WM QRS West Midlands Quality Review Service

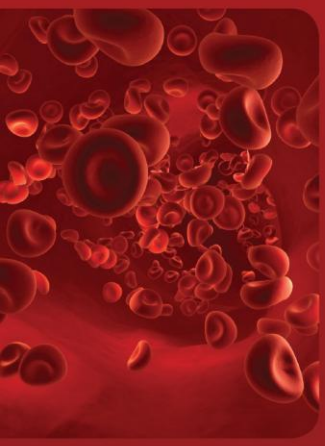
UK Forum on Haemoglobin Disorders

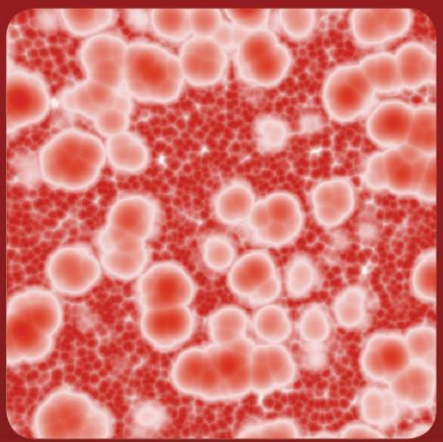
Health Services Caring for Adults with Haemoglobin Disorders

Coventry and Warwickshire

University Hospitals Coventry and Warwickshire NHS Trust

Visit Date: January 17th 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 in the Coventry and Warwickshire Adult Clinical Haemoglobinopathy Service, in particular the University Hospitals Coventry and Warwickshire NHS Trust, which took place on January 17th 2013. 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 Coventry and Warwickshire NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review.

ADULT HAEMOGLOBIN DISORDERS SERVICES IN COVENTRY AND WARWICKSHIRE

Trust Name	Abbrev-iation	Reviewed as:	Hospital
University Hospitals Coventry and Warwickshire NHS Trust	UHCW	Specialist Haemoglobinopathy Team (SHT)	University Hospital Coventry (UHC) Rugby St Cross (RSX)
South Warwickshire NHS Foundation Trust	SWFT	Linked Provider	-
George Eliot Hospital NHS Trust	GEH	Linked Provider	-
Coventry and Warwickshire Partnership NHS Trust	CWPT	Linked Provider	-

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
University Hospitals Coventry and Warwickshire NHS Trust	SHT	60 (University Hospital Coventry) 8 (Rugby St Cross)	13 major, <5 intermedia	17 (12 thalassaemia and 5 sickle cell disorder)
South Warwickshire NHS Foundation Trust	LHT	6	0	0
George Eliot Hospital NHS Trust	LHT	<5	0	0

NETWORK

A network of services for adult haemoglobin disorders was not functioning across the West Midlands and had not been formalised at the time of the visit. University Hospitals Coventry and Warwickshire Trust (UHCW) was reviewed as a specialist haemoglobinopathy team providing informal leadership for haemoglobinopathy services across Coventry & Warwickshire. The numbers of patients in Coventry and Warwickshire were known but the numbers of haemoglobinopathy patients being cared for at other locations was not. Several other hospitals in the West Midlands provided services. Sandwell and West Birmingham Hospitals NHS Trust were also visited as part of the planned programme of reviews. It was not known whether UHCW would be part of a clinical network extending to Birmingham and the surrounding area.

SPECIALIST TEAM: UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST

Coventry and Warwickshire adult haemoglobinopathy service was provided by:

- University Hospitals Coventry and Warwickshire NHS Trust, i.e. University Hospital Coventry (UHC, 1250 beds) and Rugby St Cross Hospital (RSX).
- South Warwickshire NHS Foundation Trust (SWFT)
- George Eliot Hospital NHS Trust, Nuneaton (GEH)
- Coventry and Warwickshire Partnership Trust (CWPT)

The majority of patients lived in Coventry and UHCW and CWPT provided the care for all these patients. University Hospital Coventry also provided some specialist services for patients from Warwickshire but some patients living in Warwickshire accessed all their care from their local hospital and were not seen at UHC. Patients from Warwick had in the past been offered annual review at UHCW but they had failed to attend.

Patients with haemoglobin disorders in North and South Warwickshire were seen in general haematology clinics.

