WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

South East London Network

Guy's and St Thomas' NHS Foundation Trust

Visit Date: 17th June 2015 Version 2 Report Date: October 2016

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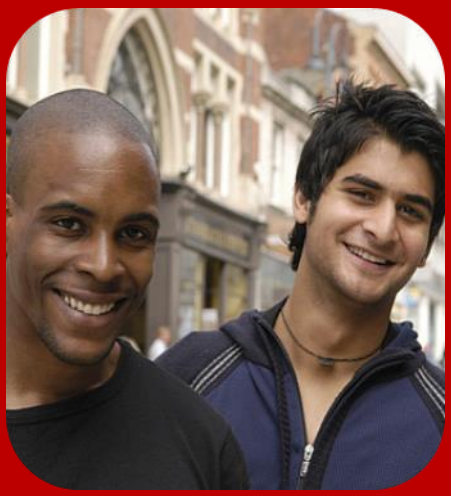


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Version No.	Date	Change from previous version
1	October 2015	N/A
2	October 2016	Includes final Network findings and compliance sections resulting from review of last Trust in Network

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Guy's and St Thomas' NHS Foundation Trust (part of the South East London Network), which took place on 17th June 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:

- Guy's and St Thomas' NHS Foundation Trust
- NHS England Specialised Commissioning
- NHS Lambeth CCG
- NHS Southwark CCG

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 Guy's and St Thomas' NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review. The NHS Sickle Cell and Thalassaemia Screening Programme funded this peer review programme.

About West Midlands Quality Review Service

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

HAEMOGLOBIN DISORDERS SERVICES IN SOUTH EAST LONDON NETWORK

At the time of the review Guys' and St Thomas' NHS Foundation Trust was commissioned as a Specialist Haemoglobinopathy Centre and was part of the South East London network, together with Lewisham and Greenwich NHS Trust, Croydon Health Services NHS Trust and King's College Hospital NHS Foundation Trust.

Care for children and young people was provided at the Evelina London Children's Hospital (ELCH). As the only children's hospital in the South East London network the number of patients with sickle cell disease cared for at ELCH had grown considerably over the previous ten years. This was, in part, due to availability of specialist services at ELCH including cardiac, respiratory, nephrology and a large Paediatric Intensive Care Unit (PICU). Approximately two thirds of all new births of babies with sickle cell disease in the boroughs of Lambeth, Southwark and Lewisham were referred to the hospital.

The Trust provided care for adult patients with more complex needs from both Lewisham and Greenwich NHS Trust and Croydon Health Services NHS Trust. Patients were referred from other NHS Trusts for tertiary opinions and supra-specialist clinics.

The Trust had links to several Local Haemoglobinopathy Teams (or linked providers) and carried out outreach annual review clinics for adult patients in Brighton and Sussex University Hospitals NHS Trust.

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
Guy's and St Thomas' NHS Foundation Trust	SHC	828 (seen in last 2 years) (568 patients registered on NHS)	13	78
Dartford and Gravesham NHS Trust	LHT	20	0	0
Medway NHS Foundation Trust	LHT	<10	0	0
Brighton and Sussex University Hospitals NHS Trust	LHT	20	0	0
East Sussex Healthcare NHS Trust	LHT	0	0	0
Western Sussex NHS Foundation Trust	LHT	0	0	0

Emergency Care

The majority of patients were admitted via the Emergency Department (ED) at St Thomas' Hospital where guidelines were in place for the emergency care of patients with sickle cell disease. Brief analgesia care plans were available on the Electronic Patient Record (EPR) for the majority of patients and approximately 20 patients had more comprehensive care plans available in the ED and in the Emergency Medical Unit (EMU).

