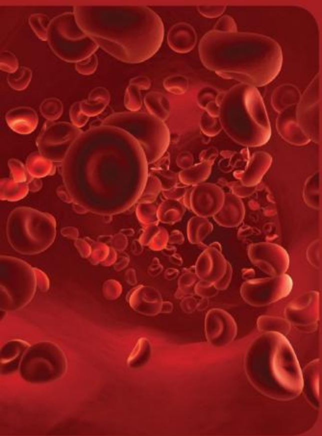
West Midlands Quality Review Service

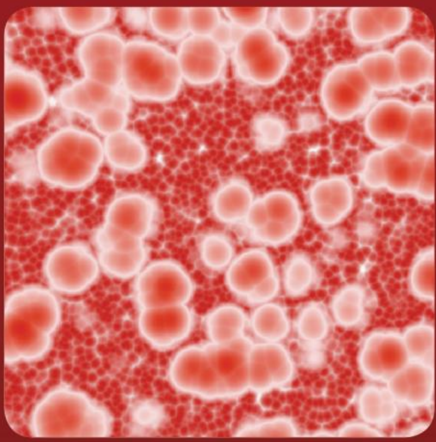
UK Forum on Haemoglobin Disorders

Health Services Caring for Adults with Haemoglobin Disorders

The Royal Wolverhampton NHS Trust

Visit Date: April 29th 2013 Report Date: July 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 at The Royal Wolverhampton NHS Trust, which took place on April 29th 20133. 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 The Royal Wolverhampton 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 SERVICE NETWORK

Trust Name	Abbrev-iation	Reviewed as:	Hospital
The Royal Wolverhampton NHS Trust	RWT	Specialist Haemoglobinopathy Team (SHT)	New Cross Hospital
Walsall Healthcare NHS Trust	MH	Linked Hospital	Manor Hospital

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
The Royal Wolverhampton NHS Trust	SHT	100	<5	<5 (thalassaemia)
Walsall Healthcare NHS Trust	LHT	17	<5	

NETWORK

A network of services for adult haemoglobin disorders was not yet functioning across the West Midlands and had not been formalised at the time of the visit. The Royal Wolverhampton NHS Trust was reviewed as a specialist haemoglobinopathy team. Several other hospitals in the Black Country provided haematology services, including Dudley Group NHS Foundation Trust and Walsall Healthcare NHS Trust and figures provided suggested there were approximately 30 adult haemoglobinopathy patients being cared for at these hospitals. Several Trusts in the West Midlands might also be considered potential members of a Network including Sandwell and West Birmingham Hospitals NHS Trust, which had a large haemoglobinopathy population, and 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). University Hospital of Staffordshire NHS Trust (patient numbers unknown) and University Hospitals Coventry and Warwickshire NHS Trust are other potential network members.

SPECIALIST TEAM: THE ROYAL WOLVERHAMPTON NHS TRUST

The Royal Wolverhampton NHS Trust (RWT) has 700 in-patient beds. In addition to the services provided in a district general hospital, the Trust also provided sub-regional services, including cardiothoracic, cancer, renal, ophthalmology and neonatal services.

The haematology service based at New Cross Hospital had clinical links with the Manor Hospital (MH), Walsall with some cross-site working and transfer of complex haematology patents to the RWT site. These arrangements did not, however, apply to haemoglobinopathy patients at the time of the visit.

Approximately 80 adult patients were known to the service with a further 17 at MH, Walsall (data from the Wolverhampton Sickle Cell and Thalassaemia Support Project). No adult patients were registered on the National Haemoglobinopathy Registry (NHR). A transient population of students with haemoglobinopathy attending Wolverhampton University and those visiting the area also used the services at RWT. There were 229 episodes (in-patient and day care) for haemoglobinopathy in the previous twelve months, representing 68 patients. Around 80 acute sickle cell crisis episodes in the last year represented 35 patients. Less than five thalassaemia major patients were regularly transfused and no patients with sickle cell disease were on regular transfusion regimens.