Approximately 95 adult patients were known to the service and 44 had been registered onto the National Haemoglobinopathy Registry (NHR). A relatively large transient population of students with haemoglobinopathy disorders attended the local universities which accounted for between eight to ten new patients per year. There were 63 acute admissions of people with sickle cell disease in 2011-12 with an average length of stay of 4.5 days.

The service was led by a consultant haematologist with support from the community nurse specialist from CWPT and a haematology registrar. A link nurse was based on the haematology ward (34). The team also had two dedicated sessions a week from an adult health psychologist.

Out of hours consultant medical cover was provided by all the haematologists in the Coventry and Warwickshire region on a rotational basis.

Emergency Department

During normal working hours the acutely unwell Coventry-based patients, or their carers and relatives, were asked to contact the community nurse specialist (CNS) for support and advice. If it was deemed necessary, the CNS arranged admission. Outside these times, or if the CNS was not available, the patient, or their carer/relative was asked to phone the haematology ward (ward 34).

Patients with sickle cell disease or thalassaemia were admitted directly to ward 34 if a bed and medical cover were available (8.30am to 8.00pm) or they were asked to present to the Emergency Department (ED). Patients needing admission were directed to ward 34, when a bed was available, or to the acute medical unit. All admissions were discussed with the consultant haematologist on call.

When an acutely unwell patient with sickle cell disease presented at GEH or SWFT and was thought to need intensive care or exchange transfusion, they would be transferred to UHC after discussion with the consultant haematologist on call and, if relevant, an intensive care consultant (although this occurred only rarely).

Patients were provided with a hand-held care protocol for their pain management.

Staff had access to clinical protocols on an “e-library”.

Out-patient and Day Case Facilities

Haemoglobinopathy patients attended a weekly clinic held every Friday afternoon. Patients were also seen at short notice at their request. The clinic was staffed by the consultant and CNS and the psychologist was also available to see patients during this clinic. Patients from Rugby were covered by the consultant in his own local haematology clinics or on the ward in Coventry in the absence of the lead consultant. Patients were reminded of their appointments by text from the CNS in the few days before the clinic. A joint clinic was held four times a year with an endocrinologist for all thalassaemia and transfused patients with sickle cell disease. A pre-clinic

discussion was held about a month before these joint clinics to complete the review proforma and plan any investigations that were needed before the review. Cardiac and liver T2* MRI imaging was available but not Ferriscan.

All patients had an annual review.

A monthly multi-disciplinary (MDT) meeting was held before clinic, attended by the consultant, CNS, ward link sister and psychologist. Patients from Coventry and Rugby were discussed at the MDT at whichever of the two UHCW hospital sites they attended. Patients from other parts of Warwickshire were discussed if they attended UHC or were referred by their local hospital haematologist.

Day care for haemoglobinopathy patients, mainly transfusion, was provided on the haematology day unit, which was co-located with the haematology ward and clinics. Manual exchange transfusions were performed electively on the day unit by the haematology link nurse. No facility for automated apheresis was available on site.

Once every four weeks the haematology day unit at UHCW opened to transfusion dependent patients on a 'Transfusion Saturday' and accommodated eight patients. Priority was given to transfusion-dependent patients who were working or in full-time education.

Phlebotomy was provided either by the CNS at the community centre or by the routine service at UHCW or by community phlebotomy clinics held all over the city.

Transition between adult and paediatric services was initiated by the community team at an age thought to be appropriate for the individual. The adult consultant attended the last two to three paediatric clinic appointments to support a smooth transition into adult services.

In-Patient Facilities

All Coventry and Rugby patients who needed admission were admitted as soon as possible to ward 34. One bed was 'ring fenced' (i.e. was kept empty and made available for emergency admissions). The majority of in-patients had haematological malignancies, but haemoglobinopathy patients were given a high priority. Typically there were one to two in-patients with sickle cell disease at any one time. Patient controlled analgesia was available.

Nursing staff rotated between the day unit and in-patient ward.

Community Services

The community service was provided by the Coventry and Warwickshire Partnership Trust (CWPT) from new premises located near the city centre approximately three miles away from UHCW. The facilities also housed other community services. The team consisted of two CNSs, one of whom focused on the children and one on the adults and, in reality, there was a high degree of cross-cover. The CNSs also provided genetic counselling

for the screening programmes for Coventry patients. They offered a drop-in service for patients requiring advice and also provided phlebotomy for patients pre-transfusion.
The CNS saw patients at home for acute assessment and visited in-patients at UHCW. The CNS also gave advice on welfare and benefit issues and signposted patients to the appropriate services.

