WM QRS West Midlands Quality Review Service

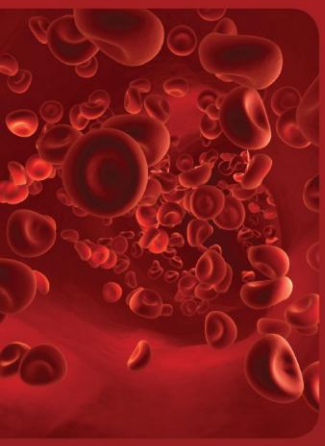
UK Forum on Haemoglobin Disorders

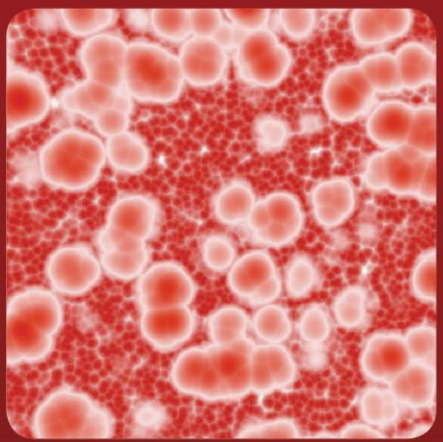
Health Services Caring for Adults with Haemoglobin Disorders

South Central England

University Hospital Southampton NHS Foundation Trust

Visit date: July 10th 2012 Report Date: September 2012





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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 University Hospitals Southampton NHS Trust (UHST). 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 University Hospital Southampton 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 SOUTH CENTRAL NETWORK

Trust Name	Abbreviation	Reviewed as:	Abbreviation
University Hospital Southampton NHS Foundation Trust	UHST	Accredited Local Haemoglobinopathy Team	A-LHT

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
University Hospital Southampton NHS Foundation Trust	A-LHT	25	<5	5 (<5 red cell exchange programme)

NETWORK

At the time of the visit there were no network arrangements in place.

ACCREDITED LOCAL TEAM: UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST

University Hospital Southampton NHS Foundation Trust serves a population of 500,000. However the prevalence of haemoglobin disorders was low with approximately 25 to 30 adult patients attending the service and approximately one to two emergency admissions every two months. Services for patients with haemoglobin disorders were led by a Consultant Haematologist.

Accident and Emergency

Unwell patients or those with crisis attended the Accident and Emergency (A&E) Department where they were assessed and the case discussed with Haematology Registrar on-call. If the patients needed admission, they were transferred to the medical team for inpatient care, supported by the Haematologist.

Outpatient / Day Case Facilities

There was a newly built outpatient suite where a monthly clinic was held for sickle patients. Flexible arrangements allowed for this clinic to be rescheduled if the consultant was away. The adult haematologist was able to attend the paediatric clinic when patients approaching transition were seen (from 14years). Outpatient attendance was approximately 50%. Automatic reminder letters and texts were sent out to patients two weeks before their appointment.

At the time of the review visit, less than five patients were also seen at The Whittington Hospital NHS Trust and University College London Hospitals NHS Foundation Trust for specialist review.

Patients requiring top up transfusions and exchange transfusion attended the Cancer Care day unit (C3), which was open six days a week and had extended day-time opening hours. A haematology day unit was due to open in May 2013. Trained nursing staff ran the day unit with support from junior medical staff and Consultants. Red cell exchange (<5 patients) was being performed manually but automated exchange was being considered. .

In-Patient Facilities

Patients requiring admission were admitted to acute medical wards under the care of the medical teams. No ward was specified for their care and patients could be admitted to any acute medical ward depending on bed availability. The haematologists provided input into the care of sickle cell patients. Specialist advice was sought, if necessary, from a specialist centre.

Community Services

Community support therefore relied on the patients' GP. At the time of the visit there was no specialist nurse or community service, following the retirement of the Nurse Counsellor and the withdrawal of funding for this post.

