WM QRS West Midlands Quality Review Service

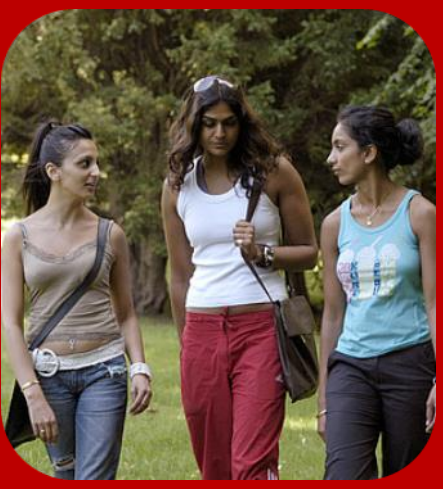
UK Forum on Haemoglobin Disorders

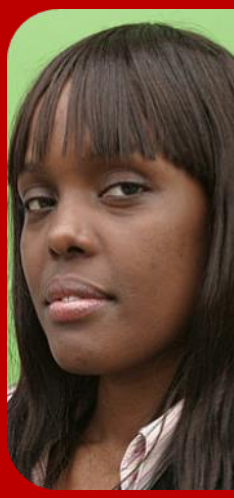
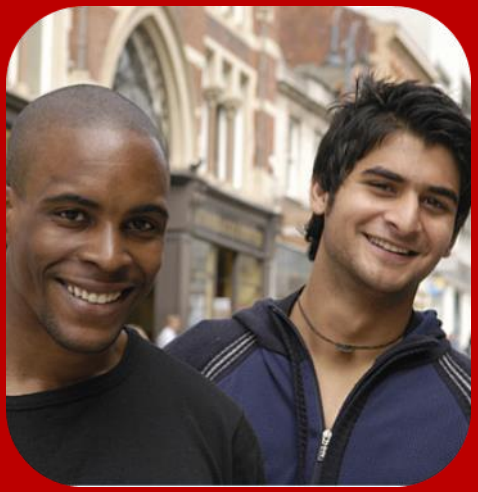
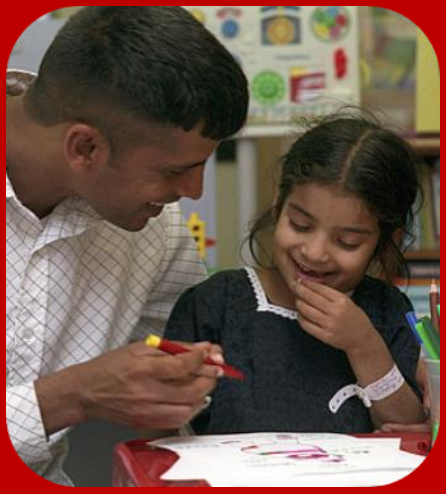
Health Services for People with Haemoglobin Disorders

East London Network

Barking Havering and Redbridge University Hospitals NHS Trust

Visit Date: 14th October 2014 Report Date: January 2015 Version 2



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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Barking Havering and Redbridge University Hospitals NHS Trust (part of the East London Network), which took place on 14th October 2014. 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:

- Barking Havering and Redbridge University Hospitals NHS Trust
- NHS England; Specialised Cancer and Blood

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

About West Midlands Quality Review Service

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

HAEMOGLOBIN DISORDERS SERVICES IN THE EAST LONDON NETWORK

NETWORK

For many years staff from Barking Havering and Redbridge University Hospitals NHS Trust (BHRUT) had had close informal links with haemoglobinopathy clinicians from Bart's Health NHS Trust, Homerton University Hospital NHS Foundation Trust and Basildon and Thurrock University Hospitals NHS Trust. The adult and paediatric consultants from these services met every six months at network review and learning meetings. A number of network protocols were in use and others were under development. Some network audits (paediatric codeine and obstetric audit) had been completed or were in progress. Some research projects had been carried out across the network and had been published.