User Feedback

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

Commissioning

Members of the review team met with the local commissioner from Coventry Primary Care Trust.

REVIEW VISIT FINDINGS

NETWORK

General Comments

Patients accessed services in a variety of locations throughout the West Midlands, however there was no evidence of a network for the provision of specialist support. Haemoglobinopathy education, learning, protocols and good practice were not shared through a wider network in the West Midlands.

Concerns

1 A number of haemoglobinopathy patients in the West Midlands had no access to specialist care and there was no agreed or commissioned plan to develop a network or to develop integrated working.

2 The quality of care for patients with haemoglobin disorders in the area might benefit from consideration by Specialist Commissioners to support the implementation of a clinical network around one or more Specialist Haemoglobinopathy Teams (SHT). This should extend to ensuring that a seamless pathway exists with community care for all patients being cared for by the SHTs.

Further Consideration

1 Reviewers did not see evidence of medical and nurse training for staff at South Warwickshire NHS and George Eliot Hospital NHS Trust, including for Emergency Department staff. It may be helpful to confirm that appropriate competences are in place.

SPECIALIST TEAM: UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST

General Comments and Achievements

This was a well-organised service providing a good level of individual care for patients. The lead consultant and community nurse were extremely hard-working and their care was highly valued by the patients. Community aspects of care were particularly strong and there was a seamless transition for paediatric patients entering adult care. Review of the case records indicated that clinical guidelines and annual review had been embedded into practice over some years. Clinic letters were of high quality and were routinely copied to patients. The haematology facilities were co-located and were of a high standard. The majority of admissions of patients with sickle cell disease were managed on the haematology ward.

Patients benefited from a psychologist who had been in post for a year. She was able to assess the effect of her interventions for individuals and was planning to develop this further for specific outcomes for patients with sickle cell disease and thalassaemia.

The guidelines and protocols were thorough, detailed and of a high standard. Overall information for patients was good and the reviewers particularly singled out the leaflet describing services available for haemoglobinopathy disorders.

Patients in Rugby had access to the specialist care offered by UCHW and there was evidence of a close working relationship with the local consultant who provided cross cover for the UHCW consultant. Unfortunately he was unable to attend the multi-disciplinary team meetings (MDT) as he was in Rugby on a Friday when these meetings were held.

Immediate RiskS

No immediate risks were identified.

Concerns

1 The patient feedback highlighted some concerns about the standards of care of patients with haemoglobin disorders in the Emergency Department (ED). Knowledge about sickle cell disease was insufficient; patients described a lack of empathy and reported that their care plans were not followed. Staff in the ED were not able to access any individual care protocols at the time of the visit. The patients also reported long waits for analgesia and this was evidenced by an audit against the 2012 NICE guidelines which showed that 53% of patients met the standard for 'pain relief by 30 minutes from presentation'.

2 Although some teaching sessions had been undertaken recently for ward 34 nurses, there was little evidence of a sustained sickle cell disease or thalassaemia training programme either in the ED or on the

haematology ward for nurses, although some aspects were included in their generic training. There was no plan in place to meet the RCN nursing competences and no clear training lead. Teaching and training in haemoglobinopathy for haematology specialist trainees was provided at UHCW (two formal sessions per year, regular diagnostic training, and ad hoc education about patients) and at other hospitals in the West Midlands rotation and on formal teaching days. It had proved difficult to get slots on ED teaching programmes, but a session was held for core medical trainees once in two years. There was no regular teaching for other medical staff.

3 Although the adult community CNS was valued by the patients and had provided service over many years, arrangements for clinical nurse support to patients attending UHCW was not clear and there was no cover for the lead nurse. The close working relationship with the paediatric CNS ensured effective transition and cover in the community but her role in relation to the acute Trust was limited by time constraints due to her duties for the community Trust. She was employed as part of the introduction of universal antenatal screening in 2004, which occupied over half of her time, but patient support had always been part of her role. The CNS reported increasing pressure from the community Trust to limit her time at the acute Trust. No formal service level agreement (SLA) was in place between UHCW and CWPT.

