WM QRS West Midlands Quality Review Service

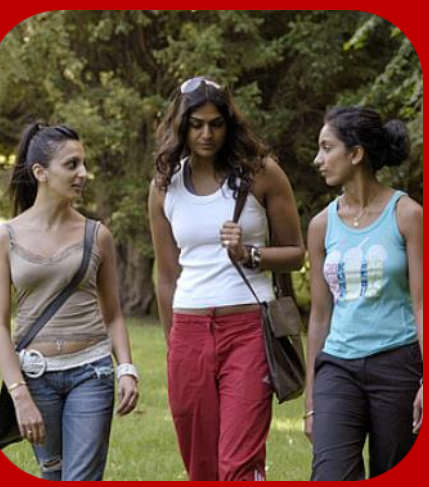
UK Forum on Haemoglobin Disorders

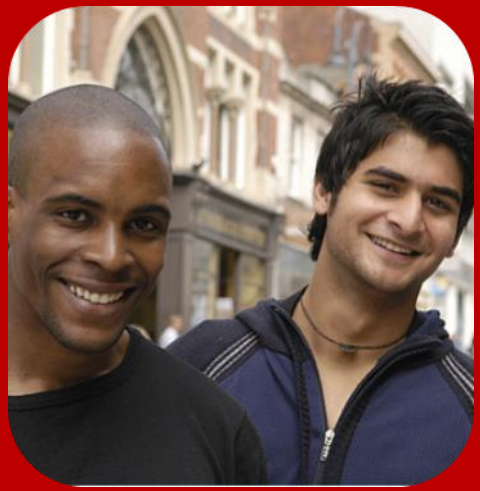
Health Services for People with Haemoglobin Disorders

South Central England Network

University Hospital Southampton NHS Foundation Trust

Visit Date: 22nd January 2015 Version 2 Report Date: October 2016





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Version No.	Date	Change from previous version
1	May 2015	N/A
2	October 2016	Includes final Network findings section and removal of network compliance section.

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in University Hospital Southampton NHS Foundation Trust (part of the South Central England Network), which took place on 22nd January 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 Midlands 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 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 Hospital Southampton NHS Foundation Trust
- NHS England (Wessex Area Team)
- Southampton City 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 (Wessex Area Team).

Acknowledgements

We would like to thank the staff of University Hospital Southampton NHS Foundation Trust, for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review. The NHS Sickle Cell and Thalassaemia Screening Programme funded this peer review programme.

About West Midlands Quality Review Service

WMQRS was set up as 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

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HAEMOGLOBIN DISORDERS SERVICES IN SOUTH CENTRAL ENGLAND NETWORK

The University Hospital Southampton NHS Foundation Trust provided haemoglobinopathy services to adults and children and young people. At the time of the review the paediatric service was commissioned as a Specialist Haemoglobinopathy Centre (SHC) and the adult service was commissioned as an accredited local haemoglobinopathy team (A-LHT).

ADULT

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 Hospital Southampton NHS Foundation Trust	A-LHT	25 - 30	<5	6
Portsmouth Hospitals NHS Trust (Queen Alexandra Hospital, Portsmouth)	LHT	11	0	<5
Poole Hospital NHS Foundation Trust	LHT	<5	0	0
Hampshire Hospitals NHS Foundation Trust (Basingstoke and North Hampshire Hospital)	LHT	<5	0	0
Isle of Wight NHS Trust (St Mary's Hospital)	LHT	<5	0	0

PAEDIATRIC

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 Hospital Southampton NHS Foundation Trust	SHC	16	0	<5
Portsmouth Hospitals NHS Trust (Queen Alexandra Hospital, Portsmouth)	LHT	16	0	<5
Poole Hospital NHS Foundation Trust	LHT	16	<5	<5
Dorset County Hospital NHS Foundation Trust	LHT	<5	0	<5 (exchange transfusion and chelation in the Trust)
Hampshire Hospitals NHS Foundation Trust (Basingstoke and North Hampshire Hospital)	LHT	0	0	0

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long-term red cell transfusions
Salisbury NHS Foundation Trust	LHT	6	0	0
Isle of Wight NHS Trust (St Mary's Hospital)	LHT	<5	0	0
Western Sussex NHS Foundation Trust (St Richard's Hospital)	LHT	0	0	0
Dorchester County NHS Foundation Trust	LHT	<5	0	<5 (top-up transfusion and chelation in the Trust)