BARKING HAVERING AND REDBRIDGE UNIVERSITY HOSPITALS NHS TRUST

ADULTS	Reviewed as:	No. adults			
		Sickle cell disease	Thalassaemia	Total	On long-term red cell transfusions
Barking Havering and Redbridge University Hospitals NHS Trust	A-LHT	379	17	396	22

CHILDREN AND YOUNG PEOPLE	Reviewed as:	No. children and young people			
		Sickle cell disease	Thalassaemia	Total	On long-term red cell transfusions
Barking Havering and Redbridge University Hospitals NHS Trust	A-LHT	287	14	301	17

At the time of the visit, Barking Havering and Redbridge University Hospitals NHS Trust (BRUHT) had hospitals on two sites, Queens Hospital in Romford and Kings George Hospital in Ilford, and served a population of over 750,000. The Trust's services for people with haemoglobin disorders were part of the East London Haemoglobinopathy Network. The main haematology service was run from Queen's Hospital and consultant haematologists visited King George Hospital daily on a rotational basis to review any in-patients with haematological problems and manage any laboratory issues. This service had a rapidly expanding population of haemoglobinopathy patients with a 7% increase in the number of adult patients since 2013 and 10% in the number of children and young people since 2011. A high local carrier rate (1 in 14 of the total population in Barking and 1 in 32 of the total population in Redbridge) led to a high rate of affected births, with between 16 and 24 births per year.

EMERGENCY DEPARTMENT

The adult Emergency Department (ED) saw approximately 20 patients with sickle cell disease per month and the adult day unit saw between 10 and 15 patients per month. On average, 70% of ED attendances and 42% of the day unit attendances were admitted. During normal working hours patients were reviewed by the haematology team (acute nurse specialist and junior doctor) in the Emergency Department. Patients could also

access the day unit or call the acute haemoglobinopathy nurse specialist directly. From 9am to 10pm, patients were admitted under the care of the haematology consultants onto the haematology ward, Mandarin B, if a bed was available. Patients arriving after 10pm were initially admitted under the on call medical team and transferred to the haematology team the next morning. If a haematology bed was not available, patients would be admitted to the Medical Admissions Unit and transferred to Mandarin B when a bed became available. All new patients admitted overnight were reviewed by the haematology consultant the next morning.

The paediatric ED saw between seven and 10 patients with sickle cell disease each month. Patients were usually reviewed by the paediatric team immediately and admitted to the Tropical Lagoon ward. Emergency Department staff were involved only if the paediatric team could not respond immediately. Patients admitted during normal working hours were also reviewed by the paediatric haematology staff grade doctor and the acute haemoglobinopathy specialist nurse. Patients admitted out of hours were reviewed the next day. The paediatric haemoglobinopathy consultant reviewed in-patients on Tuesdays and Fridays, or earlier if clinically indicated.

ADULT DAY UNIT (SUNFLOWER SUITE)

This unit managed patients with non-malignant and malignant haematological and oncological disorders, including delivery of chemotherapy. The unit was open weekdays from 9am to 7pm and provided an open access service for patients with haemoglobinopathies, including those with acute painful episodes. Transfusions, including elective manual exchanges and other planned procedures, were also undertaken. The unit had six assessment beds, 36 chairs and a procedure room.

PAEDIATRIC DAY UNIT (TROPICAL BAY)

Tropical Bay functioned as a surgical day unit and paediatric assessment unit. The unit was open five days a week from 8am to 8pm and closed at weekends and bank holidays. Tropical Bay had eight bed spaces, two cubicles and a procedure room. On Tuesdays Tropical Bay was divided by a semi-permanent partition into two distinct areas with one section used as an oncology/haematology outpatient treatment and assessment unit. Three nurses were available to cannulate children for transfusion. The Trust carried out many of the transfusions on Tuesdays as the consultants were based in the day unit, however transfusions could be accommodated on other days as well.

Children with haemoglobinopathies could be reviewed by prior arrangement on Tropical Bay on Tuesdays. On other days children were reviewed on Tropical Bay if the relevant consultant was available. If not, the review would take place in the Emergency Department. The proactive presence of the two haematology consultants on the unit on Tuesdays ensured close monitoring of chelation complications and outcomes.

IN-PATIENT CARE

Adult acute admissions were admitted to Mandarin B which was a 30 bedded haematology-oncology ward.

