WM QRS West Midlands Quality Review Service

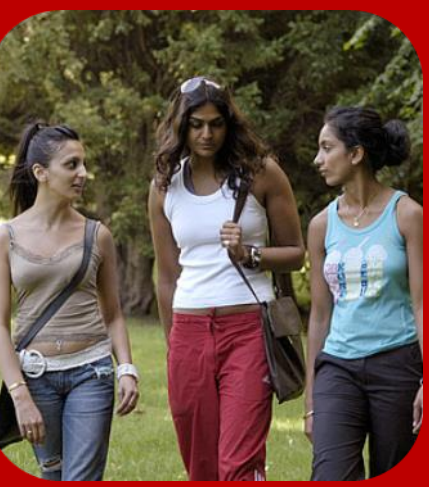
UK Forum on Haemoglobin Disorders

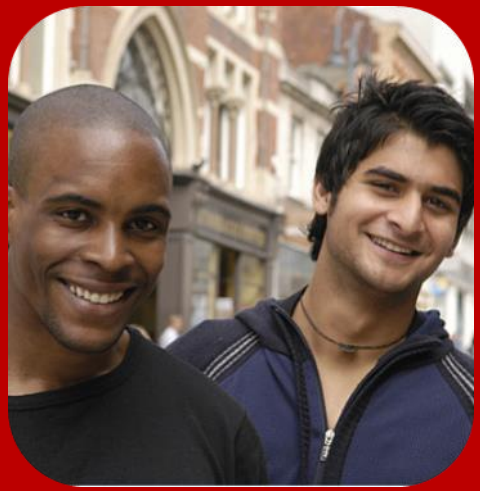
Health Services for People with Haemoglobin Disorders

South West Network

University Hospitals Bristol NHS Foundation Trust

Visit Date: 18th March 2015 Report Date: July 2015





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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in University Hospitals Bristol NHS Foundation Trust (part of South West Network), which took place on 18th March 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014 which were developed by the UK Forum on Haemoglobin Disorders working with the West Midland Quality Review Service (WMQRS). The peer review visit was organised by WMQRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

Specialist Haemoglobinopathy Centre (SHC)

Accredited Local Haemoglobinopathy Team (A-LHT): A Local Team to which the Specialist Centre has delegated the responsibility for carrying out annual reviews

Local Haemoglobinopathy Teams (LHT): These are sometimes also called 'Linked Providers'

The aim of the Standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Appendix 1 lists the visiting team and Appendix 2 gives details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- University Hospitals Bristol NHS Foundation Trust
- NHS England; Specialised Commissioning
- Bristol Clinical Commissioning Group

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation liaising, as appropriate, with other commissioners. The lead commissioner in relation to this report is NHS England; Specialised Cancer and Blood.

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. The NHS Sickle Cell and Thalassaemia Screening Programme funded this peer review programme.

About West Midlands Quality Review Service
WMQRS is a collaborative venture by NHS organisations in the West Midlands to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews - often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved. More detail about the work of WMQRS is available on www.wmqrs.nhs.uk

HAEMOGLOBIN DISORDERS SERVICES IN SOUTH WEST ENGLAND NETWORK

In the years prior to this review visit there were a number of changes in the commissioning of services for people with haemoglobin disorders including transfer of commissioning responsibility to NHS England specialised commissioning, development of a service specification against which providers are assessed and changes in the way specialised commissioning is arranged. Work between providers and NHS England to formalise the network arrangement of Specialist Centres and linking hospitals was ongoing at the time of this review. This peer review team reviewed the services at University Hospitals Bristol NHS Foundation Trust against the Quality Standards for Specialist Haemoglobinopathy Centres. University Hospitals Bristol NHS Foundation Trust was recognised by NHS England as a Specialist Centre for both the adult and paediatric haemoglobin services.

The Trust was nominally part of the South West England network although there did not appear to be a functioning network at the time of the visit. It was generally recognised that children from outside of Bristol should be seen annually in Bristol for review and Trans-Cranial Doppler screening.

