WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

South West London Network

St George's University Hospitals NHS Foundation Trust

Visit Date: 13th May 2015 Report Date: October 2015

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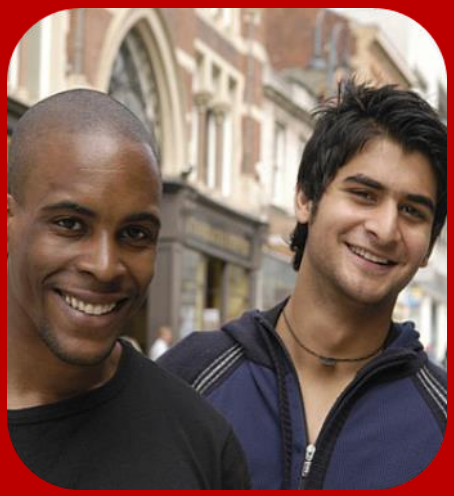


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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in St George's University Hospitals NHS Foundation Trust (part of South West London network), which took place on 13th May 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:

- St George's University Hospitals NHS Foundation Trust
- NHS England Specialised Commissioning
- Wandsworth 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 St George's University Hospitals 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 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

HAEMOGLOBIN DISORDERS SERVICES IN SOUTH WEST LONDON NETWORK

At the time of the visit services were provided for both adults and children and young people at St George's University Hospitals NHS Foundation Trust which was part of the South West London Network. The Trust had close links with Epsom and St Helier University Hospitals NHS Trust. St George's University Hospitals NHS Foundation Trust provided an automated exchange transfusion service for other Trusts in the South West London Network.

Service for 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
St George's University Hospitals NHS Foundation Trust	SHC	325	17	70
Epsom and St Helier University Hospitals NHS Trust	A-LHT	50	0	0
Ashford and St Peter's Hospitals NHS Foundation Trust	LHT	<5	0	0
Kingston Hospital NHS Foundation Trust	LHT	0	<5	<5

EMERGENCY CARE

Patients presenting at the Emergency Department (ED) were triaged initially by the ED staff and, if necessary, were admitted under the care of the haematology team, unless they required predominantly other specialist care. The ED had guidelines for the care of patients with sickle cell disease and also a folder containing individual pain protocols for approximately 90 patients.

A haematology Specialist Registrar (SpR) was on call 24/7. All admissions were discussed with the SpR by the ED staff. During working hours patients were admitted by the Haematology Core Medical Training (CMT)/junior doctor and SpR. Out of hours patients were admitted by the Medical CMT/junior trainee under the care of the haematology team and management plans could be discussed with the SpR who was on call from home.

IN-PATIENT CARE

Patients were admitted preferentially to one of the two haematology wards. One ward (Ruth Myles) was for haematology patients only, the other included haematology-oncology patients. If patients were admitted to other wards they were still under the haematology/sickle cell team. The second haematology ward (Gordon-Smith) had been opened shortly before the review and since this ward had opened it was unusual to have patients on outlying wards. If patients were admitted under other specialities they were reviewed by the haematology team on a daily basis.

Ruth Myles ward contained 14 beds, the majority single rooms and one double room. Gordon-Smith ward contained 20 beds. Nurses on both wards were trained in the care of patients with sickle cell disease.

All patients were reviewed on a SpR ward round every day, including Saturday and Sunday. Multi-disciplinary ward rounds with the consultant, clinical nurse specialist (CNS) and psychologist took place twice a week alongside consultant review of new patients and sick/complex patients as needed.

Additional reviews were also carried out by the sickle cell disease CNS and the clinical psychologist.

OUT-PATIENT CARE

A weekly haemoglobinopathy clinic took place in the haematology-oncology day unit, staffed by the lead consultant, haematology registrar (alternate weeks), CNS, community nurse and a psychologist. There were twice yearly thalassaemia clinics, shared with cardiology.

