WM QRS West Midlands Quality Review Service

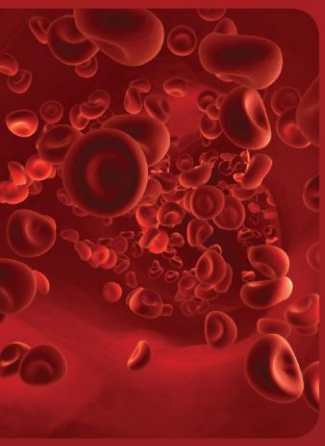
UK Forum on Haemoglobin Disorders

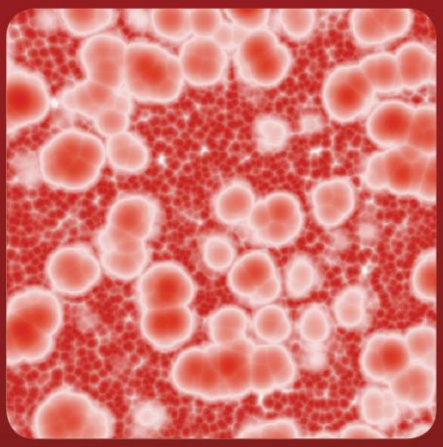
Health Services Caring for Adults with Haemoglobin Disorders

South West

University Hospitals Bristol NHS Foundation Trust

Visit date: November 14th 2012 Report Date: April 2013

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INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia in the South West, in particular University Hospitals Bristol NHS Foundation Trust, which took place on November 14th 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 University Hospitals Bristol 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 THE SOUTH WEST

Trust Name	Abbre-viation	Reviewed as:	Local Team(s) / Linked Hospital(s) LHT
University Hospitals Bristol NHS Foundation Trust	UHB	Specialist Haemoglobinopathy Team (SHT)	-

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
University Hospitals Bristol NHS Foundation Trust	SHT	82	23	8 Thalassaemia Major patients

NETWORK

Network arrangements were not in place in the South West which had a low prevalence of haemoglobinopathies. University Hospitals Bristol NHS Foundation Trust (UHB) only was reviewed, as the Specialist Haemoglobinopathy Team. Frenchay Hospital, North Bristol NHS Trust and Weston General Hospital, Weston Area Health NHS Trust had Accident and Emergency Departments (A&E) which patients with sickle cell disease occasionally attended. All known patients had been transferred to UHB and, for the occasional attendances, the local haematology teams liaised with UHB. There was a combined out of hours haematology on call rota for UHB and Weston General Hospital. Areas further afield than Bristol but within the South West that had large Trusts included Bath, Gloucester, Swindon, Exeter, Plymouth, Torquay and Taunton. Occasional haemoglobinopathy patients were sent to UHB as in-patients or out-patients, but this was not done in a systematic way. Patients from the wider geographical area were not offered annual review at the specialist centre. At the time of the visit there were no data on the number of patients in the area.

SPECIALIST TEAM: UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST

UHB had several hospital buildings on one large site. The Bristol Royal Infirmary was the main hospital building and the A&E was sited here. Adjacent to this was the Bristol Haematology/Oncology Centre (BHOC) which housed the adult sickle cell disease service. Adjacent buildings included Bristol Children's Hospital, St Michael's (the maternity unit) and the Eye Hospital.

Accident and Emergency

In the year preceding the review visit there had been 130 acute patient attendances, 85 of these had attended the BHOC directly and from there were admitted to the ward. Only 21 patients had attended A&E. Nine of these were discharged directly and 12 were admitted to the BHOC from A&E. Guidelines for the acute management of haemoglobinopathy patients were readily available in A&E at UHB and there was an automated alert system which flagged patients who had care plans and gave access to the plans. Patients were admitted under the haematology team directly from A&E either by the resident on call haematology/oncology SHO (out of hours) or by the haematology specialist during normal working hours or weekend daytime.

Out-patient and Day Case Facilities

A weekly haemoglobinopathy clinic was held on Tuesday afternoon staffed by the lead clinician, a second consultant, the specialist registrar and the nursing lead. This clinic had been in place since 2010. A psychologist had recently been appointed and ran sessions in parallel to the clinic. An annual review proforma had been introduced in 2011. The clinic was preceded by a weekly multi-disciplinary meeting. In the previous year there had been 522 attendances, but the 'did not attend' rate was 25% despite phone and text reminders sent to patients before their appointments.

A general haematology/obstetric clinic was in place and haemoglobinopathy patients were seen in this clinic. Specific specialist clinics were not in place but patients were seen by other specialists on an ad hoc basis.

The haematology day unit offered facilities for planned transfusions and an acute assessment unit. Patients called the Day Unit directly during working hours and were offered assessment and direct admission to the ward if needed. There had been 181 planned day unit attendances in the previous year, most of which were elective transfusions, but included patient reviews and blood tests.