Adults:

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
University Hospitals Bristol NHS Foundation Trust: Bristol Haematology and Oncology Centre	SHC	74	15	16

Children and Young People:

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
University Hospitals Bristol NHS Foundation Trust: Bristol Royal Hospital for Children	SHC	38	<5	<5
Gloucestershire Hospitals NHS Trust	LHT	<5	-	-
Plymouth Hospitals NHS Trust	LHT	<5	-	<5
Royal United Hospitals Bath NHS Foundation Trust	LHT	<5	-	<5
Royal Devon and Exeter NHS Foundation Trust	LHT	<5	-	<5
Taunton and Somerset NHS Foundation Trust (Musgrove Park Hospital)	LHT	<5	-	-
Great Western Hospitals NHS Foundation Trust	LHT	<5	-	<5

EMERGENCY CARE

Adult patients who were known to the service had direct access to the haematology day unit (for in hours care) and the ward (for emergency care) and did not therefore have to go through the Emergency Department (ED). The ambulance service had been advised accordingly and the care pathway had been developed and communicated to all patients.

Paediatric patients were asked to present at the ED where they were triaged as category two. Parents were encouraged to phone ahead and alert the ED that they were on their way. Children with sickle cell disease had individual clinical alerts attached to the hospital electronic records, which were available in the ED. The ED had adopted a 'one checker' policy for the administration of simple analgesia, which aimed to reduce the waiting time for analgesia. Assessment was undertaken by the ED team and, if admission was required, the on-call paediatric/oncology specialist trainee reviewed the children. After 10.30pm patients were seen by the 'hospital at night' team who could access the 24-hour consultant paediatric haematology/oncology cover for specialist advice. Medical notes were located in the documents library in the Children's Hospital building and were accessible to the clinical teams at all times. Clinical guidelines were easily accessible on the Trust network. A haemoglobinopathy teaching programme for ED medical staff was in place and took place twice a year, undertaken by the clinical lead. An email alert was sent to the clinical nurse specialist about all paediatric patients who attended the ED.

IN-PATIENT CARE

Adult patients were admitted to the 21-bedded haematology ward which was for all haematology and transplant patients.

Between four and six children and young people with haemoglobin disorders were admitted to paediatric wards each year. Ward 34 was designated for the care of children with haematology, oncology and bone marrow transplant disorders up to the age of 12. Children were admitted to the general paediatric ward (ward 30) if no specialist bed was available. Ward 35 was designated for children and young people aged 12 up to 18 years from all specialities. Three consultant paediatric haematologists provided care for a range of clinical areas including haematological malignancy, haemophilia and general paediatric haematology and also consultative support for other paediatric departments within the Children's Hospital. The department had funding for two further consultant posts. Two clinical nurse specialists (1.8 w.t.e.) provided cover for all non-malignant haematological conditions, including haemoglobin disorders. An acute pain team supported the in-patient services with specialist input for patient- and nurse- controlled analgesia. An attending system for paediatric haematology consultants was in place. The attending consultant managed in-patient care and the lead clinician was available for advice. A team of eight haematologists and oncologists provided the on-call cover for weekends.

OUT-PATIENT CARE

An adult haemoglobinopathy and general haematology clinic was held weekly. The day unit was open from 8.00am until 6.00pm Monday to Friday and one day of the weekend. An apheresis unit was available on site (since March 2014) for elective and emergency red cell exchanges.

Paediatric clinics took place in the oncology day unit facility in a dedicated monthly or twice monthly red cell clinic. This was attended by the paediatric haematology consultant, the specialist trainee (paediatric or haematology), clinical nurse specialist and the clinical coordinator, who worked across adult and paediatric services. Between 12 and 14 children attended each clinic. Trans-Cranial Doppler monitoring took place in the same clinic and was undertaken by two named sonographers using a portable machine. A pre-clinic review meeting took place before every clinic where all patients due to be seen that day were discussed. A formal multi-disciplinary team meeting did not take place. The lead clinician reviewed all patients receiving regular transfusions at least once every two months. Iron chelation monitoring was undertaken at University Hospitals Bristol NHS Foundation Trust and chelation was prescribed by the clinical nurse specialists. For patients reaching transition age, the service had adopted the national 'Ready Steady Go' programme.

Day treatment, including transfusions, took place in the adjacent day unit area shared with paediatric haematology, oncology and bone marrow transplant patients. This area contained four cubicles and two three-bedded bays. The unit was open Monday to Friday, 8.00am to 6.00pm. There was a dedicated speciality doctor for the day beds. The doctors on the day unit undertook cannulation.