The service had a nominated consultant haematologist lead although this person had had extended absence in the previous months. Support from a Band 6 nurse specialist was provided for 7.5 hours per week, predominantly based in the day unit. Support was also provided from a haematology registrar, two specialty doctors and an associate specialist.

Accident and Emergency

From 8am to 6pm Monday to Friday, acutely unwell patients were encouraged to contact or attend the Clinical Haematology Unit (CHU) where they received triage assessment. Those requiring admission were admitted to the Clinical Haematology Unit (CHU), depending on bed availability, or to the Acute Medical Unit (AMU). Outside these times patients contacted the haematology nursing staff and/or were seen directly in the AMU. Patients attended the A&E department only if they were unstable or had been brought in by ambulance. In practice, very few patients were admitted by this route.

Patients had care plans that were available on the hospital e-portal. Patients without treatment plans were treated with a general protocol, available on the intranet.

Out-patient and Day Case Facilities

The day unit was located in the CHU with the in-patient ward and was open seven days a week. The day unit offered facilities for manual exchange and routine top-up transfusions and a drop-in service for pain management. This service was primarily nurse-led. No facilities for red cell apheresis were available.

Out-patient clinics were held in the Heart and Lung Centre. Haemoglobinopathy patients were seen within general haematology clinics.

Pregnant patents were seen in the 'high risk' obstetric clinic at New Cross Hospital.

Paediatric patients of transition age were seen in a weekly clinic, which was attended by the lead consultant. Transition took place at 16 to 17 years of age. The young person was admitted to the paediatric ward, if they desired, for up to a year after transfer to the adult service, with their care managed by the adult consultant.

In-Patient Facilities

The patients were admitted to CHU or AMU depending on bed availability and most patients were managed initially in the AMU. There was a flow chart for the management of sickle cell crisis in the AMU, which had been developed in accordance with NICE guidelines. The AMU had good levels of nursing support, although staff recognised that there had not been any recent training in the care of patients with sickle cell disease. Patient controlled analgesia (PCA) was not routinely available on the AMU and the nurses had not received any training in this. When available, PCA was administered to patients by the anaesthetists.

Patients were admitted under the medical team at night and transferred to the haematology team the next day. A consultant rota existed for cover of the in-patient service and patients received daily consultant review. Out of hours all seven haematologists from RWT and Walsall provided consultant medical cover giving 24 hour advice and support.

Community Services

There were two community-based services for sickle cell and thalassaemia:

The Sickle Cell and Thalassaemia Support Project had been established for over 20 years and provided newborn and antenatal screening, general patient support and benefits advice. The Project was also able to facilitate discharge planning by working with the Trust-based CNS. A CNS and trained counsellor were available. The CNS was able to attend haematology and antenatal clinics on request. This service was available to patients from Walsall and Dudley and had a comprehensive local database of patients. The former Primary Care Trust had a service level agreement with this Project.

The Wolverhampton Sickle Cell Care and Social Activity Centre was also well established with external charitable funding. The Centre provided a holistic approach to pain management including aromatherapy and massage, advice on nutrition and lifestyle and also provided some domestic help pre- and post-hospital admission. Although the Centre had over 90 patients, they regularly provided support to 15 patients. They also communicated with the Trust CNS, although no formal SLA was in place.

There was limited interaction between these two community-based services although, for example, the Support Project would refer patients for holistic services at the patient's request.

User Feedback

The review team met with less than five patients with sickle cell disease and carers from the community Sickle Cell Care and Social Activity Centre.

Review Visit Findings

Network

There was no functioning network at the time of the visit.

Specialist Team: The Royal Wolverhampton NHS Trust

General Comments and Achievements

This was a medium-sized service within a busy clinical haematology department. The team had had limited time to prepare for the visit but had performed a gap analysis and developed a work plan to address areas of non-compliance with the Quality Standards. The clinical lead for the team had been absent for some time and the CNS had only recently been formally appointed to the role, although she had been undertaking some of the duties for over two years.