When a patient presented Monday to Friday, from 9am to 5pm, the Sickle Cell Team was notified. A decision was then made whether to observe the patient on the EMU or admit to Guy's Hospital. Outside of these hours patients with a straightforward pain crisis were admitted to the EMU under the care of the emergency team overnight and were then reviewed by the Sickle Cell Team the following morning. If the EMU was full, or the patients had a more complicated presentation, they were admitted under the medical team to the medical

wards at St Thomas' Hospital and were reviewed by the Sickle Cell Team the following morning. A haematology Specialist Registrar (SpR) and consultant were on call 24/7 and the SpR was informed about any admissions and was available to review patients overnight if necessary.

Patients also attended the Haematology Day Unit at Guy's Hospital Monday to Friday, from 9am to 5pm for acute pain management but they were required to phone ahead to ensure that a bed was available.

All patients with sickle cell disease were reviewed by a senior decision maker (Consultant, Registrar or Advanced Nurse Practitioner (ANP)) within 24 hours of admission.

In-Patient Care

Patients were preferentially admitted to one of the haematology-oncology wards at Guy's Hospital (Samaritan, Hedley-Atkins or Esther ward). Patients admitted to other wards were under the care of the haematology/sickle cell team. Daily reviews by junior medical and nursing staff took place and sickle cell disease consultants covered the wards on alternate weeks. Formal ward rounds took place three times a week (Monday, Wednesday and Friday) and consultants reviewed patients on other days as required.

The psychologists attended formal ward rounds on Monday and Wednesday and also saw patients on other days as required. At the weekend all patients with sickle cell disease were seen by the on-call non-malignant haematology SpR. If patients were admitted under other specialities the haematology team reviewed them daily.

Nurse training was provided on the haematology-oncology wards, EMU and the medical wards.

Out-Patient Care

Dedicated haemoglobinopathy clinics took place twice weekly on a Tuesday afternoon and Friday morning in the haematology out-patient clinic (Haematology 2). Late appointments were available on a monthly basis on a Tuesday (until 5pm). The clinics were attended by both of the consultants, advanced nurse practitioners (Tuesday clinic), SpR, psychology staff, community clinical nurse specialists (once weekly) and benefits advisor (fortnightly). New patient, routine follow up and annual review appointments were available. A nurse-run telephone clinic was available for hydroxycarbamide patients bled in the community or at the hospital.

A large range of supra-specialist clinics was run by the haemoglobinopathy team in conjunction with named medical or surgical specialists.

Day Unit Care

Routine planned exchange transfusions, top-up transfusions and acute pain service clinics took place on the haematology day unit, adjacent to the out-patients department. Nurses working on the unit were trained in care for transfusion and haemoglobinopathy care, including apheresis procedures. Nurses had been trained in the placement of venous access lines for this procedure.

A day care service was available during working hours for acute pain management for appropriate patients, shared with the acute oncology service.

Community Based Care

South East London Sickle Cell and Thalassaemia Centre provided the community care for Southwick, Lambeth and Lewisham. Staffing was comprised of a clinical nurse specialist for Guy's and St Thomas' patients, a clinical nurse specialist with responsibility for antenatal screening and a newly appointed benefits advisor. The community team made contact with all patients following discharge from hospital.

SERVICES FOR CHILDREN AND YOUNG PEOPLE

Trust	Reviewed as:	No. of children and young people with sickle cell disease*	No. of children and young people with thalassaemia	No. of children and young people on long term red cell transfusions
Guy's and St Thomas' NHS Foundation Trust Evelina London Children's Hospital	SHC	520	4	59

* Figures represented here are for the numbers of children receiving care with ELCH. Total numbers and shared care arrangements with other specialist centres are not depicted. Children are seen from Dartford and Gravesham NHS Trust, Lewisham and Greenwich NHS Trust, Epsom and St Helier University Hospitals NHS Trust, Basildon and Thurrock University Hospitals NHS Foundation Trust, Frimley Park Hospital NHS Foundation Trust, Surrey and Sussex Healthcare NHS Trust and Western Sussex Hospitals NHS Foundation Trust

Emergency Care

All children and young people needing acute admissions were admitted via the children's Emergency Department (ED) at St Thomas' Hospital and children were admitted to the paediatric wards at ELCH. An electronic flag to alert clinicians to the primary diagnosis was available for each registered patient. Children with moderate or severe pain were given intranasal diamorphine followed by oral or parenteral morphine. The paediatric ED and paediatric medical teams were primarily responsible for managing the patient with input from the paediatric haemoglobinopathy team during normal working hours. Out of hours, the on-call haematology SpR was available for discussion. Children were usually admitted to Mountain Ward under the care of the attending consultant paediatrician.

