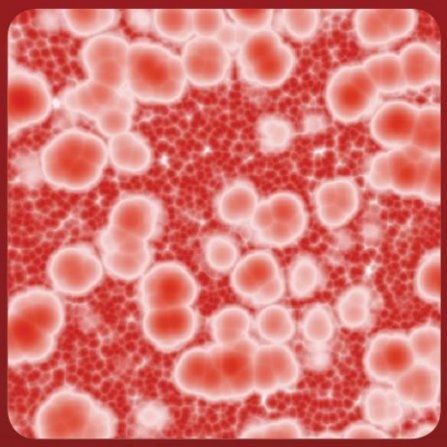
Health Services Caring for Adults with Haemoglobin Disorders

West Midlands

Sandwell and West Birmingham Hospitals NHS Trust

Visit Date: October 24th 2012 Report Date: March 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 Sandwell and West Birmingham Hospitals NHS Trust, which took place on October 24th 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 Sandwell and West Birmingham Hospitals 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 THE MIDLANDS NETWORK

Trust Name	Abbre-viation	Reviewed as:	Hospitals LHT
Sandwell and West Birmingham Hospitals NHS Trust	SWB	Specialist Haemoglobinopathy Team (SHT)	City Hospital Sandwell General Hospital Rowley Regis Community Hospital

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
Sandwell and West Birmingham Hospitals NHS Trust	SHT	450	40	36 (30 thalassaemia, 6 SCD, 10 patients with thalassaemia were transfused at Heartlands Hospital but reviewed at SWB)

NETWORK

A network of services for adult haemoglobin disorders was not functioning across the West Midlands and had not been formalised at the time of the visit. Sandwell and West Birmingham Hospitals NHS Trust was reviewed as a specialist haemoglobinopathy team. Several other hospitals in the West Midlands provided services but the numbers of haemoglobinopathy patients being cared for at other locations was not known. University Hospitals Coventry and Warwickshire NHS Trust was also visited as part of the planned programme of reviews. At the time of the visit other hospitals expected to be part of this network included two other Trusts within Birmingham, University Hospitals Birmingham NHS Trust (Queen Elizabeth Hospital) and Heart of England NHS Foundation Trust (Heartlands, Good Hope and Solihull Hospitals). Several Trusts in the wider midlands area might also be considered potential members of a Network. This could include University Hospital of North Staffordshire NHS Trust, The Dudley Group NHS Foundation Trust, The Royal Wolverhampton Hospitals NHS Trust as well as hospitals in Walsall, Redditch and Worcester. It was estimated that services in these areas had between 20 and 100 patients each. Apart from some input from SWB into the care of complex patients with sickle cell disease at The Dudley Group NHS Foundation Trust and Heartlands Hospital, there was no evidence of networking activity.

SPECIALIST TEAM: SANDWELL AND WEST BIRMINGHAM HOSPITALS NHS TRUST

Sandwell and West Birmingham Hospitals NHS Trust consisted of three hospital sites; City Hospital which was visited by the review team, Sandwell General Hospital which had an Accident and Emergency Department (A&E) with small numbers of sickle admissions and Rowley Regis Community Hospital. An estimated 450 adult patients with sickle cell disease and 40 patients with thalassaemia were known to the service at SWB. There were approximately 150 to 200 acute admissions of people with sickle cell disease per year. Over the past decade the patient numbers had steadily increased. A large young local population of haemoglobinopathy patients had resulted in over ten new transfusion dependent patients entering the service per year. A well-established Sickle Cell and Thalassaemia Unit (SCAT) was on the City Hospital site and day services and out-patients services operated from there.

Accident and Emergency

During normal working hours patients attended the SCAT Unit. Outside these times up to five patients per week were admitted through the Accident and Emergency Department (A&E). A joint patient and staff group had addressed the outcome of an audit which had shown that patients had long waits of up to four hours in A&E and a new system was introduced in 2012. At the time of the visit, patients with sickle cell disease were triaged by senior medical and nursing staff using a rapid access proforma and placed as priority 'orange'. The aim was to provide pain relief within 30 minutes of arrival. Patients who were known to the service had hand-held treatment cards which listed their usual analgesia. A list of approximately 120 known patients had

analgesia plans held in A&E. This list was updated by the SCAT senior nurse. Patients without treatment plans were treated with a general protocol which was on the intranet and available in hard copy in A&E.