In-Patient Facilities

The majority of patients were admitted to the haematology ward (Ward 62) or to the oncology ward (Ward 61). Out of hours, patients called the ward to attend for emergency review and admission if required. The average length of stay with sickle cell disease on the haematology ward was 5.22 days, but the median was around three days. The range of length of stay was 0 to 29 days. Patients requiring out of hours or weekend elective transfusions booked into Ward 62.

Small numbers of patients had been admitted to the other hospital departments (eg surgery, cardiology), usually because their main reason for admission was not due to their sickle cell disease and they were admitted under other teams, but would be reviewed by the haematology team.

The patients with sickle cell disease were looked after by the in-patient team which included an attending consultant and rotating specialist registrar, and would be seen as part of routine ward working. In addition the lead clinician saw all in-patients with sickle cell disease at least twice a week on formal ward rounds and more frequently if required.

Individualised care plans were available for patients with complex needs. Most patients had a brief analgesia plan on the electronic patient record. Patient controlled analgesia had recently been introduced.

Community Services

The lead nurse (Clinical Co-ordinator for Sickle and Thalassaemia) supported both the community service and acute services. The lead nurse received all antenatal carrier results and signposted them to the Genetics Team who were responsible for antenatal counselling. The lead nurse also received the results of any newborn affected patients and would review them in the community and offer continuous review throughout life, if required. The community service covered Bristol, North Somerset and South Gloucestershire and there were three to four affected births in these areas per year. Gloucester had a separate community service, although all children were seen annually in Bristol Children's Hospital for their Transcranial Doppler (TCD) screening. The lead nurse also saw in-patients, attended the multi-disciplinary team meetings, the adult clinic, gave information to the GPs, was involved in nurse education in the community and in the Trust, and ran the patient support group.

User Feedback

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

REVIEW VISIT FINDINGS

NETWORK

General Comments

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

Concern

1 The lack of a network or of any integrated working across the South West, and of a plan for establishing a network was concerning and should be brought to the attention of the local specialist commissioners. There seemed to be a number of haemoglobinopathy patients in the South West without access to specialist care and patients reported poor care when they attended hospitals other than UHB. There was no information about the number of patients attending other units, or if any treatment protocols were in place.

SPECIALIST TEAM: UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST

General Comments / Achievements

This service had been established for less than five years and quality was improving. The Clinical Lead and Lead Nurse were keen and committed. The Lead Nurse, in particular, had worked hard to bridge the gap patients perceived between community and acute services. Achievements included a nurse-led patient support group.

Patients who met the visiting team felt their suggestions and comments on the service were valued and listened to, in particular, about recent service improvements. Patients were confident in the care they received and said that the service was responsive. Patients gave positive feedback about the medical and nursing haemoglobinopathy team stating that they had good relationships with staff. They praised the Day Unit and haematology ward.

Other achievements included the recent appointment of a psychologist, who covered the whole of haematology, but whose job plan specifically mentioned patients with sickle cell disease. Patient Controlled Analgesia (PCA) devices had been introduced and a thorough annual review form was in use.

A&E staff reported that the haematology team, both at senior and junior level, was always easy to contact and reviewed patients rapidly.

Good Practice

1 The majority of patients were admitted directly to the ward and day unit, by-passing A&E. This was popular with patients.

2 Technology was well used with an e-mail alert system so that the admission of any patients with haemoglobin disorders to A&E, pre-assessment or the wards triggered an email to the lead clinician and lead nurse. If patients did attend A&E an 'alert' came up on the screen, guiding the A&E team to their personal care plan.

3 Clear pathways were available in the operational policy which outlined emergency care and transition. At the time of the visit it was not clear if these were fully implemented and readily available for all staff but they provided a good platform for service development.

Immediate Risk No immediate risks were identified.

Concerns

1 Only one haemoglobinopathy nurse was in post at the time of the visit with responsibility for community and in-patient services for paediatrics and adults. The staffing establishment had a 0.8 whole time equivalent clinical nurse specialist (CNS) post for adult haemoglobinopathy patients, but this post was vacant. This meant that robust cover arrangements for the lead nurse were not in place and that some aspects of the service were not adequately supported, for example the transition service and staff education.

2 Annual review data were not being collected routinely and were not being entered on the National Haemoglobinopathy Registry.

3 There was no evidence of a functioning network or integrated working with either the other Trusts in Bristol or the wider surrounding area.

4 The lead consultant had a high work load and did not have capacity in their job plan to take on further development of the haemoglobinopathy services or additional network responsibilities.

Further Consideration

1 The patient feedback raised an issue about capacity on the haematology/oncology wards. The care on these two wards was perceived as very good, but patients said they disliked being admitted onto other wards as they felt that the care was not adequate and nurse education about haemoglobinopathies was poor. The extent of this problem was not clear as the clinicians said patients were admitted outside the haematology/oncology wards less than five times in the past year, but patient perception was that it was quite a common problem. Review of admission data may help to clarify the extent of the problem.

2 The thalassaemia guidelines, whilst present, were fairly brief and would benefit from increased detail.

3 The audits were not recent (particularly the pain audit). Some audits had been performed by students or by doctors as part of projects, and this could be a useful resource for future audits.