In-Patient Care

The main paediatric ward was Mountain Ward which contained 43 beds for paediatrics, ENT (ear, nose and throat) and general surgery. Patients could be admitted to other wards, including the cardiology and neurology ward (Savannah) and nephrology and short stay surgery ward (Beach). Children admitted to ELCH were reviewed daily by the paediatric haemoglobinopathy team Monday to Friday (nurse specialist, SpR or consultant) while remaining under the care of the general paediatric consultant. Out of hours, the on-call haematology SpR and consultant for haemoglobinopathies were available for discussion. Apheresis for acute complications took place mainly on the high dependency section of Mountain Ward but could also take place on other wards or the PICU. Access to specialist services, including the acute pain service and the respiratory team, was provided. The haemoglobinopathy team were actively involved in the management of surgical patients admitted under the care of the surgical consultant.

Out-Patient Care

Out-patient care took place on Ocean Floor with all day sickle cell disease and thalassaemia clinics on a Friday led by the paediatric consultant with two registrars (one haematology and one paediatric). The clinic was supported by three nurses, an advanced nurse practitioner (transition / adolescent), lead clinical nurse specialist and community-based clinical nurse specialist as well as a child and adolescent mental health (CAMHS) practitioner.

Specialist clinics were run on a monthly basis. Regular clinics included a joint neurology clinic every third Thursday, a joint nephrology clinic every third Tuesday and a joint respiratory clinic every third Wednesday.

Families had access to a benefits adviser, play specialist and phlebotomy service until 5.30pm. Trans-Cranial Doppler scanning took place on Friday mornings and additional days were arranged as required.

Day Unit Care

The Husky Day Unit was a six bedded unit used for transfusions. It was open from 8am until 8pm Monday to Friday and also every other Saturday for patients on chronic transfusions. It was nurse-led and all nurses were competent in cannulation. All patients had an individual cannulation plan.

Community Based Care

The community team was part of Guy's and St Thomas' NHS Foundation Trust and based at The Wooden Spoon Centre. Community nurses ran counselling clinics and also participated in the fortnightly multi-disciplinary team meetings. The community nurse specialists attended the out-patients clinic on Fridays. Patients were reviewed and supported in the community following discharge from hospital, for recurrent admissions or recurrent 'did not attend'. A support group was held at the centre.

VIEWS OF SERVICE USERS AND CARERS

Adult service

The visiting team met 10 patients with sickle cell disease and received feedback from them. Common themes raised by patients were:

- Patients and carers considered that there was insufficient space available on the Day Unit and that access to this service was limited and had become increasingly so since its original introduction. Patients were keen to see this service extended so that it was available seven days a week with longer opening hours.
- Patients occasionally experienced delay to treatment on the Day Unit but pain medication was generally received within twenty minutes of arrival.
- Patients expressed a preference for accessing the Day Unit rather than attending the Emergency Department (ED). Most said that, if no beds were available when they called the unit, they tried to manage at home until the next day when a bed might be available.
- There appeared to be minor inconsistencies in knowledge and capabilities of the service. Patients considered that there was a lack of clarity around the number of beds allocated. For example, one patient reported being able to book a bed the day before although others were not aware that booking ahead in this way was possible.
- Patients said that they trusted the care provided at St Thomas' Hospital (both in the ED and on the general medical wards) less than the care they received through Guy's Hospital and suggested that there were delays in providing pain relief and that clinical protocols and care plans were not always adhered to at St Thomas's. They reported often feeling "labelled", disbelieved and treated with "suspicion" by staff at St Thomas' Hospital. Patients said sometimes they were not treated with empathy, respect and understanding when admitted through the ED at St Thomas' Hospital. They expressed concerns that ED staff lacked knowledge about Sickle Cell Disease and indicated that their experience led them to avoid accessing care through this route. On occasions the care plan was not followed as they were told "it does not look like you are in that much pain".
- Patients' knowledge of their care plans was inconsistent. Some patients knew of them but did not know they could hold them. Those that knew of their plan said it was updated at an annual review. Patients felt that the care plans were very useful when dealing with ambulance staff. One patient reported that care plans were not always followed in the ED.
- Patients were very appreciative of the specialist team and the care that they provided and agreed that they had made a positive impact on their experiences and were a good source of support.
- Patients felt they could confidently raise issues and provide feedback to the specialist team and they were taken seriously. They believed, however, that the team's 'hands are tied' and that, although their