Tropical Lagoon ward was the main location for all acute paediatric admissions including those with Sickle Cell Disease (SCD). Children with SCD were admitted preferentially into Bay 1, which was the area allocated for higher risk patients. There were 26 beds and six cubicles suitable for admitting children up to the age of 16 years. The medical protocols for managing acute sickle cell disease emergencies were easily available on the Trust intranet system as well as in hard copy in the ward office. A noticeboard about SCD was near Bay 2. Children and young people were transferred to Bart's Health NHS Trust for emergency exchange, continuous positive airway pressure (CPAP) or other high dependency care or to Imperial College Healthcare NHS Trust or Great Ormond Street Hospital NHS Foundation Trust for intensive care.

The haematology team liaised with surgical, critical care, obstetric and other teams about the care of adults, children and young people with haemoglobin disorders, including at least daily review of patients admitted for surgery.

OUTPATIENT CLINICS

Adult follow-up sickle cell and thalassaemia clinics were held on the first and third Wednesday afternoon of the month and adult new patient clinics were held on a Monday morning (for both haemoglobinopathy and other haematology patients). More urgent slots were available on a Wednesday morning for recently discharged or other unwell patients and those starting hydroxycarbamide or exjade. Annual reviews were undertaken in these clinics which were attended by both acute and community adult specialist nurses as well as a benefits advisor and chaplain in rotation. The haemoglobinopathy psychologist held a parallel clinic all day on a Wednesday. Nurse-lead hydroxycarbamide and exjade telephone monitoring clinics were held every Wednesday morning. There was a joint haematology/obstetric clinic on the third Tuesday of the month.

The paediatric haemoglobinopathy clinic was held in paediatric outpatients on the second and fourth Wednesday afternoons of the month. A Trans Cranial Doppler clinic was held every other Monday afternoon in conjunction with a nurse led hydroxycarbamide/ exjade telephone monitoring clinic. A new haemoglobinopathy baby clinic was held on the fourth Tuesday of the month on Tropical Bay. All babies were reviewed by 12 weeks of age and started on Penicillin V. The acute and community paediatric nurse specialists also attended these clinics.

TRANSFUSIONS

At the time of the visit only long term top-up transfusions programmes were available at BHRUT. The Trust had plans to purchase two red cell apheresis machines and hoped to perform all elective exchanges on the automated system when they became available. This would also enable emergency exchange transfusions to be carried out on the apheresis machines where possible. The Trust hoped to re-patriate a further nine patients from the area who were in exchange programmes at other hospitals.

COMMUNITY SERVICES

The community service was based at the haemoglobinopathy centre at King George's Hospital. The nursing team provided genetic counselling, antenatal screening and support for adults and children with haemoglobinopathies. This service covered four boroughs (Redbridge, Barking and Dagenham, Havering and West Essex). The adult and paediatric community specialist haemoglobinopathy nurses attended the adult and paediatric clinics and the monthly multidisciplinary meetings. The paediatric community specialist nurse was the named coordinator of the transition process from the age of 12 years.

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REVIEW VISIT FINDINGS

NETWORK

Network standards will be reviewed at each SHC and A-LHT within the network and this report (Appendix 2) gives compliance with network standards as identified during this visit. Network-related issues will not be included until the final SHC in the network has been reviewed. At this point this report will be re-issued including final compliance with network Quality Standards and a section on network-related issues.

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ACCREDITED LOCAL HAEMOGLOBINOPATHY TEAM:

BARKING HAVERING AND REDBRIDGE UNIVERSITY HOSPITALS NHS TRUST

SERVICES FOR ADULTS

General Comments and Achievements

The Haemoglobinopathy Team had strong medical and nursing leadership. Considerable investment in the service had taken place since the 2013 peer review visit with expansion of nursing, medical and psychology staff. There was also evidence of improvement in 'Did Not Attend' rates, re-admission rates, time to analgesia and registration on the National Haemoglobinopathy Registry.

Patient feedback about the Sickle Cell Disease team was very positive and patients were aware of service improvements in the two years preceding the review visit, coinciding with expansion of the team. Patients and carers interviewed were particularly positive about the contribution of the medical and nursing leads. Patients and carers had also noticed an increased awareness of their needs and improved care in the Emergency Department. Positive comments were also made about the impact of training.

All members of the Haemoglobinopathy Team had relevant and up to date training. There was also some evidence of training packs and training slides for non-haematology staff.