Local Teams / Linked Hospitals:

No evidence was supplied for other hospitals although there were known to be patients in Portsmouth, Bournemouth/Poole and Salisbury.

Review Visit Findings

Accredited Local Team: University Hospital Southampton NHS Foundation Trust

General Comments and Achievements

The haemoglobinopathy service was led by a recently appointed and committed consultant who had the appropriate training to take it forward. A monthly clinic had been instituted and there was collaborative working with the paediatric haemoglobinopathy consultant. The service dealt with small numbers of patients and required development and resourcing to meet the Quality Standards. However, the Trust acknowledged these issues. There was dialogue with local commissioners and an action plan had been developed.

The reviewers were impressed by the comprehensive care plans which had been developed for individual patients and which were readily accessible electronically in the A&E department. Clinical staff in A&E were complimentary about the support from the haematology team although they said that they found the acute sickle cell crisis protocol insufficiently detailed. Management plans were written by the consultant in individual patient records.

Flexible arrangements were in place for transfusions, including at the weekends, which was greatly appreciated by the patients.

Reviewers visited the A&E department and outpatient suite. Outpatient facilities were of a high standard.

User Feedback

The sickle cell and thalassaemia patients who attended the review visit expressed overall satisfaction with the service and felt that things had improved with the arrival of the new consultant. However, they stressed the gap left by the retirement of the previous specialist nurse counsellor and were keen to see this post re-

introduced. Patients accessed national groups (Sickle Cell Society and UKTS) and some users had participated in a sickle cell patient group in Reading.

Immediate Risk

No immediate risks were identified.

Concerns

The reviewers had a number of significant concerns relating to quality and safety for patients. It was acknowledged, however, that there was a clear commitment to improve the service to meet the required standards.

1 The service relied on access to the lead consultant for advice. There was an absence of written protocols or guidelines for other medical staff, including junior doctors, to follow. This led to concerns about the management of acute complications arising out of hours or when the consultant was not available. In particular, the sickle cell painful crisis protocol was not detailed enough and would not comply with the NICE guideline. There was also no protocol for emergency red cell exchange.

2 The lead consultant was working in isolation and did not have enough job-planned time to deliver and develop all aspects of the service, including responsibilities for the screening programme and training of other medical staff.

3 There was no specialist nurse and funding for this post had been withdrawn. The previous post-holder had a number of roles including teaching of ward staff and supporting patients. They had also provided a clinical and community service for paediatric patients and specialist counselling in relation to the national screening programmes. Although paediatric and screening services were outwith the remit of the peer review, reviewers were concerned for younger patients, counselling for at risk couples and those entering transition.

4 Transition arrangements were patchy with only local patients transferring to the Southampton service. Other young adults, looked after as children in Southampton, were referred back to their local adult haematology services. The level of care they received subsequently was unknown and there were no apparent arrangements for specialist review.

5 Ward and outpatient nurses did not have appropriate training in care of patients with sickle cell and thalassaemia, although the Trust was aware of the RCN nursing competencies. No suitably experienced nurse was available to deliver specialist training.

6 Although data on patients were being entered into the National Haemoglobinopathy Register, there was no formal system for recording annual reviews.

Further Consideration

1 The patient pathway should be reviewed as a whole to ensure high quality care is available from birth through to adult care.

2 Strong consideration should be given to reinstating the specialist nursing post. This would help to address the concerns in relation to training, patient support and transition. The roles of this post could be reviewed In light of the relatively low numbers of adult patients and could possibly be combined with paediatric, transition and screening responsibilities to provide support for the whole pathway of care,

3 At the time of the visit, UHST was not able to deliver all aspects of specialist care. Consideration should be given to formally strengthen links with one specialist centre(s) (SHT), with the aim of UHST becoming an accredited linked hospital / local team.

4 Guidelines and protocols should be developed and made available to all staff. These could be developed in conjunction with the specialist centre with which the Trust decides to link.