concerns were passed on to more senior management, action was not apparent and they did not receive a response.

- Patients indicated that they were keen to have greater access to community services and facilities so community staff could provide support to a wider group of patients within the community. Patients who attended either the community-based or hospital-based support groups valued the opportunity to meet with other people using services for mutual support, information and contact.
- All patients who attended indicated that they were keen to be able to provide anonymous feedback about service provision on an ongoing basis and to be involved in developing and improving the service.
- Younger patients who attended the review session indicated that they would be keen to be kept informed about service details, events, developments and information through the increasing use of social media (e.g. Facebook, Twitter, Instagram) and web technologies.

Service for Children and Young People

The visiting team met with four patients with sickle cell disease and six carers and received feedback from them. They also reviewed responses to 50 questionnaires. The results of an additional parent/ carer support survey were available.

Common themes raised by patients and carers were:

- Parents valued the service and found hospital staff friendly, helpful and caring
- Parents were very appreciative of the community service. They particularly valued the antenatal / neonatal education and support in the first year. One parent reported a delay in results being communicated and subsequent follow up.
- Patients expressed concern about the knowledge of haemoglobin disorders of some staff in the Emergency Department.
- The support group was welcomed but awareness of this was limited.
- The transition service was helpful.

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REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

The South East London network encompassed Guy's and St Thomas' NHS Foundation Trust (Guy's), King's College Hospital NHS Foundation Trust (King's) as specialist haemoglobinopathy centres. Accredited Haemoglobinopathy Teams were based in Croydon Health Services NHS Trust and Lewisham and Greenwich NHS Trust. In addition the network had other linked hospitals. Evidence was available for clinical collaboration, patient stakeholder meetings and access to research across the network.
This was a well organised and functional network offering good links to highly specialised services. Relationships between the various parties were strong. A particularly notable and well-attended education programme was in place with sharing of expertise and good practice. Guidelines and patient information had been widely shared across the wider South Thames region.

Progress since Last Visit

This was the first peer review for children's services since 2010 and the first visit for adult services since 2012. Since the last visits a network administrator had been appointed based at King's who had responsibility for the collection of data for the network and for arranging meetings. A monthly tertiary outreach clinic was established between King's College Hospital and Croydon University Hospital. Transcranial Dopplers and annual reviews were undertaken at the tertiary clinic, attended by the lead paediatrician and a paediatric haematologist from King's.

Good Practice

1 Regular network meetings were in place and pathways for referral of complex cases into a range of specialist clinics were clear.

2 Strong informal clinical and educational links existed between the centres.

3 An excellent newsletter for patients and relatives contained information on services and articles of interest about developments in therapy and research.

4 A network website had been developed, as had patient conferences.

5 An outreach paediatric psychology service was established through King's College Hospital providing support to local patients at the Sickle Cell and Thalassaemia Community Centre in Croydon.

Immediate Risks: No immediate risks were identified.

Concerns

1 Formal engagement with the commissioners in defining the network and inter-relationships between the hospitals had not yet taken place.

Further Consideration

1 Although the pathways to relevant specialist services were in place further work was required to define more clearly the criteria used to decide which patients should be referred to which specialist service.