Patients were occasionally seen by the haematology team at A&E in Sandwell General Hospital and then transferred to City Hospital.

Out-patient and Day Case Facilities

The out-patient clinics and day case facilities were situated in the SCAT Unit, adjacent to the hospital. A move to new facilities just off the main hospital corridor was planned to take place shortly after the visit. The new facilities were the same size as the previous Unit and did not offer room for expansion. The service had not planned to extend working hours as part of the change. The Day Unit offered facilities for top-up transfusions and a drop-in service for pain management which was well attended by patients. This service was primarily nurse-led, but patients were reviewed by the haemoglobinopathy doctors if required. The service had one nurse manager (acting) and three nurses. There was one nurse vacancy which was covered by bank staff. The Trust planned to advertise for a permanent nurse manager. The SCAT nurses provided support to ward patients and to A&E and were involved in nurse education. Only 13% of patients attending the day service ended up being admitted to hospital from the day unit. The remainder were discharged home the same day. No facilities for red cell apheresis were available.

Two haemoglobinopathy out-patient clinics per week took place in the SCAT Unit, and there was a quarterly endocrine clinic.

In-Patient Facilities

The patients were admitted from A&E or from SCAT to Ward D41, which had opened one week before the review. This was a 19 bedded facility which had been recently refurbished to high standards. It was a shared facility with acute medicine. Whilst the nursing staff reported that the patients with sickle cell disease were all housed on this ward concerns were expressed that this was the fourth ward move in six years. The Trust was already considering moving the patients with haemoglobin disorders from this ward to another unspecified site. Ward D41 had good levels of nursing support, although they recognised that there had not been any recent training in the care of patients with sickle cell disease. Patient controlled analgesia (PCA) was not available and the nurses on Ward D41 had not received any training in this, although this was planned. Patient leaflets on analgesia were available on the ward.

Patients were admitted under the medical team at night and transferred to the haematology team the next day. The two haemoglobinopathy consultants alternated on the wards through a ‘1 in 2’ rota, and out of normal working hours there was a ‘1 in 5’ consultant rota. During working hours there was one specialist registrar and one core medical trainee for the haemoglobinopathy team.

Community Services

Community services were provided by three community nurses. One nurse covered adult services and visited in-patients, attended out-patient clinics and managed a case load of 150 patients. Monthly multi-disciplinary meetings between the community and hospital teams had started in 2012. The Trust did not have a service level agreement with the community and the community nurse did not have an honorary contract with the Trust.

User Feedback

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

REVIEW VISIT FINDINGS

NETWORK

General Comments

Patients accessed services in a variety of locations throughout the West Midlands however there was no evidence of a network for the provision of specialist support. Haemoglobinopathy education, learning, protocols and good practice were not shared through a wider network in the West Midlands. The team who met reviewers had not had any interaction with the commissioners of the service.

Concern

A number of haemoglobinopathy patients in the West Midlands had no access to specialist care and there was no plan to develop a network or to develop integrated working. The quality of care for patients with haemoglobin disorders in the area might benefit from consideration by Specialist Commissioning to support the implementation of a network around the SHT.

SPECIALIST TEAM: SANDWELL AND WEST BIRMINGHAM HOSPITALS NHS TRUST

General Comments / Achievements

This was a large haemoglobinopathy service with committed medical staff who were highly valued by the patients and responsive to their needs. The team had recently strengthened links with the community team and commenced multi-disciplinary team meetings, which were clearly documented with a good proforma. The service was patient-centred, for example, following patient complaints about A&E care there had been a patient/staff event which had led to changes in A&E delivery of care and service improvements. Personalised

letters to patients were sent following complex consultations, with summaries of management plans, which were more patient-focussed than simply sharing copies of GP letters.