COMMUNITY BASED CARE

Paediatric clinical nurse specialists undertook out-reach work in the community, including school visits and taking blood samples for hydroxycarbamide monitoring and pre-transfusion samples, thereby reducing the number of hospital visits.

VIEWS OF SERVICE USERS AND CARERS

The visiting team met a large number of patients and carers with both sickle cell and thalassaemia and received feedback from them. Ten questionnaires had been completed by users of the service for children and young people.

Common themes raised by patients and carers were:

- The efforts and care offered by key medical and nursing staff within both adult and paediatric services were much appreciated by the patients interviewed by the visiting team.

Service for children and young people:

- Carers felt that they were very well supported by the hospital-based nurse specialists, who undertook phlebotomy in the community, thereby reducing the number of hospital visits.
- A number of carers expressed concern about long waiting times in the Emergency Department and in out-patient clinics. Other carers reported long waits for accessing specialist care out of hours.

Adults

- Most patients considered that they received the required referrals to other experts but were concerned that some doctors did not appear to have sufficient understanding about their primary condition when treating a secondary condition.
- Timely annual reviews were in place and patients received a copy of the proforma.
- The administrative clerk was praised for being proactive and flexible with appointments and bookings. Patients reported problems when she was not available.
- Concerns were expressed about the quality of care available when the lead clinician and nurse were unavailable as some considered that junior staff had insufficient knowledge about their condition.
- Inexperienced staff at clinic appointments
- Long delays in receiving timely analgesia were reported by some patients. Patients also reported some errors in being given appropriate analgesia.
- Bed moves from the main haematology ward were seen as an increasing problem. Some patients commented that they felt other patient groups were given priority both on the ward and within the day unit. Patients felt that they were the last to be seen on the day unit and first to be sent home if no beds were available.
- Lack of staff:
    - With only one doctor on-call, long waits were experienced and patients considered insufficient prioritisation was given to patients with sickle cell disease who were in crisis.
    - Patients with problematic veins relied on one or two nurses for cannulation. Delays were sometimes experienced due to the lack of a porter to collect the blood from the blood bank.

REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

Adults:

A functioning network of providers of care for adults with haemoglobin disorders was not in place at the time of the review visit. It was estimated that there were over 100 patients within the region but, for adults, there was no information available to reviewers about either the location of these patients or the care that was in place for them.

A business case for additional medical, nursing and managerial support in order to develop the University Hospitals Bristol NHS Foundation Trust service as a specialist centre and establish a managed clinical network had been submitted to specialised commissioners but no decision had been made at the time of the review. The lead clinician at the Trust had insufficient job plan time for the development of a network service.

Children and Young People:

The paediatric service at University Hospitals Bristol NHS Foundation Trust provided a comprehensive tertiary service for local children with haemoglobinopathy disorders. Strong clinical links, developed through the collaborative management of children with haemophilia and cancers, existed with some regional hospitals in the South West and these links had been used to develop a network for the management of children with haemoglobin disorders. Children received their annual reviews at the Trust and were seen by local paediatricians at other times. All eligible children in linked hospitals within the region underwent Trans-Cranial Doppler monitoring at University Hospitals Bristol NHS Foundation Trust. Evidence was in place of the use of shared guidelines and escalation of care to University Hospitals Bristol NHS Foundation Trust. These informal arrangements worked well but no formal network was in existence.

Progress since Last Visit

No progress had been made in the formalisation of haemoglobinopathy networks since the previous review visits (children and young people: 2010; adults: 2012).

Concerns

1 The number of adults with haemoglobin disorders, their geographical distribution across the region and details of how they accessed care were not available at the time of the review.

2 No progress had been made in the formalisation of haemoglobinopathy networks since the previous peer review visits (children and young people: 2010; adults: 2012), partly because the lead clinician had insufficient job plan time to support the development of a network service.

Further Consideration

1 The Specialist Teams may wish to consider developing links with another Specialist Centre for support with, for example, staff training and guideline development , and for access to specialist expertise.

2 The peer review programme had contacted all hospitals in England about their referral patterns for the care of patients with haemoglobin disorders. Yeovil District Hospital NHS Foundation Trust was uncertain about its referral pattern and further discussions, as part of development of the haemoglobinopathy network, may be helpful.

NETWORK CONFIGURATION

The network configuration at the time of the review was as follows.