2 It will be important for the paediatric team at Croydon University Hospital to work collaboratively with the other local teams to ensure that the excellent work undertaken is maintained.

NETWORK CONFIRGURATION

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

Specialist Haemoglobinopathy Centre	Accredited / Local Haemoglobinopathy Teams
Guy's and St Thomas' NHS Foundation Trust:	• Dartford and Gravesham NHS Trust
	• East Sussex Healthcare NHS Trust
	• Medway NHS Foundation Trust
	• Queen Victoria Hospital NHS Foundation Trust
	• Frimley Health NHS Foundation Trust
	• West Hertfordshire Hospitals NHS Trust
	• East Kent Hospitals University NHS Foundation Trust
	• Croydon Health Services NHS Trust (Croydon University Hospital, Adults): Accredited Local Haemoglobinopathy Team (Adults)
	• Lewisham and Greenwich NHS Trust: Accredited Local Haemoglobinopathy Team (Adults and Children)
King's College Hospital NHS Foundation Trust:	• Maidstone and Tunbridge Wells NHS Trust
	• Western Sussex Hospitals NHS Foundation Trust
	• Brighton and Sussex University Hospitals NHS Trust
	• East Sussex Healthcare NHS Trust
	• Medway NHS Foundation Trust
	• Croydon Health Services NHS Trust (Croydon University Hospital, Paediatric)

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SPECIALIST TEAM: GUY'S AND ST THOMAS' NHS FOUNDATION TRUST

Service for Adults

General Comments and Achievements

This was a large service with very strong medical and nursing leadership. The service was valued by both patients and senior managers within the Trust. Patient feedback about the acute and community teams was excellent. At the time of the review staffing levels were sufficient for the number of patients and appropriate cover was available. The psychology service was well-resourced and embedded into both in-patient and out-patient care. Activity levels had increased significantly over the previous year for reasons which were not clear or fully explained.

There was a clear commitment to training for all groups of staff. The department had an active research programme and a successful record of publications.

Progress since Last Visit

The previous peer review took place in September 2012 and good progress had been made since then. A second consultant had been appointed (this had previously been a locum position) and this had resulted in robust cover arrangements for both in-patients and out-patients.

The Advanced Nurse Practitioner posts had increased from one to two and both post-holders had been trained to undertake extended roles including independent assessment of patients on wards and in out-patients, nurse-run clinics, and emergency apheresis. This had increased clinic capacity, facilitated working across both

hospital sites and improved the timeliness of discharge. One of the ANPs was undertaking training for transfusion prescribing.

A data manager had been appointed and robust mechanisms were in place to ensure that nearly all patients had an annual review and data were recorded on the National Haemoglobinopathy Registry. A benefits advisor had also been appointed and attended out-patient clinics.

The majority of in-patient care had been transferred to Guy's Hospital where most patients were managed on haematology wards. Patient-controlled analgesia had been introduced and the day care pain service had expanded to see more patients.

There was increased availability of supra-specialist clinics and improved links with other hospitals, including out-reach clinics at Brighton and Sussex University Hospitals Trust and University Hospital Southampton NHS Foundation Trust.

Good Practice

1 Key staff members were named on patient information.

2 The Advance Nurse Practitioners carried out independent assessment and management of patients, which facilitated annual reviews and provided greater flexibility of service provision for patients, for example, the telephone clinic for hydroxycarbamide monitoring.

3 The transition process was excellent and included specific nursing and psychology input.

4 Annual reviews were performed and data entered into the National Haemoglobinopathy Registry. This had facilitated audit of clinical outcomes and standards. The annual review proforma for clinic letters was comprehensive and ensured consistency between review clinics.

5 A range of combined specialist clinics were being undertaken to address the increasing co-morbidities of older patients.

6 Community nursing teams were informed of all discharges and contacted the patients at home to advise on any on-going concerns.

Immediate Risks: No immediate risks were identified.

Concerns

1 The pathways for the management of pain for patients with sickle cell disease required review to address the concerns of the patients about their treatment in the Emergency Department and to improve access to day care.