The facilities were of a good standard and the co-location of the haematology ward and day unit facilitated cross-cover of staff with haematology expertise. The haematology nurses appeared to have a good working knowledge of sickle cell disease. The day unit operated a seven-day a week service and was able directly to triage patients presenting with acute crisis. There appeared to be an increasing uptake of this service, which was appreciated by the patients. There was also a direct mobile phone number that patients could use to access the haematology nursing staff.

Overall, the patients and staff appreciated that services had improved considerably over the last 10 years though there were still areas for improvement.

The patient and carers interviewed expressed some concerns about the level of knowledge amongst junior medical and nursing staff in the AMU and reported waits for bolus analgesia. A recent audit showed that approximately half the patients received analgesia within the 30 minute standard.

Good Practice

1 A DVD of a patient recounting her experience of living with sickle cell disease had been produced and was used for training as well as being shown to the Trust management. This was a powerful tool which had helped to focus clinical staff and could be used for medical and nurse training

2 The programme and documentation for developing the nurse competences in the care of people with haemoglobinopathies was of high standard and a good example for other Trusts.

Immediate Risks

No immediate risks were identified.

Concerns

1 Some staffing-related concerns were identified:

a) The extended absence of the clinical lead had impacted on the management of patients' care and the development of specialist expertise among staff. Although other consultants had been covering in-patient and out-patient care, the review team was concerned that:

i. Review of the clinical notes found some patients were receiving repeated top-up or exchange transfusion during acute episodes. No patients were on long-term transfusions, which is unusual for this number of patients. While this may reflect the clinical patient mix, it is suggested that a review of transfusion practice against current guidelines should be undertaken to see if some patients might benefit from a long-term transfusion programme. The Trust should also explore with neighbouring Trusts in the West Midlands area whether there is a case for an apheresis service.

ii. Patient details were not being entered in to the National Haemoglobinopathy Registry (NHR) and there was no evidence of systematic annual review, although some partly filled proformas were seen in the case notes provided. Patients were seen by a variety of consultants in general haematology clinics.

iii. Arrangements for access to specialised services (for example orthopaedics with specialist expertise in caring for people with haemoglobin disorders) were not in place.

iv. Guidelines, even where present, were not sufficiently detailed, particularly for non-haematology staff.

b) The single CNS had limited hours for carrying out the role, which resulted in limited delivery of specialist training for nurses, particularly outside the haematology service. Recent evidence of training was not available despite a comprehensive training plan. Limited time was available for supporting out-patients. There was a reliance on this individual to deliver the work streams that had been identified though the work plan but no robust cover in her absence, although the ANP was knowledgeable about haemoglobin disorders. A business case was in place to increase speciality support for haemoglobinopathy as part of a general haematology expansion.

2 Although the haematology department had clinical links with Walsall for other haematological conditions, the numbers of haemoglobinopathy patients in Walsall and arrangements for their care were unclear.

Further Consideration

1 Copies of clinic letters and care plans were not always offered to patients and care plans could not easily be identified though the e-portal. This had been recognised and a system of flagging notes was proposed.

2 Patients in the AMU, where the majority of episodes were managed initially, were unable to access patient controlled analgesia (PCA) and relied on bolus injections. Some patients found this unacceptable and it led to delays in pain control. Consideration should be given to introducing PCA in the AMU as recommended in NICE guidelines.

3 Feedback from the support groups and the users indicated that there were particular issues around patients receiving Pethidine, which on occasion had led to conflict between patients and medical staff. Consideration should be given to meeting with patient groups to review the issues around pain management and to explore alternative analgesia tailored to individual needs.

4 Consideration should be given to holding a regular dedicated haemoglobinopathy clinic which might help to focus resources for out-patient specialist care, including NHR entry, as well as providing a valuable resource for training medical and nursing staff.

5 Two separate community teams were available for patients with some overlapping duties and patients accessed both for support and advice. The Sickle Cell Care and Social Activity Centre had no formal link with the Trust. Clinical accountability and risk management for this group was unclear. The working arrangement for both groups should be reviewed to ensure:

a) The most efficient use of resources in providing care and support.

b) That both teams are able to link with the Trust multi-disciplinary team.