DAY CARE

All routine planned exchange transfusions, top-up transfusions, blood tests and non-urgent reviews took place on the haematology day unit, next to the Ruth Myles ward. Appropriately trained nurses were available to care for patients with haemoglobinopathies undergoing transfusions. There was a large established automated transfusion programme (over 50 patients) staffed by nurses trained in the use of ultrasound to obtain peripheral venous access. Phlebotomy was performed until 6.30pm but other interventions were only available during working hours (Monday to Friday, 9am to 6pm).

COMMUNITY BASED CARE

Community care was based at Balham Health Centre where there was a nurse manager, specialist nurse for adults, specialist nurse for children and a genetics counsellor. The specialist nurse for adult care attended the haemoglobinopathy clinics and the multi-disciplinary meetings. There was also close working with the community nurses for Croydon and Merton.

Service for 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
St George's University Hospitals NHS Foundation Trust	SHC	164	14	12
Epsom and St Helier University Hospitals NHS Trust	A-LHT	40	0	0
Kingston Hospital NHS Foundation Trust	LHT	9	0	0
Ashford and St Peter's Hospitals NHS Foundation Trust	LHT	<5	0	0
The Royal Surrey County Hospital NHS Trust	LHT	<5	0	0
Western Sussex Hospitals NHS Foundation Trust	LHT	<5	0	0
Surrey and Sussex Healthcare NHS Trust	LHT	10	0	0

EMERGENCY CARE

Most children who presented at the Emergency Department (ED) had direct access to the designated children's ward (Freddie Hewitt). Families were encouraged to call the ward prior to arriving.

Children were triaged by the ward nurses or junior doctor. More severely unwell children were directed to the ED. Following initial assessment, the paediatric team or haematology SpR was responsible for reviewing the child and planning further management. Care plans were available electronically in the ED

IN-PATIENT CARE

Most children with acute sickle cell-related complications were seen on Freddie Hewitt Ward where a direct access pathway allowed for rapid assessment. The ward-based junior paediatric team was responsible for the assessment and the haematology Specialist Registrar (SpR) allocated to the paediatric haematology team was

involved in the management of these children. Children requiring admission were also seen by the attending paediatric consultant or paediatric haematologist within 12 hours of admission. Daily ward rounds were conducted by the paediatric haematology team (consultant and /or SpR).

Children who required acute exchange transfusions were generally managed on the paediatric intensive care unit which contained eight paediatric intensive care beds and four high dependency beds. There were an additional four step down beds to manage unwell children. Depending on available experienced staff, automated erythrocytapheresis could be organised. If manual exchange was required this was carried out by the haematology SpR with support from the paediatric team. There was no routine access to a specialist paediatric pain service for nurse or patient controlled analgesia.

A play therapist was available 8.00am to 4.30pm. The ward also included a play room and school classroom. There were no teenage and young person's facilities on the ward. Tertiary paediatric surgery was available on site.

DAY UNIT CARE

The day unit, Jungle Ward, was a shared facility for medical and surgical day cases and was used for elective transfusions. Despite extended opening hours (until 8.00pm Monday to Friday) this facility was not able to provide late transfusions. Pre-transfusion testing, usually the day before transfusion, could be organised after 5pm. At least two nurses competent in cannulation and portocath access were routinely available. Responsibility for coordination of transfusions lay with the paediatric haematology consultant or haemophilia nurse specialist.

OUT-PATIENT CARE

Paediatric haemoglobinopathy clinics were held on alternate weeks (Wednesdays) in the Dragon Centre. Clinics were attended by a paediatric haematology consultant, consultant paediatrician and haematology SpR. Phlebotomy services where available within the out-patient department Monday to Thursday, 9.00am to 4.15pm. Phlebotomy required on Friday was accessed through a community clinic based in Battersea. Out-patient Trans-Cranial Doppler clinics were available in the imaging department following referral from clinic.

COMMUNITY BASED CARE

Balham Health Centre provided community care for children from the Wandsworth area. The team consisted of a nurse manager, specialist nurse and genetics counsellor.