5 UHST should consider working with commissioners and other hospitals in the region to develop a service for all patients from Wessex, as part of a local network. This would increase the critical mass of patients and enable the development of more specialist expertise.

COMMISSIONING

General Comments and Achievements

A specialist commissioner from South Central Specialist Commissioning Group (SCG) and a local commissioner from Southampton City Clinical Commissioning Group met with members of the visiting team. Despite being identified as part of the 'Minimum Take' for specialist commissioning for 2012/13 the service was not being commissioned by the SCG due to difficulties with counting and coding specialist activity. The commissioning arrangements at the time of the visit were through the Primary Care Trusts.

Whilst a service was provided for patients through the haematology team this was not a specialist tertiary level service. In order to ensure that patients in the Southampton and Wessex area can access high quality equitable specialist care consideration should be given to establishing commissioning arrangements for this group of people, to ensure formal access to specialist tertiary care. Commissioning arrangements could extend to all patients in the area including those attending other providers such as Portsmouth and Bournemouth /Poole and Salisbury. It was noted that thalassaemic patients attended The Whittington for annual review. The most appropriate link could be identified and then formalised.

Concerns

1 Patients with haemoglobin disorders in Wessex did not have access to appropriate specialist care (apart from a small number of patients who attended London hospitals for annual review).

2 The arrangements for the care of adults from Portsmouth, Poole / Bournemouth and Salisbury were not clear.

3 Specialist nursing support was not available, including for at risk couples, parents of newly diagnosed babies, young people, those entering transition and adults. The absence of this post left an unacceptable void with no links between community services, primary care or acute care and no specialist support available to patients and families.

Further Consideration

1 Given the low prevalence of haemoglobin disorders, commissioners should consider:

a. Working with UHST to formally agree a specialist centre with which the Trust service could link, probably as an accredited linked hospital / local team.

b. Commissioning care for all Wessex adults with haemoglobin disorders from UHST and the agreed specialist centre, as part of a local network of care.

c. Agreeing and commissioning a model of care covering all aspects of the care pathway from birth through transition to adult care.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Kate Ryan	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Central Manchester University Hospitals NHS Foundation Trust.
Rhonda Foster	Specialist Nurse	Croydon Health Services NHS Trust
Natasha Lewis	Nurse	East London NHS Foundation Trust
Dr Elizabeth Rhodes	Consultant Haematologist	St George's Healthcare NHS Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group

WMQRS members:

Pip Maskell	Quality Manager	KeyOpps Ltd. Director - *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	N	Literature was generic to the Trust and did not cover all aspects of the Quality Standard.
HN-102 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy and transfusion services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. How to contact the service for help and advice, including out of hours e. Staff of the service f. Community services and their contact numbers h. Relevant support groups g. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns h. How to get involved in improving services (QS HN-199)	N	No formal written information was given to patients, apart from 'b'. Community support was organised through the GP as there was no Community Nurse Counsellor. Feedback on service and complaints were through PALS.

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	There was no specific advice for patients, however, a selection of generic information booklets were available for patients and carers.
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	Communication through clinic letters was not clear and did not cover all aspects of the Quality Standard.
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	Clinic letters were sent to GP's with a copy to the patient on request. There was an Acute Care Pathway for sickle patients who had painful crisis. This was in EDocs (electronic letters) and was accessible by A&E Medical staff.

Ref	Quality Standard	Met Y/N	Comment
HN-106 C 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	No formal arrangements were in place for transition. However, there was an informal discussion with paediatric haematology consultants and a combined review in paediatric haematology clinic prior to transferring care to the adult team.
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	Formal arrangements for involving patients and carers were not yet in place. .
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	Limited time was allotted to care of patients with haemoglobin disorders in the job plan of the Lead Consultant. However, there was regular participation in CPD activity and there were plans to join UCL / Guys and St. Thomas' Hospital for CPD.
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	In the absence of the Lead Consultant there were no active clinics or treatment of patients.