NETWORK

University Hospital Southampton NHS Foundation Trust was part of the South Central England network of services providing care for people with haemoglobin disorders. The other tertiary centre in the region was Oxford University Hospitals NHS Trust, but there was no clinical link between the two centres. The Trust served a local population of 500,000 and also provided tertiary level care across a range of haematological diseases to a population of 3.5 million in Wessex and Hampshire. Adult patients with complex haemoglobinopathy problems were managed with support from the specialist haemoglobinopathy teams from The Whittington Hospital NHS Trust and Guy's & St Thomas' NHS Foundation Trust. Several local hospitals referred patients with haemoglobin disorders to University Hospital Southampton NHS Foundation Trust: Queen Alexandra Hospital, Portsmouth Hospitals NHS Trust, Hampshire Hospitals NHS Foundation Trust (Basingstoke and North Hampshire Hospital), Poole Hospital NHS Foundation Trust and Isle of Wight NHS Trust.

The paediatric haemoglobinopathy service worked as a Specialist Haemoglobinopathy Centre with linked providers in a number of district hospitals in Wessex and Hampshire (see table above). The network had been created alongside the already-established Paediatric Oncology Network links. Although no formal haemoglobinopathy network multi-disciplinary team meetings had been established, some haemoglobinopathy patients were discussed in the weekly oncology multi-disciplinary team meetings. All haemoglobinopathy annual reviews took place in the University Hospital Southampton NHS Foundation Trust, where there was provision of Trans-Cranial Doppler screening for stroke risk, which took place at the time of the patients' annual review appointments, and T2* MRI scans for iron overload monitoring.

Sixteen children and young people were cared for by the paediatric service at Queen Alexandra Hospital in Portsmouth but underwent their annual reviews at University Hospital Southampton NHS Foundation Trust. The adult service at Portsmouth cared for a further 11 patients with sickle cell disease. At the time of the visit there were no arrangements in place for annual reviews of adult patients from Portsmouth by the team in Southampton.

OUT-PATIENT CLINICS

Out-patient clinics were held on a monthly basis within the oncology clinical areas.

Paediatric out-patient clinics took place in the paediatric out-patient department. It was not clear how many patients received hydroxycarbamide therapy. The department followed standard Trust policy with regards to patients who failed to attend out-patient appointments, although no patient was ever discharged from the follow-up service. Children who were diagnosed with sickle cell disease from the neonatal screening programme were referred directly to the paediatric haemoglobinopathy consultants, who ensured that such children were entered into hospital care within the specified time frame. The regional haemoglobinopathy

screening laboratory was situated in Portsmouth Hospital and the lead adult haemoglobinopathy clinician attended some of the screening meetings.

EMERGENCY ADMISSIONS

Adult patients with haemoglobin disorders who attended the Emergency Department (ED) were triaged as 'code blue' for immediate review. They were then assessed by senior ED staff who discussed the case with the on-call Haematology Specialist Registrar. ED staff had easy access to individualised care plans and patient letters for patients with sickle cell disease via the Trust's 'edoc' system. Patients requiring admission were transferred to the Acute Medical Unit (AMU) team for in-patient care, supported by the haematology team out of hours and taken under haematology care within the first 24 hours after admission. Approximately two adults with haemoglobin disorders were admitted per month. In December 2014 the Trust had opened a new 20-bedded ward (D2) for haemato-oncology and patients with non-malignant haematological disease including haemoglobin disorders.

All paediatric haemoglobinopathy patients were provided with open access to the Paediatric Assessment Unit (PAU). Clinical details of patients who had open access to the PAU were available in hard copy in folders in the PAU workstation. These folders usually contained an open access referral letter and one or two clinic letters per patient. All parents were told of this open access and were provided with telephone numbers on how to contact the PAU for emergency access to the service. Patients were admitted to a PAU bed for assessment by a paediatric junior doctor and, if deemed necessary, an in-patient bed was offered to them for further treatment. Although no individual treatment plans were available, further details, such as clinic letters and discharge summaries, could be accessed from the edoc system.

The PAU was staffed by a general paediatric consultant and two junior doctors (SHO and registrar) within hours. Out of hours an SHO and registrar provided cover, with access to the non-resident general paediatric consultant and paediatric haematology consultant for further advice. Although these patients were admitted under the care of a general paediatric consultant, a senior paediatric haematology review was available within 24 hours of admission.

Very few paediatric haemoglobinopathy patients attended the ED due to the open access available to them through the PAU.