4 The haematology-oncology unit did not have an Arterial Blood Gas analyser which made acute management of patients with acute chest syndrome difficult.

COMMISSIONING

General Comments

An acute commissioner from the local Primary Care Trust cluster covering Bristol, North Somerset and South Gloucester met with the review team. The service for adults with haemoglobin disorders was commissioned as part of the acute haematology contract based on cost and volume with little direct commissioning input. The Trust had begun to identify activity to transfer to specialised commissioning from April 2013.

The acute commissioners attended the monthly Trust Commissioning Quality Review but the Adult Haemoglobin Disorders services had not featured in the monthly reporting.

Further Consideration

1 The service provided at UHB was primarily for the local population although some advice was sought by other Trusts in the region. As there were no other tertiary providers of haemoglobinopathy services in the South West it was considered important that commissioners identified any unmet need. Patients of other providers in the South West region could be directed to the Specialised Haemoglobinopathies Team at UHB to ensure equity of access to tertiary services for all South West patients. It was assumed that the number of additional patients would be very small.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Jo Howard	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Guy's & St Thomas' NHS Foundation Trust
Dr Nicholas Jackson	Consultant Haematologist	University Hospitals Coventry and Warwickshire NHS Trust
Rhonda Foster	Specialist Nurse / Service Manager	Croydon Health Services NHS Trust
Nicola Howard	Senior Commissioning Manager	London Specialised Commissioning Group
Sharon Ensor	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 for haemoglobin disorders was buried within the general information on all services at BHOC. Consideration might be given to specific information for Adult Haemoglobin Disorders (AHD).

Ref	Quality Standard	Met Y/N	Comment
HN-103 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	N	Information on health promotion for 'e' 'i' – 'iii' was not available.
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	Information on the GP letters provided clear guidance on discharge. The letter provided by the CNS on hydroxycarbamide was good.
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 was a section about analgesia on individual patients' protocols, but this was not carried by patients. Annual reviews were planned.
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	Transition information was clear and had an age-linked timeline within a checklist for the different stages.

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	There was a named consultant with sessions in their job plan, but other workload issues often prevented these being used for haemoglobinopathy work. There was not capacity in the job plan for further service development, locally or towards forming a network.
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHTs this should be a named deputy within the SHT with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHT. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHT advice and support.	Y	
HN-203 All	**Lead Nurse** A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders.	Y	
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	Cover was not available for the Lead Nurse

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	Nurse staffing on the wards did not have the frequency of contact to develop the appropriate competences in the care of people with haemoglobin disorders. Only one training day per year was available for staff. The introduction of RCN competences was planned.
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 insufficient evidence of planned training.
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 a programme of training covering A&E was in place.
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	The level of administrative and clerical support was insufficient. Whilst there was 0.8 HTA administrative support they did not offer support in data collection.
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	Y	Although Ferriscan was not available.
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	Y	
HN-401 All	**Facilities available** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	Transfusions and phlebotomy were available. Out-patient clinics were not available, but in view of small patient numbers this was considered to be appropriate for the needs of the population.

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	Transition guidelines were good but it was not clear how they would work in the absence of the CNS.
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First out-patient appointment b. Annual review for both sickle cell disease and thalassaemia	Y	For sickle cell disease there was a detailed proforma and information in the guideline. For thalassaemia there was a good proforma, but only a single sentence in the guideline.
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	Although these were brief on thalassaemia and would benefit from expansion.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-505 All	**Chelation Therapy** Clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT / SHT.	Y	There were no details on ophthalmological checks for patients on desferrioxamine and these could be added.
HN-506 All	**Clinical Guidelines: Acute Complications** Clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision **For patients with thalassaemia:** k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	N	Clinical guidelines on the management of acute complications for 'h' and 'i' were not in use for sickle cell disease and 'b','h', and 'j' were not available for thalassaemia.
HN-507 All	**Emergency Department Guidelines** Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department.	Y	The emergency guidelines were easily accessible and there was a good alert system.

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	The guideline covering 'c' was brief and would benefit from expansion.
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	Consideration might be given to sharing guidelines with other Bristol A&E departments.
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	The guidelines were good.
HN-511 All	**Thalassaemia Intermedia** Clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy.	N	Guidelines covering indications for splenectomy were insufficient.

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	The document had good pathways.
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	Multi-disciplinary meetings were held weekly prior to clinic.
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	Y	The detailed service specification covered the community aspects.
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 being entered on adverse reporting and although some Annual Reviews were undertaken data were not recorded.

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 service was only monitoring 'a'.
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	Clinical audits had not been carried out for 'b'. Audit for 'c' had not been undertaken since 2009.
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	A rolling programme of audit was not in place.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	Patients were enrolled in TAPS.

Ref	Quality Standard	Met Y/N	Comment
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months	N	Arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses' were not robust.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comment
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	Comment
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	Comment
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	Commissioners had not agreed the configuration of the clinical networks in the south west.

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	Commissioners had not undertaken a review of the network for AHD.