Further Consideration

1 Although a training programme was in place for ED, patient feedback suggested that it may benefit from review.

2 Reviewers suggested that consideration be given for additional pain specialist input into alternative management protocols for acute painful episodes and chronic pain.

3 Although staffing levels were appropriate at the time of the visit, increased activity was impacting on the ability to deliver on all aspects of the service, for example the adolescent Advance Nurse Practitioner was undertaking more work with adult patients which was impacting on his work with younger patients. Short to medium-term service planning may be helpful especially considering the numbers of patients transferring from paediatric to adult care, the increased healthcare needs of the older patients and projected numbers of patients requiring apheresis and blood transfusion.

4 The psychology service could be encouraged to share practice and outcomes with the wider haemoglobinopathy community to support introduction of specialist psychology posts in line with the national service specification.

5 Consideration should be given to developing specialist midwifery practice to support the clinic and in-patient activity. The combined obstetric clinic would also benefit from regular psychology input.

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SPECIALIST TEAM: GUY'S AND ST THOMAS' NHS FOUNDATION TRUST – EVELINA LONDON CHILDREN'S HOSPITAL

Services for Children and Young People

General Comments and Achievements

This was a good service with a large and expanding population base and strong medical and nursing leadership including community support. Good collaborative working relationships between sub-specialist services were evident. Managerial engagement was high with an understanding of the needs of the service. Evelina London Children's Hospital had a strong identity with plans for expansion and a speciality-focussed vision. Overall, the facilities were of a high standard. The long running Trans-Cranial Doppler service provided specialist training and was committed to a national quality assurance programme.

Progress since Last Visit

The previous peer review visit took place in May 2010 and there had been a number of developments since that time. Approval for additional staffing had been obtained and at the time of this review posts for a clinical nurse specialist and an additional paediatric haematologist were being advertised. The active research programme had expanded and a number of joint clinics had been established.

Good Practice

1 Patient information was good. The travel advice information was of a particularly high standard.

2 The transition pathway was robust, well organised and appropriately supported.

3 Very good community services were in place, which included:

   a. Excellent school care plans

   b. Forums for school nurse training

   c. Good engagement with local general practitioners

   d. Good 'fail-safe' arrangements for patient follow-up, particularly after hospital discharge.

4 There was an active and on-going programme of quality improvement projects with evidence of implementation of change, such as the transfusion pathway and parent/carer support survey.

5 Management guidelines for stroke and acute pain were comprehensive.

Immediate Risks: No immediate risks were identified.

Concerns

1 At the time of the review there was no cover available for absences of the lead clinician although a job had been advertised for the appointment of a second consultant.

2 Access for children and young people to a psychologist with an interest in haemoglobin disorders was not available. Although the team had a full time Child and Adolescent Mental Health Services (CAMHS) practitioner who offered psychological and counselling support.

Further Consideration

1 The Trust may wish to consider the development of a more structured teaching and training programme for all health professionals, including the Emergency Department staff.

2 In contrast to sickle cell disease, patient information on thalassaemia was limited.

3 Once the additional nurse specialist has been appointed, reviewers suggested that the role of the nurse specialist should be expanded to include formal nurse-led clinics and support of a nurse-led transfusion pathway.

4 Network pathways for the management of acutely unwell children required clarification. Network pathways for sick children were shared with King's College Hospital and both sites were covered by the same emergency retrieval team with either paediatric intensive care unit taking patients in turns if the other was full. However children with neurosurgical and liver emergencies were directed to Kings College Hospital whilst ENT (ear, nose and throat), nephrology and cardiology were directed to Evelina London Children's Hospital.

Although pathways for emergency retrieval worked well, for less unwell children there was uncertainty over which of the two specialist centres the local hospitals would preferentially access for advice or if needed, make arrangements for transfer of children.