COMMISSIONING

No commissioner was present at the visit. The team met with the Trust Chief Executive who indicated that the Trust had not engaged in dialogue with commissioners regarding commissioning of services for people with haemoglobinopathies.

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 Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Srinivasan Narayanan	Consultant Haematologist	University Hospital Southampton NHS Foundation Trust
Jon Currington	National Programme Director For Cancer & Blood	NHS England
Sarah Mills	Senior Nurse	Barts Health NHS Trust
Sia Nyandemo	Patient Representative and CEO	Sickle Cell Carers Awareness Network
Elaine Miller	Volunteer Representative	UK Thalassaemia 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	Support included a psychological support service, however, the information about this service was not easily available on the ward or day unit.
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	Some information about haemoglobin disorders was available however, there was no evidence for 'e' and nothing for thalassaemia.
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	The generic leaflet briefly covered 'a' and 'b'. There was no evidence of 'c' in the clinical letters.
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	There were no patient-held records.
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.	N	There was no lead nurse in-put and no formal patient information leaflets on transition.

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	The mechanisms for receiving feedback from patients and carers were vague and there was no rolling programme of audit. However, many patient questionnaires were available.
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.	N	There was no job plan and no an overall lead role identified for service development.
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.	N	Cover for the lead consultant was not provided by a named deputy within the SHT with regular experience caring for people with haemoglobin disorders.
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.	N	Limited time was dedicated to this role and therefore the lead nurse identified was not able to undertake the full lead role responsibilities. However, a business case had been developed to improve this situation.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	As QS HN-203

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	Comprehensive documentation for nurse competences and an induction programme for junior doctors were available. However the evidence was unclear as to when these were implemented.
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	A brief education and training plan was in place, however, this had insufficient detail.
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 were plans to roll out a training programme for the Emergency Department and Maternity Services.
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	Clerical support was ad hoc.
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 evidence was provided covering the specialist services 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	The day unit was open from 7am to 7pm and at weekends.

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	However, the paediatric lead clinician, the co-ordinator for the transfer of care, was not named for these purposes.
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, the team was in the process of producing written guidelines and a template for annual services.
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.	N	However, the team was in the process of producing written guidelines and a template for routine monitoring.
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.	N	No formalised written guidelines were available, however, there was evidence for 'a', 'b', 'c' and 'd'.
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 'k' and most of the guidelines presented were brief and recently written. The AMU guidelines were not consistent with the guidelines in the folder, particularly 'g'.
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.	N	Only pain and acute chest guidelines were available on the intranet.

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.	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	'a' was not covered and no evidence was in the case notes for 'b' and 'c'
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	No local clinical guidelines were available for thalassaemia.

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.	N	'c' and 'e' were not covered in the operational policy.
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	However, a work plan was agreed for implementation.
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	No service level agreements were in place for community services.
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	Data were not entered on the NHR.

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	There was no evidence for 'b' to 'f'.
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, initial audit commenced in March 2013 to capture those patients admitted who were on penicillin, folic acid and received analgesia within 30 minutes of arriving at hospital. There was no formal audit for thalassaemia patients.
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	No audit of implementation of guidelines had been undertaken.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N	There was no participation in trials relating to 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	Y	There were minutes of meetings and a review process was in place.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Some documentation had no author. Some documents were out of date, for example, the management of sickle cell crisis.

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.

<table>
<tr><th>Ref</th><th>Quality Standard</th><th>Met Y/N</th><th>Comments</th></tr>
<tr><td>HY-501</td><td>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.</td><td>N</td><td>Network arrangements were not yet in place.</td></tr>
<tr><td>HY-502</td><td>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.</td><td>N</td><td>Network arrangements were not yet in place.</td></tr>
<tr><td>HY-701</td><td>Annual Meeting
The network should hold a meeting at least annually involving network leads (QS Error! Reference source not found.) 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.</td><td>N</td><td>Network arrangements were not yet in place.</td></tr>
</table>

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	The configuration of services for people with haemoglobin disorders across the network was not yet agreed.

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	Clinical quality review meetings were not yet in place.