Haemoglobinopathy patients were admitted to the general paediatric ward under the care of the general paediatrician on duty. Patients were admitted either to a general bay or to an isolation cubicle, depending on clinical needs. The ward was not gender segregated. Parent beds were available for all in-patient beds.

DAY UNIT

The adult service Haematology Day Unit (C7) was open from 8am to 8pm weekdays and from 8am to 4pm on Saturdays. The unit carried out top-up and manual exchange transfusions during these periods. The Trust had plans to expand the apheresis service in order to offer automated exchange transfusions in the future, but at the time of the visit there was no access to automated red cell exchange.

The Paediatric Day Unit operated on weekdays from 7am to 8pm, with no weekend service available. Fewer than five children with sickle cell disease received regular top-up transfusions at the Day Unit. The unit was largely nurse-led, with nurses undertaking venepunctures and cannulation. A dedicated play specialist worked at the Day Unit.

COMMUNITY SERVICES

At the time of the visit the Trust had no specific community services for people with haemoglobin disorders. A full-time clinical nurse specialist (CNS) had recently been appointed to cover both adult and paediatric haemoglobinopathy services in both acute and community settings, but was not yet in post.

TRANSITION

At the time of the review approximately five patients per annum were transitioning to the adult service. Formal transition arrangements were not yet in place.

COMMISSIONING

As part of the service specification compliance exercise for services for people with haemoglobin disorders, the two tertiary hospitals for the region had been 'derogated' by commissioners. NHS England commissioners had been actively involved in discussions about access to appropriate specialist care for patients from Wessex. A CQUIN scheme was under development with the aim of supporting improvements to services for people with haemoglobin disorders and the development of the local network.

VIEWS OF SERVICE USERS AND CARERS

Patient satisfaction surveys were distributed before the review, and reviewers met four patients and carers during the review. Most carers commented that there was an urgent need of a nurse practitioner to provide support within the community. The Trust had recently appointed a clinical nurse specialist whose role extended into the community.

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REVIEW VISIT FINDINGS

NETWORK

At the time of the review visit, Southampton was part of the South Central England network. The other specialist centre in South Central England was Oxford but there were no clinical links between the two centres. The Southampton Network had small numbers of patients (less than 50 adults and less than 50 children). The adult service was reviewed as an Accredited Local Haemoglobinopathy Team as only some specialist services were provided and the Trust was receiving support from other specialist services (Guy's and St Thomas' NHS Foundation Trust for patients with sickle cell disease and the Whittington Hospital NHS Trust for those with thalassaemia). In view of the small number of patients locally, the service was unlikely to build up sufficient specialist experience for the management of complex cases.

The paediatric service was providing more specialist aspects of care including annual reviews and Trans-Cranial Doppler monitoring but the lead physician was due to retire and the new postholder was likely to need additional support to develop specialist skills.

Further Consideration

1 The development of formal links with a specialist centre or centres in London, rather than with Oxford, would appear to match referral patterns and transport links. A formal link with a specialist centre or centres would ensure that specialist expertise and support was available for patients from Southampton and surrounding areas. Reviewers suggested that further consideration should be given to establishing appropriate formal links. Network compliance for a South Central England Network combined with Oxford has therefore been removed from this report.

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ACCREDITED LOCAL TEAM: UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST

SERVICE FOR ADULTS

General Comments and Achievements

The service was led by a consultant haematologist who had a variety of other clinical commitments. Although there was great enthusiasm for development of the service, time within his job plan was limited. There was evidence of collaborative working and good relationships with both the managerial team and the paediatric

service. The facilities available within haematology were of high quality, and a new haematology ward (D2) had recently opened.

Progress since Last Visit

The previous review took place in July 2012. Progress since the review had been limited, but the Trust had appointed a new clinical nurse specialist although this person was not yet in post at the time of the review. Patients who met the reviewers during the visit gave very good feedback on the standard of clinical care available.

Good Practice

1 The Day Unit facility was of a high quality and offered extended hours in the evenings and at weekends. The review team was impressed with the cannulation record used in the Day Unit, which recorded date, time, number of attempts and operator.

2 There were strong links between the pain service and haematology services. The pain specialists were involved in the care of patients who experienced complex pain.