The A&E staff reported good support from the SCAT nursing staff and the haematology consultants. Regular teaching sessions took place for A&E nursing and medical staff. There was evidence of extensive patient consultation about the planned move of the Unit.

Patients with sickle cell disease and thalassaemia gave positive feedback about the medical and nursing teams and felt confident in their care. They reported that relationships with staff were good. The SCAT Unit was praised and users felt this service demonstrated that they were valued within the Trust. Patients valued the service saying that both the acute pain service and transfusions were provided in a timely fashion. Concerns were expressed about A&E and although these predated recent changes, the patients still reported that they would rather use the SCAT Unit than attend A&E. Several patients requested out of hours services, both for transfusion and for the acute pain service.

Good Practice

1 The SCAT Unit was one of the first in the UK. It was the model of care that had been adopted by many other services. It was praised by patients with sickle cell disease and thalassaemia. The patients felt safe and confident in the treatment they received there. The acute pain service was effective and offered high quality care to patients.

2 Patients benefitted from the excellent new in-patient facilities and from all in-patients being situated on one ward. There was good patient feedback about in-patient care and about communication between the SCAT Unit and acute service.

3 The opportunities for patient feedback were well used and suggestions from patients had been incorporated into the service.

4 The patient leaflets that were reviewed were well written and well set out.

5 The quarterly specialist endocrine clinic was attended by nearly all the patients with thalassaemia.

Immediate Risk

No immediate risks were identified.

Concerns

1 There were no senior nursing staff on the SCAT and the most senior member of the team was in an acting role. In her absence she was replaced by bank staff. Although there were plans to appoint a permanent post the skill mix in this team was still a concern due to inadequate senior nursing support given the numbers of patients with haemoglobin disorders.

2 In view of the large numbers of patients due to transition from the paediatric service, which included 200 transfusion-dependent children, there was an urgent need for capacity planning. The new SCAT Unit did not include room for expansion, and there was no room for expansion in the consultant job plans. A review and overall plan for developing appropriate capacity were required.

3 The lack of integrated and partnership working was a concern in a number of ways:

a) Networking and collaboration was absent even across the adult haemoglobinopathy service providers in the Birmingham Trusts.

b) Poor transition services resulted from lack of collaboration with the paediatric service. A temporary transition co-ordinator and joint specific transition clinics had been in place, but were not active.

c) Joint working with community services was limited.

4 For such a large service several specialist aspects were not in place:

a) Despite other hospitals in Birmingham having apheresis services, red cell apheresis was not available in SWB and patients travelled to Bristol or London for this service.

b) T2* and R2 MRI was not available, although the R2 MRI was available at the Birmingham Children's Hospital NHS Foundation Trust. Adult patients had to travel to London to have a T2* MRI.

c) Patients did not have access to specialist renal or orthopaedic services.

d) Although patients were seen on an ad hoc basis in the antenatal clinic they did not have support from a comprehensive obstetric sickle cell disease service.

5 Annual reviews were not taking place in a consistent fashion. Developing and using Annual Review Protocols and proformas would help address these issues.

6 Patients were not being registered on the National Haemoglobinopathy Registry (NHR). Adverse events had not been reported on the NHR. The team was not able to provide accurate data on activity. This information will be needed for future service planning and to meet the national service specification. The service may need data collection support to take this forward.

7 Both an audit and patients themselves had identified that the time to first analgesia experienced in A&E could be very long with a range of times extending to over four hours.

Further Consideration

1 The community service did not have a service level agreement for service provision and the community nurse did not have an honorary contract despite working in the in-patient and out-patient services. Reviewers were therefore concerned about the governance of this post.

2 This was a large SHT service and although some teaching for medical staff was undertaken there was little evidence of participation in education or research activity related to haemoglobin disorders. There was a lack of structured training both within the hospital and across the network, which may in part, be due to the lack of senior nursing support.

3 There was no provision of services out of normal working hours for transfusion or out patients. This would be of great benefit for the local AHD patient population.

4 Protocols were in place, but were brief, especially those pertaining to chronic patient care, they would benefit from expansion.