VIEWS OF SERVICE USERS AND CARERS

The visiting team met nine patients and carers with sickle cell or thalassaemia and received feedback from them. Responses to 37 questionnaires were also received.

Common themes raised by patients and carers from the adult service were:

- Great appreciation for the excellent support from both acute and community CNS staff.
- An appreciation and acknowledgment of the service improvements over the past four years.
- Concerns that there were often long waits in the Emergency Department for analgesia.
- Nursing support on the adult wards was variable in quality.

Common themes raised by patients and carers from the paediatric service were:

- Excellent support was provided from the adult CNS who also carried out home visits which were greatly appreciated.
- The use of text reminders a week before an appointment.
- Concern was expressed around problems engaging with the patients' local school nurse, social services and education services because of a lack of knowledge of sickle cell disease.

- Reviewing the process of appointments and the introduction of text reminders for adult patients (if they are also carers of children with sickle cell disease).

Common themes raised by patients and carers from both services were:

- Some patients felt that staff did not always listen to their concern.
- Concerns about staffing levels for community staff in outlying areas. This had resulted in a child having to attend clinic at St George's University Hospitals NHS Foundation Trust more regularly and a greater level of absence from school.
- Patients found that support and understanding from GPs was variable.

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REVIEW VISIT FINDINGS

NETWORK

St George's University Hospitals NHS Foundation Trust was the specialist centre for the network. Services at Epsom and St Helier University Hospitals NHS Trust will be reviewed later in the visiting programme. This report therefore includes network-related issues and compliance with network standards as identified during this visit (Appendix 2). These may be updated following the visit to Epsom and St Helier University Hospitals NHS Trust.

General Comments and Achievements

An informal network within South West Thames area was in place, but no formal network. The network did not have medical or administrative support and support for the network was not included in staff job plans. Outside the specialist centre the only hospital in the network with significant numbers of patients was Epsom and St Helier University Hospitals NHS Trust. Other hospitals had very small numbers of patients.

Progress since Last Visit

Since the last visits (children: April 2010; adults October 2012) informal, multi-disciplinary meetings had been established between St George's University Hospitals NHS Foundation Trust and Epsom and St Helier University Hospitals NHS Trust and provided a good starting point for the development of a formal network.

Concerns

1 The South West London haemoglobinopathy network was not yet functioning effectively as a network and network Quality Standards were not yet achieved.

2 Variations in care across the network were evident, in particular:

   a. Community care was only available in the boroughs of Wandsworth, Merton, Croydon and Lambeth.

   b. There was no evidence of adequate haemoglobinopathy expertise of staff working in Emergency Departments or haematology services in the local hospitals across the network, and no evidence that clinical protocols were available at these sites, although paediatric protocols had been distributed to hospitals in the network. Small numbers of haemoglobinopathy patients attended the local hospitals but they should be prepared to manage these patients in an emergency.

3 Network arrangements for the management of acutely unwell children, coordination of annual reviews and management of children with thalassemia were unclear.

Further Consideration

1 This was a relatively small network with, at the time of the visit, only one adult haematology consultant specialising in the care of people with haemoglobin disorders. For the paediatric service there was support from a paediatric consultant (1PA) and cover was provided by another paediatric haematologist. Collaboration with another network may help the South West London network meet some of the relevant Standards, for example around education and training, and may support access to additional specialist expertise.

2 Reviewers also suggested that education and training events and sharing of adult specialist centre's protocols may be helpful for local hospitals across the network.

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SPECIALIST TEAM: ST GEORGE'S UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

SERVICE FOR ADULTS

General Comments and Achievements

The service was greatly appreciated by patients and carers and this was reflected in the feedback from patients during the visit and also in the patient and carer survey, with several comments praising the clinical nurse specialist (CNS) and day unit staff.

The service had a high profile within the Trust and had featured in the Trust's Annual General Meeting. Data had also been presented at the Trust Clinical Quality Review meeting. A comprehensive audit programme was in place which included regular pain audits. Medical students were involved with the service and had participated in the audits.