Immediate Risks

1 Guidelines covering acute care of people with haemoglobin disorders (all aspects) were not present in either the adult or the paediatric service. This had been identified at the previous adult service peer review visit and had not yet been addressed. In particular, reviewers considered that the lack of guidelines for the most common sickle cell complications (acute pain and acute chest syndrome) constituted an immediate risk to clinical safety and clinical outcomes.[1]

Concerns

Several areas of concern had been identified at the previous peer review visit (July 2012) and had not yet been addressed:

1 Patients were registered on the National Haemoglobinopathy Registry but no further data were entered, partly due to the lack of data management support.

2 Psychological support with time allocated for work with patients of the haemoglobinopathy service was not available. Reviewers were told that patients could be referred to the hospital psychology service.

3 Limited documentation relating to the clinical and managerial aspects of the service was in place at the time of the review.

Further Consideration

1 Consideration should be given to the priorities for the newly appointed clinical nurse specialist. The expectation that this individual would develop guidelines and protocols, provide education, community and outreach support as well as giving care to both adult and paediatric patients may be unrealistic.

2 A range of patient and service user information was available, but reviewers suggested that further support and information could be accessed through the voluntary sector organisations or from a range of web-based resources.

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[1] *Response from Trust: For the adult services, the guidelines are now written and are to be uploaded onto the UHS intranet by 6th February. Before the guidelines are available on the intranet an email has been sent to the relevant clinical leads to inform and remind them about the clinical management of patients with haemoglobin disorders and for the most common complications (acute pain and acute chest syndrome)*

Specialist Haemoglobinopathy Service: University Hospital Southampton NHS Foundation Trust

Services for Children and Young People

General Comments and Achievements

The paediatric haematology service was supported by two consultants. The lead haemoglobinopathy consultant had been appointed a year before the peer review visit, and good cover by the deputy lead clinician was in place. The two consultants shared the workload of the large paediatric haemato-oncology Primary Treatment Centre within the department, along with haemophilia and general haematology and pathology commitments. Both consultants were extremely enthusiastic about their haemoglobinopathy service, but other competing service demands precluded service development-related activities. The paediatric haematology service was highly valued within the department and the consultants provided a forward-thinking and nurturing environment for the service.

Although job plans indicated the provision of one programmed activity per consultant for haemoglobinopathy work, in reality, very little of that time was spent on the haemoglobinopathy service because of the significant workload related to oncology and haemophilia in the department.

The substantive employment of a clinical nurse specialist in the service after a gap of four years, following the retirement of a community-based sickle cell counsellor, was a welcome development within the service.

Progress since Last Visit

Services at University Hospital Southampton NHS Foundation Trust were not reviewed during the 2010/11 peer review visits to services for children and young people with haemoglobin disorders.

Good Practice

1 The paediatric Day Unit was open until 8pm during the week. Transfusion waiting times were minimal as all nurses were proficient in phlebotomy and cannulation.

2 All haemoglobinopathy patients were provided with open access to the Paediatric Assessment Unit, which helped bypass Emergency Department waits. Parents who met the reviewers were very happy with this arrangement.

Immediate Risks

1 Guidelines covering acute care of people with haemoglobin disorders (all aspects) were not present in either the adult or the paediatric service. This had been identified at the previous adult service peer review visit and had not yet been addressed. In particular, reviewers considered that the lack of guidelines for the most common sickle cell complications (acute pain and acute chest syndrome) constituted an immediate risk to clinical safety and clinical outcomes.[2]

Concerns

1 Patients were registered on the National Haemoglobinopathy Registry but no further data were entered as there was a lack of data management support.

2 Psychological support with time allocated for work with patients of the haemoglobinopathy service was not available.

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[2] *Response from Trust: Mitigating actions for the paediatric service is that guidelines are being produced and uploaded onto the UHS intranet by 13th February. Before the guidelines are available on the intranet an email has been sent to the relevant clinical leads to inform and remind them about the clinical management of patients with haemoglobin disorders and for the most common complications (acute pain and acute chest syndrome).*

3 Limited documentation relating to the clinical and managerial aspects of the service was in place at the time of the review.

Further Consideration

1 Consideration should be given to the priorities for the newly appointed clinical nurse specialist. Expectations were that this individual would develop guidelines and protocols, provide education, community and outreach support as well as giving care to both adult and paediatric teams, and this may be unrealistic.

2 A range of patient and service user information was available, but reviewers suggested that further support and information could be accessed through the voluntary sector organisations or from a range of web-based resources.

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COMMISSIONING

General Comments and Achievements

The service provided for patients through the haematology team was not a specialist service for adults. At the time of the review there was uncertainty about the number of patients within the region and the nature of services provided at linked hospitals such as Portsmouth.