4 Due to the contracting arrangements patients living outside Coventry did not have access to specialist nursing support.

5 Specific haemoglobinopathy training for nurses and in-patient support was only provided by the community CNS who had limited capacity to contribute.

Further Consideration

1 A programme of nurse education should be developed for ward, day unit and ED staff to address the concerns of the patients regarding variable standards of care and to improve analgesia management in the Emergency Department (ED).

2 The role of the CNS in relation to the acute service should be reviewed with a formal SLA between the acute and community Trusts. The existing skills and experience of the CNS should be utilised to lead on nurse education across the acute and community service, and ensure consistent standards for community and chronic care, and for in-patients and emergency presentations.

3 Although the patients were highly appreciative of the 'Transfusion Saturday', some concerns were raised about delays between blood units and cannulation problems. Consideration should be given to a review of transfusion practice and staffing levels for these sessions.

4 The community nurses had made efforts to set up a support group but had become discouraged by lack of interest from the patients. It may be helpful to consider with patients, other mechanisms for patient involvement and support.

5 Reviewers did not see evidence of medical and nurse training for staff at Rugby St Cross Hospital, including for Emergency Department staff. It may be helpful to confirm that appropriate competences are in place**.**

Good Practice

1 'Transfusion Saturday' was popular with patients and provided a welcome forum for patients to meet up with their peers.

COMMISSIONING

General Comments and Achievements

Coventry PCT led on both the acute contract with UHCW and on the contract with community services, without any involvement from specialised commissioning. The contract for the next financial year was being negotiated with Coventry and Rugby Clinical Commissioning Group (CCG). Community services were commissioned for Coventry patients only and Warwickshire patients did not have access to this support.

Further Consideration

1 Specialist commissioners should be involved in the contracting round for 2013/14 for CWPT to ensure that the service provided is in line with the service specification for haemoglobinopathy services and that this service specification is included in the Trust contracts. To provide an equitable and high quality service to all patients across Coventry and Warwickshire consideration should be given to commissioning a combined service for all patients and carers across Coventry and Warwickshire, bringing together acute and community services, under a single lead clinician and nurse.

2 Integrated working between the CCG and specialist commissioner will provide an overview for both the service provided at the acute Trust and the community service and to ensure that community support is available for all patients treated at UHCW rather than being restricted to Coventry residents.

3 Patients from South and North Warwickshire were seen locally and were not referred for annual review at UHCW although the haematologist reported that the consultants in these Trusts had access to the management protocols and would seek advice from UHCW for complex problems.

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 Olu Wilkey	Consultant Paediatrician	North Middlesex University Hospital NHS Trust
Dr Jenny Welch	Consultant Paediatric Haematologist	Sheffield Children's NHS Foundation Trust
Joanne Bloomfield	Specialist Nurse & Manager	Nottingham University Hospitals NHS Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Dr Asa'ah Nkohkwo	Adviser	Sickle Cell Society
Ravinder Raj	Information Officer	Sickle Cell and Thalassaemia Support Project
Elaine Miller	Volunteer Representative	UK Thalassaemia Society
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 SHT
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y	The leaflet on psychology services was particularly good. Patients were referred to Coventry city social services for access to generic social workers.
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	Comprehensive leaflets were available with a balanced quantity of information.

Ref	Quality Standard	Met Y/N	Comment SHT
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	Whilst some of the information was good a simpler version might be useful. Adults were given the information designed for parents of children with haemoglobinopathy disorders rather than one designed specifically for adults. For 'b', 'c' and 'd' there was nothing specifically about thalassaemia. Information on vaccination and staying well was limited.
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	
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	Although some of the patients did not seem to use them.
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	The leaflet available would have been enhanced if the process for transition was described.

Ref	Quality Standard	Met Y/N	Comment SHT
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	A rolling programme of audit was planned. Changes and responses to patient complaints were timely.
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	The lead consultant was working more than the 1 PA allocated to haemoglobin disorders.
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.	N	The lead nurse was not employed by the Trust, therefore the working arrangements, and consequently the roles and responsibilities, were not formal.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	There was no cover for absences of the lead nurse.