The new in-patient ward was of high quality and had decreased the number of patients on outlying wards.

Progress since Last Visit (October 2012)

1 The psychologist provided a comprehensive service to patients and received good patient feedback.

2 Patient leaflets had been improved since the previous visit and a wide range of high quality leaflets for patients with sickle cell disease was available.

Good Practice

1 The Sickle Cell Pain Management Service was an innovative development which provided high quality patient care. A consultant anaesthetist, clinical psychologist and pain physiotherapist provided a monthly multi-disciplinary pain clinic, monthly patient education sessions and individual psychology sessions.

Immediate Risks: No immediate risks were identified

Concerns

1 Cover for absences of the lead consultant was not available, except that a locum consultant provided cover for in-patient care. A substantive consultant post was out to advert at the time of the review. Cover for the clinical nurse specialist was also not available.

2 The service had very limited administrative and data collection support. As a result, the data expected by the Quality Standards were not yet collected and monitored by the service and annual reviews were not yet entered on the National Haemoglobinopathy Registry.

Further Consideration

1 The transition pathway appeared fragmented. Two sets of patient information (community and acute Trust) which may have led to confusion for patients and carers, reflected in their feedback of the service.

2 Three sets of acute complication guidelines were available in the Emergency Department which may cause confusion.

3 Out of hours transfusions were not available.

4 The number of patients with thalassaemia cared for by the service was relatively small and the service may wish to consider formalising links or defined pathways to supra-specialist services to ensure that these patients have access to appropriate specialist expertise.

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SERVICE FOR CHILDREN AND YOUNG PEOPLE

General Comments and Achievements

The service was predominantly consultant-led with a high level of input from the paediatric haematology service. Within the Trust there was a good level of awareness of haemoglobinopathy disorders and a sickle cell forum had been staged at the Trust annual general meeting (AGM). Accessibility to play therapy services was good.

The 'Full Circle' holistic therapies service provided access to alternative therapies for patients and families. The service also provided an in-patient and out-patient service for adult patients with sickle cell disease and thalassaemia. Patient feedback highlighted the community service for their caring and supportive role.

Progress since Last Visit

Since the last visit ((April 2010) there had been some progress with the development of a transition programme. Collaboration with the paediatrics team had improved with one PA of consultant paediatrician time allocated to work with the paediatric haematology team.

Good Practice

1 The school care plans were of a good standard and met patient needs well.

2 The introduction of a text reminder service and personalised telephone calls to patients and carers a week before clinic appointments had resulted in a reduction of 30% in 'did not attend' rates.

3 The first paediatric study day had been well received and further dates were planned.

Immediate Risks: No immediate risks were identified.

Concerns

1 Staffing of the service was of concern for a combination of reasons:

   a. The paediatric service did not have a clinical nurse specialist for patients with haemoglobin disorders. Some cover was provided by the adult service and the haemophilia team.

   b. Patients and families did not have access to a clinical or health psychologist with an interest in haemoglobin disorders.

   c. The service had no data collection or administrative support.

2 Arrangements for acute and chronic pain management were unclear. The pain management audit had identified that only 36% of patients had received a first dose of analgesia within the recommended 30 minutes.

3 Robust arrangements of internal quality assurance of Trans-Cranial Doppler screening, including maintenance of a log book of activity, were not yet in place. Stored records of scanning images carried out before the implementation of the hospital PACS system were not easily accessible.

4 Annual review data were not entered on the National Haemoglobinopathy Registry.

Further Consideration

1 Despite extended opening hours, the paediatric day case facilities did not offer the opportunity for late afternoon transfusions.

2 The transition pathway appeared fragmented. Two sets of patient information (community and acute Trust) which may have led to confusion for patients and carers, reflected in their feedback of the service.

3 Appropriate facilities for teenage and adolescent patients were not available. This group of patients accounted for approximately a third of the total paediatric patient population.