Specialist Haemoglobinopathy Centres	Local Haemoglobinopathy Teams
• University Hospitals Bristol NHS Foundation Trust (Bristol Haematology and Oncology Centre and Bristol Royal Hospital for Children)	• Gloucestershire Hospitals NHS Foundation Trust • Great Western Hospitals NHS Foundation Trust • North Bristol NHS Trust • Northern Devon Healthcare Trust • Plymouth Hospitals NHS Trust • Royal Cornwall Hospitals Trust • Royal Devon and Exeter NHS Foundation Trust • Royal United Hospitals Bath NHS Foundation Trust • South Devon Healthcare NHS Trust • Taunton and Somerset NHS Foundation Trust • Weston Area Health NHS Trust • Yeovil District Hospital NHS Foundation Trust (subject to clarification)

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UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST

SERVICE FOR ADULTS

General Comments and Achievements

A small, highly motivated team was trying to provide high quality care with limited resources. The Trust notes were well organised and legible. The facilities had been recently refurbished and were of a high standard. There had been difficulties with the provision of community support and counselling in the months before the review due to changes in community nurse provision. A 0.6 w.t.e. Trust-based clinical nurse specialist post was funded but it had not been possible to recruit to the post.

Progress since Last Visit

Since the previous review in 2012, annual reviews had become embedded into practice and a psychologist session dedicated to work within the service had been established. Guidelines had been updated, including those for patient-controlled analgesia. Administrative staff had been appointed, enabling systematic reporting to the National Haemoglobinopathy Registry to take place.

Some concerns identified at the previous visit had not yet been addressed, including clinical nurse specialist staffing levels. The service had been unable to recruit to the additional clinical nurse specialist post.

Good Practice

1 The palliative care team was regularly involved with the management of patients with both acute and chronic pain.

2 A clinical alert system was in place for all known patients in both the adult and paediatric service. If any patient attended another area of the Trust, an email was automatically sent to the lead clinician and clinical nurse specialist.

3 Minuted weekly multi-disciplinary meetings were held prior to clinics. These meetings were attended by the lead clinician and deputy, clinical nurse specialist, psychologist and specialist trainee. In-patients and clinic patients were discussed.

4 The team offered direct access to the haematology unit at all hours.

5 A good annual review proforma was in use which was also copied to the patient.

Immediate Risks No immediate risks were identified

Concerns

1 The lead nurse/clinical coordinator had insufficient time available to carry out work in the community. The role was based in the acute Trust and covered both the adult and paediatric service. There was no cover for the absences of the clinical coordinator.

2 The service was reliant upon a small amount of allocated consultant time. The lead clinician also headed up the acute myeloid leukaemia/ myelodysplastic syndrome service and had commitments to clinical and laboratory-based research.

3 Audits and patient feedback indicated delays in the delivery of analgesia. A plan to institute a Patient Group Directive to allow nurse-led first dose analgesia was under development at the time of the visit with the aim of addressing this issue.

Further Consideration

1 Reviewers suggested that the Trust may wish to consider redesigning the unfilled clinical nurse specialist post, possibly combining with another clinical area to make the post more attractive.

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SERVICE FOR CHILDREN AND YOUNG PEOPLE

General Comments and Achievements

The paediatric haemoglobinopathy team at University Hospitals Bristol NHS Foundation Trust provided high quality care to a relatively small, but steadily growing number of children with haemoglobin disorders. The service was greatly valued by patients and carers. There was evidence of good teamwork within the department and hospital facilities were of a high standard, including a dedicated teenage in-patient unit for patients with haematology/oncology disorders. Play specialists and hospital school facilities were also available and were of a high standard.

Progress since Last Visit

Since the last visit (2010) the Trust had developed and established a Trans Cranial Doppler service and had also formalised the process of transition to adult care. The clinical nurse specialist's role extended to school visits for education purposes, and home visits for blood sampling for hydroxycarbamide monitoring and pre-transfusion cross match. Some children with haemoglobin disorders in local linked hospitals underwent annual reviews at their local clinics by a paediatric haematologist from University Hospitals Bristol NHS Foundation Trust.

Good Practice

1 Nurse-led prescribing for hydroxycarbamide and iron chelation was in place.

2 A clinical alert system was in place for all known patients in both the adult and paediatric service. If any patient attended another area of the Trust an email was automatically sent to the lead clinician and clinical nurse specialist.