Ref	Quality Standard	Met Y/N	Comment SHT
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	A programme for competences in the care of people with haemoglobin disorders was planned for nurses on the ward but had not been delivered. Evidence was about generic rather than specialist competences in the care of people with haemoglobin disorders.
HN-206 All	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-205).	N	A generic haematology training plan was in place and although it was intended to work towards the RCN competences it was not clear who was responsible for this or how it would be delivered.
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	A plan was in place and had been offered to all levels of staff in the Emergency Department but the offers made in 2012 had not yet been taken up.
HN-298 All	**Administrative and Clerical Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	The letters sent to GPs were good.
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 SHT
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	There was a list and there were policies for each but due to the relatively small numbers of adults with haemoglobin disorders the specialists may not have had significant experience of patients with haemoglobin disorders and therefore consideration could be given to collaboration across the wider network.
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	The facilities were excellent
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	'Transfusion Saturday' was a pragmatic solution that also offered patients group contact.

Ref	Quality Standard	Met Y/N	Comment SHT
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	
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	The proforma was excellent and there was evidence of annual reviews being undertaken over three to four years.
HN-503 All	**Clinical Guidelines: Routine Monitoring** Clinical guidelines on routine out-patient monitoring and management between annual reviews should be in use. Local Haemoglobinopathy Team guidelines should specify the indications for early referral to the Specialist Haemoglobinopathy Team.	Y	
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
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	
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).	Y	
HN-507 All	**Emergency Department Guidelines** Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department.	Y	The guidelines were available on the 'e-library'.

Ref	Quality Standard	Met Y/N	Comment SHT
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	Y	
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.	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	Y	
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community (QS HN-205) and representatives of support services (QS HN-301).	Y	The meetings were well documented.
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	Arrangements were not formal.
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.	Y	121 patients had been entered into the National Haemoglobinopathy Registry and there was documentation for two adverse events.

Ref	Quality Standard	Met Y/N	Comment SHT
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	Y	
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 audit did not cover 'b' although this had been discussed at the most recent audit review meeting, and an audit of current antibiotic use and immunisation status was underway.
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	Y	
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	

Ref	Quality Standard	Met Y/N	Comment SHT
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months	Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Network arrangements were not yet in place.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	N	Network arrangements were not yet in place.
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-205 and HN-206.	N	Network arrangements were not yet in place.

Ref	Quality Standard	Met Y/N	Comments
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	Network arrangements were not yet in place.
HY-502	**Clinical Guidelines** Network guidelines should have been agreed covering: a. Annual review (QS HN-502) b. Routine monitoring (QS HN-503) c. Transfusion (QS HN-504) d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-302) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-302) g. Transfer for critical care (QS HN-509) h. Specialist management (QS HN-510) i. Thalassaemia intermedia (QS HN-511) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHTs.	N	Network arrangements were not yet in place.
HY-701	**Annual Meeting** The network should hold a meeting at least annually involving network leads (QS HY-201) and lead consultants and lead nurses for each LHT / SHT in the network (QSs HN-201 and HN-203) to review the network's progress towards achievement of Quality Standards and its implementation of agreed service development plans.	N	Network arrangements were not yet in place.

Ref	Quality Standard	Met Y/N	Comments
HY-702	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Register (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	N	Network arrangements were not yet in place.
HY-703	**Audit** The network should have an agreed programme of audit and review covering, over the whole programme, network-wide achievement of QSs HN-702, HN-703 and HN-704.	N	Network arrangements were not yet in place.
HY-704	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	Network arrangements were not yet in place.
HY-798	**Review and Learning** The network should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses', especially those involving more than one service within the network.	N	Network arrangements were not yet in place.

COMMISSIONING

Ref	Quality Standard	Met Y/N	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks and, within each network, the configuration of services for people with haemoglobin disorders across each network, in particular: a. Designated SHT/s for the care of adults with sickle cell disease b. Designated SHT/s for the care of adults with thalassaemia c. Accredited LHTs for care of adults with sickle cell disease or thalassaemia d. Other LHTs/ Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	N	There had been no engagement with specialised commissioners and no liaison between the CCG and specialised commissioners to agree the configuration of the services. The services provided by the community team were only available to Coventry residents.

Ref	Quality Standard	Met Y/N	Comments
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by each network, in particular, achievement of QS HY-702 and HY-798.	N	There was no commissioner engagement in reviewing the quality of care provided across the network.