4 Arrangements for communication between acute and community services may benefit from review to ensure all relevant staff are updated appropriately.

5 The number of patients with thalassaemia cared for by the service was relatively small and the service may wish to consider links or defined pathways to supra-specialist services to ensure that these patients have access to appropriate specialist expertise.

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COMMISSIONING

Concerns

1 Commissioners had not yet addressed the issue of support required for the development of an effective network of care for people with haemoglobin disorders.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead/s:

Dr Jo Howard	Consultant Haematologist	Guy's and St Thomas' NHS Foundation Trust
Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust

Visiting Team:

Mina Abedian	Health Psychologist	Guy's and St Thomas' NHS Foundation Trust
Amanda Cope	Advanced Nurse Practitioner	Birmingham Children's Hospital NHS Foundation Trust
John James	Chief Executive	Sickle Cell Society
Dr Krishna Kotecha	Consultant Paediatric Oncologist with a Special Interest in Haematology	University Hospitals of Leicester NHS Trust
Roanna Maharaj	Service User	
Lara Odelusi	Nurse	North East London NHS Foundation Trust
Rhonda Skeete	Specialist Nurse	Croydon Health Services NHS Trust
Katherine Stevenson	Haemoglobinopathy Specialist Nurse	Central Manchester University Hospitals NHS Foundation Trust
Dr Christine Wright	Consultant Haematologist	Sandwell and West Birmingham NHS Hospitals Trust

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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	29	67
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	55	29	53

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	A good range of leaflets were available for patients with sickle cell disease. Leaflets for patients with thalassaemia could be clearer and all leaflets could be made more accessible.	Y	Leaflets were only displayed during the haematology clinic times as the area was used for other clinics.

		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	As Quality Standard HN-101	Y	As Quality Standard HN-101

		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	Y	The postscript on letters as a reminder for immunisations was a good idea and added to all letters to GPs.	Y	
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	Formal care plans were not in place for patients with thalassaemia but patients were given detailed letters following their annual review. Care plans were in place for patients with sickle cell disease.	Y	

		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		Y	School care plans were good. See main report.
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	Information was in place but there were separate booklets for the acute Trust and community services which did result in some confusion for patients. See main report.	Y	

		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		Y	
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	Y	Patient feedback had helped in the development of the chronic pain management programme.	Y	Feedback was collected and the Trust had developed the text messaging service before appointments as a result of feedback. Other issues arising from the patient survey had not yet been addressed, such as out of hours care or delays for analgesia in the Emergency Department.

		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		Y	
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	Consistent cover for the lead clinician was not yet in place. Locum cover was provided for in-patient care but not for out-patients. The permanent post was out to advert at the time of the review. See main report.	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)	N	A lead nurse was in place but did not have sufficient time for liaison with other services within the network.	N	There was no lead nurse in place for the service. Some cover was provided by the adult clinical nurse specialist (CNS) and a nurse from the haemophilia team covered one day per week. 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-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 cover for out-patient medical staffing ('a') or the clinical nurse specialist 'd'. Only 50% of nurses on Ruth Myles ward and less than 50% on Gordon Smith ward had competences in caring for people with haemoglobin disorders. See main report.	N	There was no clinical nurse specialist in place ('d') or clinical health psychologist with an interest in haemoglobin disorders ('g'). 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).	N	There was no clear training plan in place for nursing staff. A good online nursing package was available and medical training was good.	N	A training plan was in place but it was not clear that all staff attended training and therefore maintained their competences.

		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.	N	A locum was available for in-patient advice only. See HN-202. See main report.	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	Records of training for Emergency Department staff were good. It was not clear if all nursing staff on general wards accessed training.	Y	A paediatric induction programme was in place.
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	Good in-patient training was available but trainees may benefit from additional out-patient sessions.	Y	

		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		N	Reviewers did not see sufficient evidence of appropriate competences.
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	Insufficient administrative support was available for data collection.	N	No support for the service was available.
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.	Y	A good chronic pain management team was in place. Access for patients in local hospitals to this service was not clear.	N	There was no access to a psychologist with an interest in haemoglobinopathies ('a').