Ref	Quality Standard	Met Y/N	Comment
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	No Lead Nurse was available.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	No cover was available as there was no Lead Nurse.
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	Apart from the Lead Consultant, no other support was available.
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 compliance with this Quality Standard.
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	No formal arrangements were in place and the limited time in the Lead Consultant's job plan meant that training was not provided for other staff. However, the A&E nursing staff had received some training in haemoglobin disorders.
HN-298 All	**Administrative and Clerical Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	There was no formal administrative support. The retired Nurse Counsellor had previously helped with data collection and updating the list.

Ref	Quality Standard	Met Y/N	Comment
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	N	No formal arrangements were in place but patients had access to these services, if required.
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	Consultants for other specialist services were not named. An obstetrician looked after patients with haemoglobin disorders with the haematologist in a High Risk Pregnancy Clinic, although specialist expertise in haemoglobinopathies was not available.
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	Y	The Laboratory had CPA accreditation and participated in the NEQAS scheme.

Ref	Quality Standard	Met Y/N	Comment
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	Facilities for phlebotomy/OP clinics were available. Patients attended the Cancer Care day unit for transfusion, but building work was due to start soon for a dedicated Haematology Day Unit. There was no dedicated ward for Non-Cancer Haematology patients. Patients were admitted to medical wards under the medical team with haematologist input. This arrangement was appropriate for the number of patients. Day Care and Outpatient facilities were good.
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 functioned on Saturdays for transfusion and phlebotomy.
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	Formal guidelines were not available.
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	No evidence of formal annual reviews was in the folders presented or in the patient records seen by reviewers.

Ref	Quality Standard	Met Y/N	Comment
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	Formal guidelines were not available.
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	Formal guidelines were not available.
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	Formal guidelines were not available.

Ref	Quality Standard	Met Y/N	Comment
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	Basic guidelines were available at A&E. Information on relevant telephone numbers was useful but guidelines did not cover care of patients with thalassaemia and none of the documents that were available were dated.
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	Formal guidelines were not available.
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	Formal guidelines were not available.
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	Formal guidelines were not available.

Ref	Quality Standard	Met Y/N	Comment
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	Pregnancy guidelines were available but were out of date. Other guidelines were not available.
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	Formal guidelines were not available.
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	Formal arrangements were not in place. Some of the elements were covered and co-ordinated by the Lead Consultant.
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	There was no evidence of multi-disciplinary meetings. No lead nurse or community support service was available with whom the lead consultant could meet.

Ref	Quality Standard	Met Y/N	Comment
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 in place with the local PCT or CCG for community services and no one was in post to provide a link between community services and the acute trust.
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	Some data were entered into the National Haemoglobinopathy Register and there were plans to input annual updates and reviews.
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	Some data monitoring was evident but this did not cover all aspects of the Quality Standards and there was no evidence of analysis of the data collected.
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	No audits were undertaken.

Ref	Quality Standard	Met Y/N	Comment
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	Guidelines were not yet in place and so implementation could not be audited.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N/A	Not applicable.
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	Formal arrangements were not yet in place.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	There was little evidence of document control and some of the evidence presented was out of date.

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.

Ref	Quality Standard	Met Y/N	Comments
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.
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.

Ref	Quality Standard	Met Y/N	Comments
HY-701	**Annual Meeting** The network should hold a meeting at least annually involving network leads (QS HY-201) and lead consultants and lead nurses for each LHT / SHT in the network (QSs HN-201 and HN-203) to review the network's progress towards achievement of Quality Standards and its implementation of agreed service development plans.	N	Network arrangements were not yet in place.
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 was no agreed network model or pathway of care. There was some informal linking to London providers but there appeared to be other local providers in the area with no links to Southampton. There was no community care provision.
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	Commissioner reviews were not yet in place.