Immediate Risks No immediate risks were identified

Concerns

1 Newly born affected children and their parents were no longer visited by a community-based counsellor. The lead nurse/clinical coordinator had responsibility for the home visit but, due to the changes in the role, the workload had become more hospital-based. Delays of up to three months in informing parents of the haemoglobinopathy screening result were reported. GPs sometimes informed patients and started penicillin prophylaxis.

2 The clinical guidelines for the care of children with sickle cell disease were out of date, particularly the section dealing with pre-operative transfusions, which had not been updated to reflect the latest research data.

3 Reviewers were concerned about the time that the lead consultant had allocated for work with the service. At the time of the visit there were vacancies in the consultant rota and the lead consultant was extremely stretched with other commitments in the job role.

4 The service collected little data about its activities and outcomes. Patients were starting to be entered onto the National Haemoglobinopathy Register (NHR) with approximately 60% of patients on the register at the time of the review. Serious adverse events and outcome data were not yet being entered onto the NHR.

5 There was no dedicated psychology support available for children and young people with haemoglobin disorders cared for by the Trust. Generic psychology support was available via the CAMH service.

Further Consideration

1 Development of a parent support group was suggested by the previous peer review of 2010 but was not yet in place.

2 Patient and carer information was limited in some areas, particularly for patients with thalassaemia.

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COMMISSIONING

General Comments and Achievements

The review team met a member of the NHS England commissioning team who was in an interim appointment and had taken up post shortly before the review visit.

Concerns

1 Concerns identified in the University Hospitals Bristol NHS Foundation Trust and network sections of this report will require commissioner support and monitoring.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead/s:

Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Subarna Chakravorty	Consultant Paediatric Haematologist	Imperial College Healthcare NHS Trust

Visiting Team:

Nkechi Anyanwu	Clinical Nurse Manager	Guy's and St Thomas' NHS Foundation Trust
Helen De Marco	Senior Clinical Psychologist	University College London Hospitals NHS Foundation Trust
Dr Moira Dick	Consultant Paediatrician	Kings College Hospital NHS Foundation Trust
Dr Rachel Kesse-Adu	Consultant Haematology and Sickle Cell Disease	Guy's and St Thomas' NHS Foundation Trust
Edel Robinson	Haemoglobinopathy Liaison Sister	Birmingham Children's Hospital NHS Foundation Trust
Aldine Thomas	Clinical Nurse Specialist Haemoglobinopathies	Barts Health NHS Trust
Dr Christos Sotirelis	Service User	

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varied depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' – where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	43	36	84
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	55	36	65

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	49	30	61
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	61	30	49

Pathway and Service Letters

HN-	Specialist services for People with Haemoglobin Disorders
HY-	Haemoglobin Disorders: Network
HZ-	Haemoglobin Disorders: Commissioning

Topic Sections

Each section covers the following topics:

-100	Information and Support for Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment
-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

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Specialist Services for People with Haemoglobin Disorders