COMMISSIONING

General Comments and Achievements

The reviewers met with the commissioner for haemoglobinopathy services for London although, at the time of the review, the structure of the commissioning team was changing. The commissioner reported that there had been no formal designation of Guy's and St Thomas' NHS Foundation Trust as a Specialist Haemoglobinopathy Centre (SHC) though it was considered to be functioning as one. Enhanced tariffs had been agreed for the SHC role in the past through local commissioning to support aspects of the service for the wider network.

Immediate Risks: No immediate risks were identified.

Concerns

1 Some of the issues identified in this report will require commissioner monitoring and support to ensure they are addressed.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead/s:

Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust
Dr Kate Ryan	Consultant Haematologist	Central Manchester University Hospitals NHS Foundation Trust

Visiting Team:

Albin Bendiola	Acute Paediatric Sickle Cell and Thalassemia Nurse	Barking Havering & Redbridge University Hospitals NHS Trust
Joanne Bloomfield	Specialist Nurse & Manager	Nottingham Sickle Cell and Thalassaemia Service
Helen DeMarco	Senior Clinical Psychologist	University College London Hospitals NHS Foundation Trust
Dr Krishna Koetcha	Consultant Paediatric Oncologist with a Special Interest in Haematology	University Hospital of Leicester NHS Trust
Susie McKeown Wade	Clinical Nurse Specialist - Red Cell	Leeds Teaching Hospitals NHS Trust
Kalpna Sokhal	Service User	The Sickle Cell Society
Rita Protopapa	Quality Assurance Programme Manager (Haematology)	St George's University Hospitals NHS Foundation Trust
Dr Farrukh Shah	Consultant Haematologist	Whittington Health NHS Trust
Teresa Warr	Commissioner	NHS England South
Cherryl Westfield	Service user	

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

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

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders – Adult Service	43	40	93
Specialist Services for People with Haemoglobin Disorders – Service for Children and Young People	49	43	88
Haemoglobin Disorders Clinical Network - Adult Service	9	6	67
Haemoglobin Disorders Clinical Network - Service for Children and Young People	9	6	67
Commissioning	3	0	0
Total	**113**	**95**	**84**

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 Health Watch (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	Comprehensive information was available with leaflets clearly available in out-patient and ward areas. Named staff were identified on patient information.	Y	In contrast to sickle cell disease limited information was available for 'f' and for patients with thalassaemia. The telephone number given for the Sickle Cell Society was incorrect.

		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	The pregnancy leaflet was in a draft version.	Y	Information was in draft form awaiting approval for publication on the website.

		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 information letter was sent to the patient's GP.	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	Care plans for complex patients were available in wards and the Emergency Department but not yet on the Electronic Patient Record.	Y	Care Plans were very detailed.

		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	A good quality care plan was in place and arrangements for school liaison, including education, were of a high standard. The Trust may wish to consider the development of a thalassaemia-specific care plan.
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	A good protocol was available.	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		N	Information was available but did not include 'b', 'e' and 'f'.
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 was obtained through the support groups. Patients considered that feedback was encouraged but that clinical staff were often unable to act on it or give feedback.	Y	A transfusion survey had taken place and service changes had been made as a result.

		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.	Y		N	Cover was not available at the time of the review, although an advert for a new post had been advertised.
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	Y		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-204 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y	The ward was well-staffed and nurses were trained in femoral line insertion. Patients had good access to a psychologist with an interest in haemoglobinopathy disorders.	N	There was no access to a clinical or health psychologist with an interest in haemoglobin disorders. Access to psychology support was via the local Child and Adolescent Mental Health Service (CAMHS). See main report.
HN-205 All	**Competences and Training** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).	Y	A good, regular training programme was in place which included patient participation in nurse teaching on wards.	Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		Y	
HN-207 All	**Training for Emergency Department Staff** The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	Y		Y	The service would benefit from a robust and structured training programme. See main report.
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	A regular programme of teaching was in place and the specialist registrar attended thalassaemia clinics at the Whittington Hospital.	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	Log books were unavailable at the time of the visit but were reviewed by the Clinical Lead immediately after the review visit.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-299 All	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y		Y	
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		N	Access to a psychologist with an interest in haemoglobin disorders was not adequate. 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-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	Y		Y	