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
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)	N	Input from an acute pain team was not available.	Y	

		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	Named links were in place. It may be helpful to consider national pathways for some conditions in order to ensure access to staff with appropriate expertise.	Y	Named links for services were in place. A joint endocrine clinic was in place. Paediatric surgery was offered for the region and was of a high standard.

		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	Facilities for teenagers and young adults could be improved. See main report.
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.	N	Phlebotomy was performed until 6.30pm but other interventions were only available during working hours (Monday to Friday, 9am to 6pm). See main report.	N	Although facilities were open until 8pm, transfusions were not available out of hours. 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-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	There was no named co-ordinator for transition ('c'). There were two sets of guidelines in use in the acute Trust and the community. Arrangements for 'g' at hospitals other than St Helier were not clear. See main report.	N	There was no named co-ordinator for transition ('c'). There were two sets of guidelines in use in the acute Trust and the community. Arrangements for 'g' at hospitals other than St Helier were not clear. See main report.
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	Information for 'g' could be clearer.	Y	Guidelines for access to long-term transfusions could be clearer.

		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		Y	Information for 'g' required updating.

		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	Three sets of Emergency Department guidelines were available. See main report.	Y	Guidelines for 'l' were not comprehensive and required further detail. The in-patient management sheet was good.
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		Y	

		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		N	Guidelines did not include information for 'b' in non-transfused patients.

		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		Y	

		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 local quality assurance process was not clear. Some previous results were not easily available. The process for notifying clinicians of abnormal results was not clear (i).

		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	N	There was no policy for 'd'. All other aspects of the Quality Standard were met.	N	There was no evidence for points 'd', 'f', 'h', 'I', 'j' and 'k'. In practice for processes for 'f' were in place.

		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		Y	
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	There was no formal network in place.	N	There was no formal network in place.
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		N	There was no evidence of review meetings.

		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.	N	Patient data and adverse events were entered on the National Haemoglobinopathy Registry (NHR). Annual reviews were being done but were not being entered on NHR because of lack of data support. See main report.	N	Annual review data were not entered on the National Haemoglobinopathy Registry. See main report.
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 as expected by the Quality Standard were not available.	N	Data as expected by the Quality Standard were not available.

		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	N	Data were not yet monitored.	N	Most data were not yet monitored. Data were available for 'e', 'f', and 'g'.

		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	Y		N	No audits had been carried out for 'l', 'j' or 'k'. Audits for 'a', 'b' and 'c' could be more clearly documented. All other audits had been undertaken.

		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.	Y	Network-wide audits had not yet taken place as a formal audit was not in place.	N	
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		Y	
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	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-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	
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	No formal mechanisms for involving patients and carers was in place.	N	A formal 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	Network leads had not yet been identified.	N	Network leads for all the areas had not yet been identified.
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	An education and training programme was not yet in place.	N	An education and training programme 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	Network transition guidelines were not yet in place.	N	Network transition guidelines 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**
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	Network clinical guidelines were not yet in place.	N	Network clinical guidelines were not yet in place although St George's guidelines had been shared with other hospitals in the network.
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	Ongoing monitoring was not yet in place.	N	Ongoing monitoring 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	Network audits had not yet been agreed.	N	Network audits had not yet been agreed.
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	An agreed policy was not yet in place.	N	An agreed policy 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	The informal network meetings only involved St George's University Hospitals NHS Foundation Trust and Epsom and St Helier University Hospitals NHS Trust.	N	The informal network meetings only involved St George's University Hospitals NHS Foundation Trust and Epsom and St Helier University Hospitals NHS Trust.

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COMMISSIONING

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	The configuration of services had not yet been agreed.	N	The configuration of services had not yet been agreed.
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**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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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