COMMISSIONING

Concern

A member of the Sandwell and West Birmingham Clinical Commissioning Group (CCG) attended the review, but was unaware of the commissioning arrangements for the service. However it was thought to be part of a block contract for acute services at the Trust. A Joint Strategic Needs Assessment (JSNA) for the service was not planned by the CCG. Specialist commissioners had not engaged with the Specialist Haemoglobinopathy Team nor were they actively involved in considerations for services for patients with adult haemoglobin disorders across the West Midlands.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Jo Howard	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Guys & St Thomas' NHS Foundation Trust
Joanne Bloomfield	Specialist Nurse & Manager	Sickle Cell and Thalassaemia Service Nottingham
Verna Davis	Nurse/Manager	Central Manchester University Hospital NHS Trust
Rosena Geoghegan	Advanced Nurse Practitioner Candidate in Haemoglobinopathy	Our Lady's Children's Hospital, Dublin
Ravinder Raj	Information Officer	Sickle Cell and Thalassaemia Support Project
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Elaine Miller	Voluntary Sector Representative	UK Thalassaemia Society
Jacqueline Simpson	Service User	Croydon
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	However, information on how to contact the services needed further clarification. Information about how to report safeguarding concerns was not seen.

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	The leaflets were well written and clearly set out. A good range of additional leaflets was available, including a leaflet on pregnancy. Some of the leaflets only referred to sickle cell disease but not thalassaemia, specifically; 'b', 'e', 'i', 'e', 'ii'.
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	There was a good standard GP letter about the side effects of chelator agents.
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	N	Cards were issued to patients but there was no evidence of a permanent record of consultations where care had been discussed. A record was not routinely offered to 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	

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	
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	However, the number of PA's was insufficient for the service.
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	Good cover 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	The lead nurse was in an 'acting' position. The permanent post was out to advert at the time of the review.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	Bank staff were used.

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	The staffing levels on the day unit were inadequate and there was no evidence of competence training relating to adult haemoglobin disorders, however, the nurse staffing levels on the in-patient ward were excellent.
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 a training plan for the Day Unit, but not for the Ward.
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	However, there was evidence of a structured plan for A&E and the Day Unit.
HN-298 All	**Administrative and Clerical Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	Administration staff were part of the service, but there was no data management support.
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	No specialist services were evident for apheresis, nephrology, orthopaedics, psychology or MRI.
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	Day Unit and In-patient facilities were new and high quality.
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	However, cross-matching was available up to 9 pm from Monday to Friday and at the weekend.

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)	N	Only generic transition guidelines were in place.
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	N	However, there was a guideline for first out-patient appointments for thalassemia.
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	However, the guidelines were brief and the protocol for carrying out an exchange transfusion needed to be expanded. The hospital transfusion policy needed to be updated.

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. An undated audit showed deficiencies in iron overload monitoring. This could be improved by formal annual reviews.
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	There was no evidence for ‘d’, ‘h’ and ‘j’.
HN-507 All	**Emergency Department Guidelines** Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department.	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-508 All	**Clinical Guidelines: Chronic complications** Clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team.	N	Pulmonary hypertension was the only guideline seen for chronic complications.
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	N/A	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	Y	Specialist management guidelines for 'a' was available only for sickle cell disease.
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	There was no evidence for 'c'. The protocol covering 'a' and 'b' lacked detail.

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	
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	There was no SLA or honorary contract.
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	The data provided was incomplete and did not comply with national guidelines.

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	The monitoring was incomplete and 'c' was out of date.
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	However, audit was undertaken for 'c' and for patients with thalassaemia.
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	Y	There was no network so 'b' was not applicable.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N	Active participation in research was not evident.

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.	N	There was some evidence of document control, however many documents were undated.

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	Network arrangements were not yet in place.
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	Network arrangements 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.	N	Network arrangements were not yet 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	Network arrangements were not yet in place.
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 arrangements were not yet in place.
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	Network arrangements were not yet in place.

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	Network arrangements were not yet in place.
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	Network arrangements were not yet in place.
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	Network arrangements were not yet in place.
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	Network arrangements were not yet in place.

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	There had been no commissioner input to the configuration of services.

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	There was no commissioner oversight of the service.