The arrangements for paediatric services were a little clearer, with Southampton providing specialist support and access to specialist imaging and opinions.

Progress since Last Visit

No evidence of any change to commissioning arrangements (compared to the previous peer review visit) was provided. Network arrangements continued to be uncertain, as did the location of the most appropriate links with specialist centres. University Hospital Southampton NHS Foundation Trust had not been able to meet the service specifications set out by the Clinical Reference Group, alone or in collaboration with Oxford University Hospitals NHS Trust. There was a clear understanding of the issues, and a local CQUIN was under development to try and address the well-documented problems.

Immediate risks: No immediate risks were identified

Concerns

1 Adult patients did not have access to the full range of appropriate specialist care. This had been identified at the previous peer review visit and had not yet been addressed.

2 Network arrangements and links with specialist centres had not yet been formalised. This had been identified at the previous peer review visit and had not yet been addressed.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Leads:

Dr Josh Wright (adult lead)	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Subarna Chakravorty (paediatric lead)	Consultant Paediatric Haematologist	Imperial College Healthcare NHS Trust

Visiting Team:

Dr Penelope Cream	Clinical Psychologist	St George's Healthcare NHS Trust
Dr Bernard Davis	Consultant Haematologist	Whittington Health NHS Trust
Rachel McFee	Service User representative	OSCAR Patient Group, Sandwell
Elaine Miller	Service User representative	UK Thalassaemia Society
Luhanga Musumadi	Advanced Nurse Practitioner	Guy's and St Thomas' NHS Foundation Trust
Dr Marie Pelidis	Consultant Paediatric Haematologist	St George's Healthcare NHS Trust
Lola Oni	Specialist Nurse Consultant & Professional Services Director	The London North West Hospitals NHS Trust

WMQRS Team

Sue McIldowie	Quality Manager	West Midlands Quality Review Service

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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 varies 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	41	10	24
Commissioning	3	0	0
Total	**44**	**10**	**23**
Service for Children and Young People	**Number of Applicable QS**	**Number of QS Met**	**% met**
Specialist Services for People with Haemoglobin Disorders	48	16	33
Commissioning	3	0	0
Total	**51**	**16**	**31**

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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

SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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)	N	Generic patient information about Trust services was available, but no specific written information about haemoglobinopathy services	N	Generic patient information about Trust services was available, but no specific written information about haemoglobinopathy services.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	N	Limited information was available. Service user feedback (patient survey and interviews during visit) confirmed this.	N	Limited information was available. Service user feedback (patient survey and interviews during visit) confirmed this.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	Y	Information was provided to GPs through clinic letters after each visit.	Y	Information was provided to GPs through clinic letters after each visit.
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	Individual care plans were available in the Trust's edoc system. These covered information about acute management of pain, past medical history, blood group and baseline results. Clinic letters were copied to patients.	Y	Clinic letters and discharge summaries were available in the Trust's e-doc system. Clinic letters were copied to parents.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	School Care Plans were not being prepared.
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	N	No formal transition arrangements were in place.	N	No formal transition arrangements were in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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 patient 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	The Trust used the 'Family and Friends' test, but there was no specific feedback collected for this service.	N	The Trust used the 'Family and Friends' test, but there was no specific feedback collected for this service.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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 had limited time for service development. See main report.	Y	The lead consultant had limited time for service development. See main report. The consultants attended CPD events.
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.	N	Consultant cover was available for out of hours work via the department on-call rotas. There was no nominated individual for the care of patients during any periods of absence of the lead consultant.	Y	Good cover arrangements were in place for the lead consultant.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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)	N	A lead nurse was due to commence in post in April 2015.	N	A lead nurse was due to commence in post in April 2015.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	There was no evidence of compliance with points 'd', 'e' and 'g'.	N	No evidence was presented. There was no clinical nurse specialist in post at the time of the review.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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).	N	Royal College of Nursing competences were available on ward D2, including plans for training. There was some evidence of regional Specialist Registrar training but no evidence of training sessions for Emergency Department staff.	N	No evidence was presented regarding competences and training of nursing staff. Emergency Department medical staff training was not undertaken. A regional Specialist Registrar training record was present.
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.	N/A		Y	The lead consultant and deputy were available for advice.
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	N	No training for Emergency Department staff was undertaken.	N	No training for Emergency Department staff was undertaken.
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	N	Safeguarding and equality and diversity were part of the mandatory training for all staff. It was not clear if all staff had undertaken this training.	N	Safeguarding and equality and diversity were part of the mandatory training for all staff. It was not clear if all staff had undertaken this training.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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		Y	
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**	Two members of staff within medical physics had the necessary skills and provided cross cover.
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.	N	No formal data management support was available.	N	No formal data management support was available.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	Reviewers were told that patients could be referred to the hospital psychology department, but timescales for this were not clear. There were good links in place with the pain team. See main report.	N	Timely access to a psychologist was not available.
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	Although the adult service was not commissioned as an SHC, it met this standard and reviewers suggested that arrangements for access to a respiratory physician with an interest in chronic sickle lung disease should be strengthened, possibly through links with a physician in a larger centre.	Y	Reviewers suggested that arrangements for access to a respiratory physician with an interest in chronic sickle lung disease should be strengthened, possibly through links with a physician in a larger centre. Paediatric intensive care services were also available on site.