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-101 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, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199)	Y		N	Limited information was available including clinical nurse specialist details, information on who to contact out of hours, and how to give service feedback.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-102 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 and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	Y		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-103 All	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service	N	Information for 'a' and 'b' was included in clinic letters. Information was available on hydroxycarbamide and immunisations. Indications for seeking advice from the team was not covered in the information seen by reviewers.	Y	No standardised information was in place but GP letters were clear and covered all aspects of the standard.
HN-104 All	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	Y	Patients' notes showed evidence of annual reviews, regular monitoring liaison with GPs, reproductive medicine, audiology, ophthalmology and endocrinology. No Emergency Department care plan was in place but the majority of patients were admitted directly to the haematology unit. A care pathway and guidelines were in place for the Emergency Department, should a patient present there.	Y	Letters were routinely given to parents.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-105 All	**School Care Plan (Paediatric Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school	N/A		N	A formal school plan was not routinely in use. School visits were undertaken by nurses. Parents reported that liaison with schools worked well.
HN-106 SHC (A-LHT)	**Transition to Adult Services** Young people transferring to the care of adult services should be offered written information covering at least: a. Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer b. A joint meeting between children's and adult services to plan the transfer c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Arrangements for monitoring during the time immediately after transfer	Y	The national Ready-Steady-Go protocol was followed. The clinical nurse specialist attended the paediatric clinics during the transition period as coordinator for the transition. Information for points 'a' and 'c' could be clearer.	Y	The national Ready-Steady-Go protocol was followed. The adult clinical nurse specialist attended the paediatric clinics during the transition period as coordinator for the transition.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-107 SHC	**Information about Trans-Cranial Doppler Ultrasound** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated	N/A		N	No written information was available.
HN-199 All	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	N	An annual patient survey was carried out. It was not clear if any action had been taken as a result of patient feedback received, although the survey results were due to be discussed at the annual service review meeting.	N	A patient information leaflet was available on how patients could provide feedback to the services and an annual survey was carried out. Other aspects of this Quality Standard were not met.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-201 All	**Lead Consultant** A nominated lead consultant 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 in place. Although sessions were identified for the service the consultant also had a significant haematology-oncology workload. See main report.	Y	A lead consultant was in place at the time of the visit but there were two w.t.e vacancies in the consultant rota and the lead consultant was extremely stretched with other commitments in the job role. See main report.
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y	A named deputy was identified for clinics. In-patient care was covered by the haematology –oncology consultants.	Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	Y	The community clinical nurse specialist was employed by the Trust. There was a 0.6 w.t.e. vacancy for a further Trust-based clinical nurse specialist.	Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-204 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 for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	The clinical nurse specialist had insufficient time to cover the community aspect of the role and there was no cover available. Point 'e' was not met. Medical staffing was insufficient (see main report.)	N	The clinical nurse specialist / coordinator had insufficient time to provide community visits to families of newborn children with haemoglobin disorders and had no cover for absences. The service did not have access to a clinical or health psychologist with an interest in haemoglobin disorders. Medical staffing was insufficient due to the two vacancies in the consultant team. See main report.
HN-205 All	**Competences and Training** 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-204).	Y	There was evidence of training for all staff groups.	Y	Training logs were available.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		Y	
HN-207 All	**Training for Emergency Department Staff** The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	Y		N	No training logs were available but staff indicated that training for staff in the Emergency Department was provided.
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	The transfusion trainee attended both the haemoglobinopathy clinics and multi-disciplinary team discussions.	Y	Registrars attended clinics and pre-clinic multi-disciplinary team meetings and cared for emergency admissions.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-210 SHC	**Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A		Y	
HN-299 All	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y		N	Insufficient administrative and clerical support was available. A medical secretary prepared clinic letters and a clerk prepared clinic notes.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.	N	Access to a social worker was via a generic referral system and it was not clear that this was timely.	N	Timely access was not available to either a psychologist ('a') or a social worker ('b') although the service could access social services for safeguarding concerns. Generic psychology support was available from the CAMH service but it was not clear how timely this was. See main report.
HN-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	Y		Y	Reviewers suggested that arrangements for access to a respiratory physician with an interest in chronic sickle lung disease be strengthened, possibly through links with a physician in a larger centre.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	Y	All services were provided within the Trust.	Y	All services were provided within the Trust.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-304 All	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		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. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y		Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	Facilities were available from 8am until 6pm on weekdays and one day of the weekend.	Y	Facilities were open from 8am until 6pm on weekdays.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-501 SHC A-LHT	**Transition Guidelines** Network-agreed 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. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y	The national 'Ready Steady Go' guidelines were in use.	Y	The national 'Ready Steady Go' guidelines were in use.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	Y		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-503 LHT	**Clinical Guidelines: LHT Management and Referral** Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A	.	N/A	
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. Offering access to exchange transfusion to patients on long-term transfusions c. Protocol for carrying out an exchange transfusion d. Hospital transfusion policy e. Investigations and vaccinations prior to first transfusion f. Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. g. Areas where transfusions will usually be given h. Recommended number of cannulation attempts	Y		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-505 All	**Chelation Therapy** Network-agreed clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, 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/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y	Point 'f' was not applicable.	Y	Point 'f' was not applicable.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed 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 k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y		Y	Some guidelines were in need of updating.
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y		N	The pre-operative transfusion guideline required updating to reflect latest research data. See main report.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed 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 i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y		Y	
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y		Y	
HN-510 All	**Thalassaemia Intermedia** Network-agreed 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		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-511 All	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y	Guidelines were available in the Emergency Department and via the Trust Document Management System.	Y	Guidelines were available on wards, in the Emergency Department and in linked hospitals.