		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	Combined clinics had been implemented in order to address patient's co-morbidities. See main report.	Y	
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	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
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	Available facilities were appropriate at the time of the visit but the service faced potential capacity issues. Some patients reported difficulty in accessing beds.	Y	Facilities for adolescents were limited.
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	Out of hours top-up transfusion was available, but exchange transfusion was not. A weekend exchange transfusion service had recently been piloted (2014) with poor take-up by patients. A recent patient survey of transfused patients did not identify any patients who wished to have out of hours transfusion at present.	Y	Out of hours care was available at weekends.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-501 SHC A-LHT	**Transition Guidelines** Network-agreed guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y	Excellent guidelines were in place.	Y	
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	A good GP letter proforma was in place.	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	See network section.	N/A	See network section.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Offering access to exchange transfusion to patients on long-term transfusions c. Protocol for carrying out an exchange transfusion d. Hospital transfusion policy e. Investigations and vaccinations prior to first transfusion f. Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. g. Areas where transfusions will usually be given h. Recommended number of cannulation attempts	Y		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-505 All	**Chelation Therapy** Network-agreed clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y		Y	

		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	Guidelines were not in place for 'j' but referral to nominated specialist teams was in place. Good guidelines were in place for 'a' and 'f'.	Y	The stroke and acute pain guidelines were particularly comprehensive.
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)	N	Guidelines for endocrinopathies and liver disease were not available.	Y	
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y		Y	
HN-510 All	**Thalassaemia Intermedia** Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y		Y	
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		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-601 All	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	Y		Y	

		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	Community staff were employed by the Trust.	N/A	Community staff were employed by the Trust.
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).	Y		Y	
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	
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	Y	All annual reviews were input onto the National Haemoglobinopathy Registry.	Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
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	No data were available for Emergency Department attendances.	Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-703 SHC	**Annual Data Collection – Network Patient Data** The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia: a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network services during the course of the year: i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: i. Date seen in clinic ii. Date offered and prescribed penicillin d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year e. Number of network patients on long-term transfusion f. Number of network patients on chelation therapy g. Number of network patients on hydroxycarbamide h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients j. Number of network patients whose care was transferred to another service during the year k. Number of network patients who died during the year l. Number of network patients lost to follow up during the year	Y	Trust data were available but not network data.	N	Evidence of data collection was seen but it did not cover the whole network.

		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	Data were not available for 'g' and 'j'. Other aspects of the audit programme were good.

		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 been agreed.	Y	
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		y	

		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 Services		Services 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.	Y	Evidence of support for user events across the network was provided.	Y	Evidence of support for user events across the network was provided.
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	Y		Y	
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.	Y		Y	An extensive and robust programme of education was evident.

		Adult Services		Services 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	Good local guidelines were in place however formal network agreements were not defined.	N	Good local guidelines were in place however formal network agreements were not defined.

		Adult Services		Services 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.	Y	The extent to which the guidelines had been adopted across the network was not clear.	Y	However differing guidelines for thalassaemia (local / international) were being used within network. The network would benefit from clarification of referral pathways for paediatric patients. Local and network guidelines for managing chronic complications in children with sickle cell disease could be considered. Also consideration should be given to local and network guidelines for managing paediatric patients with thalassaemia.
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	Network data were not yet monitored.	N	Network data were not yet monitored.

		Adult Services		Services 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	However a preliminary audit programme was in place.	N	However a preliminary audit programme was in place.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	Y	A network research policy was in place. Both Croydon and Lewisham had access to trials via the network.	Y	Evidence of collaborative research was provided.
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).	Y		Y	

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COMMISSIONING

Ref	Quality Standard	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	There was no formal engagement with the commissioning team or designation of the Trust as an SHC.
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	Evidence of clinical quality review meetings addressing Haemoglobin Disorders and the network Standards was not seen.
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.

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