		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	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.	N	There was no access to neuropsychology.	N	There was no access to neuropsychology.

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Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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 hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y		Y	Late opening on weekday evenings (until 8pm) was in place.

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Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	N	Transition guidelines were not yet in place.	N	Transition guidelines were not yet in place.
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.	N	Monitoring checklists were not in place.	Y	No checklists were in place, but annual review clinic letters were comprehensive.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	Network agreed clinical guidelines were not in place.	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	N	No haemoglobinopathy specific guidelines were in place, but the Trust transfusion policy was available.	N	No haemoglobinopathy specific guidelines were in place, but the Trust transfusion policy was available.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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.	N	Network agreed clinical guidelines were not available. See main report.	N	Network agreed clinical guidelines were not available. See main report.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	N	Network agreed clinical guidelines were not available. See main report.	N	Network agreed clinical guidelines were not available. See main report.
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	N	Network agreed clinical guidelines were not available. See main report.	N	Network agreed clinical guidelines were not available. See main report.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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)	N	Network agreed clinical guidelines were not available. See main report.	N	Network agreed clinical guidelines were not available. See main report.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N	Network agreed clinical guidelines were not available. See main report.	N/A	
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	N	Network agreed clinical guidelines were not available. See main report.	N	Network agreed clinical guidelines were not available. See main report.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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.	N	Clinical guidelines were not available. See main report.	N	Clinical guidelines were not available. See main report.

		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	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	A Trans-Cranial Doppler ultrasound (TCD) reporting format was not presented (point 'h'), and it was not clear what mode of TCD was being undertaken. A standard operating policy was in place. There were two operators from nuclear physics who undertook the scans. No formal competency document or training log of operators was available. Numbers of scans performed each year were not shown.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	N	A service organisation policy was not in place.	N	A service organisation policy was not in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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).	N	Multi-disciplinary meetings as envisaged by this Quality Standard were not yet in place.	N	Multi-disciplinary meetings as envisaged by this Quality Standard were not yet in place. The paediatric team at Portsmouth confirmed that some patients were discussed as part of the pre-existing haematology-oncology multi-disciplinary team meetings when necessary.
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 **Error! Reference source not found.**).	N	There was no established network in place.	Y	The consultant attended the South Thames Regional Network meetings.
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	The adult lead consultant attended these meetings.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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.	N	Patients were registered on the NHR but no additional information was entered.	N	Patients were registered on the NHR but no additional information was entered.
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	N	Data were not monitored. No administrative/clerical support was available to help with data management.	N	Data were not monitored. No administrative/clerical support was available to help with data management.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	N/A		N	Network patient data were not collected.

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Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	An audit of the management of pain with respect to NICE Guidance was performed in 2014 but there was no evidence of other audits.	N	An audit of Trans-Cranial Doppler (TCD) provision to eligible children was performed but there was no evidence of other audits.

		Adult Service		Service for Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	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	There was no rolling programme of audit in place.	N	There was no rolling programme of audit in place.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N/A		N	The service did not actively 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	The service did not record the numbers of annual procedures.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	There had been no critical incidents to discuss. Established departmental Morbidity and Mortality meetings were in place.	Y	There had been no critical incidents to discuss. Established 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	The limited documents available were in a document controlled format.	Y	The limited documents available were in a document controlled format.

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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	This work had not yet been undertaken.	N	This work had not yet been undertaken.
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 **Error! Reference source not found.** and QS **Error! Reference source not found.**. 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 (**Error! Reference source not found.**) 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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