		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-512 SHC	**Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)** Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least: a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)	N/A		N	The guidelines did not cover points ‘e’, ‘f’, ‘g’ and ‘k’.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-601 All	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	Y		N	No service organisation policy was in place. Policies for DNA (Did Not Attend), failsafe arrangements for new-born screening and a new-born screening policy were available.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
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, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	Y	Documented multi-disciplinary team meetings occurred before each clinic, attended by medical staff, psychologist and clinical nurse specialist. See main report.	N	Minuted multi-disciplinary meetings were not in place. Informal pre-clinic meetings were undertaken.
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/A		N/A	
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	N	Network review and learning meetings were not yet in place.	N	Network review and learning meetings were not yet in place but there was informal liaison between clinicians around specific patient care issues.
HN-605 SHC	**Neonatal screening programme review meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	N/A		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	Y	A new administrator had recently been appointed and was entering National Haemoglobinopathy Registry data**.**	N	No data support was available. Annual reviewers were starting to be entered onto the National Haemoglobinopathy Registry (NHR) with approximately 60% patients registered at the time of the review. The service was planning for the administrator to enter full NHR data for children and young people as well as for adults.
HN-702 All	**Annual Data Collection - Activity** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y		N	Monitoring of data for points 'b', 'c' and 'd' were available. Admission data were not seen by reviewers.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-703 SHC	**Annual Data Collection – Network Patient Data** The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia: a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network services during the course of the year: i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: i. Date seen in clinic ii. Date offered and prescribed penicillin d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year e. Number of network patients on long-term transfusion f. Number of network patients on chelation therapy g. Number of network patients on hydroxycarbamide h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients j. Number of network patients whose care was transferred to another service during the year k. Number of network patients who died during the year l. Number of network patients lost to follow up during the year	Y	No formal network was in place. This information was collected and presented for the Trust.	N	No formal network was in place. Data for 'b', 'c' and 'd' were not seen by reviewers.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including 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 g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	N	Point 'k' was not met. The audit for point 'f' showed non-compliance with time to analgesia. A recovery plan was in progress.	N	Audit for points 'b', 'c', 'f', 'g' and 'k' were not yet carried out. See main report.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-705 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	No audit of guidelines was in place.	Y	
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		N	The service did not participate in research.
HN-707 SHC	**Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required	N/A		N	Quality assurance data were not yet in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-798 All	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility	Y		Y	Departmental morbidity and mortality meetings were in place.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	A formal clinical network was not yet in place.	N	A formal clinical network was 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	A formal clinical network was not yet in place.	N	A formal clinical network was 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-204 and HN-205.	N	A formal clinical network was not yet in place.	N	A formal clinical network was not yet in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	A formal clinical network was not yet in place.	N	A formal clinical network was not yet in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
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-303) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303) g. Specialist management (QS HN-507) h. Thalassaemia intermedia (QS HN-510) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.	N	A formal clinical network was not yet in place.	N	A formal clinical network was not yet in place.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	N	A formal clinical network was not yet in place.	N	A formal clinical network was not yet in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QSs HN-703, HN-704, HN-705 and HN-707.	N	A formal clinical network was not yet in place.	N	A formal clinical network was not yet in place.
HY-703	**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	A formal clinical network was not yet in place.	N	A formal clinical network was not yet in place.
HY-798	**Network Review and Learning** The SHC should meet at least twice a year with its referring LHT teams to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from any positive feedback or complaints involving liaison between teams d. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams e. Consider the content of future training and awareness programmes (QS HY-202)	N	A formal clinical network was not yet in place.	N	A formal clinical network was not yet in place.

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COMMISSIONING

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular: a. Designated SHC/s for the care of people with with sickle cell disease b. Designated SHC/s for the care of adults with thalassaemia c. Any agreements for delegation of annual reviews to accredited LHTs for care of people 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 yet agreed the configuration of the network.	N	Commissioners considered that specialist haemoglobinopathy care for the local population was commissioned. The Trust did not consider that a formal designation process had been undertaken. Formal network arrangements for the care of patients in linked local hospitals were not yet in place.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, in particular QS HN-703 b. Each network, in particular, achievement of QS HY-702 and QS HY-798. c. Service and network achievement of relevant QSs	N	Clinical quality review meetings were not yet in place.	N	Clinical quality review meetings were not yet in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	Network review and learning meetings were not yet in place.	N	Network review and learning meetings were not yet in place.

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