Facilities, particularly the adult day unit, were of high quality and spacious with assessment beds where patients could be assessed and treated for part of the day. Staff had good awareness of the needs of patients with haemoglobin disorders and there was good access to individual care protocols and specialist staff.

A good range of well-written patient leaflets was available in both the Outpatient Department and the wards.

Progress since Last Visit

Services for adult patients with haemoglobin disorders were previously peer reviewed in February 2013. Since the last visit a comprehensive transition programme had been introduced. There had also been improvements in the 'time to analgesia' for patients arriving at the Emergency Department although the Trust recognised that further improvements were still required. The number of patient registered on the National Haemoglobinopathy Register had increased. The amount of specialist nurse support available had also increased and a 0.4 wte psychologist had been employed. Arrangements for multi-disciplinary review and learning had been introduced.

Good Practice

1 Training of medical and nursing staff on the haematology ward and on the day unit was comprehensive, including thorough induction training and a rolling programme of ongoing training.

2 Nurse-led clinics for hydroxycarbamide and iron chelation monitoring were innovative and well-organised, leading to improved quality of care for patients.

3 A comprehensive transition programme from paediatric to adult care had recently been introduced. A transition co-ordinator was in place and all patients were followed up throughout the transition process.

Immediate Risks: No immediate risks were identified.

Concerns

1 **Care in the Emergency Department**

Whilst there was evidence of improvements in the Emergency Department, the most recent audit showed that only 37% of patients received analgesia within 30 minutes of admission. Patient feedback on Emergency Department services indicated that several patients had either avoided the Department or, if they had attended, had encountered either long waits for analgesia or staff who had poor knowledge about Sickle Cell Disease.

2 **Clinical Guidelines**

a. Some of the acute care guidelines contained insufficient detail for use by a junior haematologist or non-haematologist in the emergency situation. The role of the non-expert in the emergency pathways of care, particularly in the absence or non-availability of the haemoglobinopathy lead, should be clarified.

b. The manual exchange protocol contained little practical detail on the how to set up and complete an exchange. The process described in the protocol was more appropriate to a paediatric procedure. Staff were reliant on either calling the lead clinician or transferring the patient, which could lead to inappropriate delays if the patient was particularly unwell.

c. Several other acute care protocols (acute chest syndrome, priapism, fever and sepsis and stroke) were brief and/or inaccurate. The priapism protocol contained procedures which should be carried out only by a urologist.

3 **Psychology staffing**

A 0.4 w.t.e psychologist was in post but was only able to provide basic psychology support, primarily to adults. This level of staffing was insufficient to provide adequate time for neuropsychological evaluation and support for all patients.

4 **Cover for clinical lead and lead nurse**

The haemoglobinopathy service was heavily reliant on the clinical lead and lead nurse. It was not clear that the quality of care provided was the same when they were away as robust arrangements for cover for absences were not yet in place. Reviewers suggested that the potential for delegation or sharing some responsibilities with other staff within the team should be explored.

5 **Out of hours advice**

At the time of the visit, the lead nurse was providing a single-handed, specialist telephone on-call service which was operating out-of-hours and over weekends. The Trust and commissioners had plans to develop a 1:5 on call rota by January 2015.

Further Consideration

1 At the time of the review visit a business case for apheresis machines was under consideration by the Trust Board. Reviewers supported this development as it would be of considerable benefit to patients who were travelling out of the area to receive erythrocytopheresis.

2 Enrolment to the National Haemoglobinopathy Registry and annual reviews/adverse event reporting had been hindered by a lack of administrative and data collection support. A significant proportion (67%) of patients was entered on to the Registry but this may not be sustainable without additional support.

3 Some patients were not aware of the National Haemoglobinopathy Registry. It was not clear if they had been given patient information or had previously consented. It may be beneficial to review this process.

4 Patient feedback was very positive but some patients said that they did not receive information about changes made as a result of their feedback. It was clear that changes were occurring and it may be helpful to increase the feedback to patients and carers about changes made.

5 Document control was not evident on all documents with some guidelines lacking dates for release and updates.

6 Although induction training was very good, the pocket guide to haematology used by junior doctors and shown to the team on the visit did not contain information about haemoglobinopathies and may benefit from this addition.

7 A small area on the adult day unit was designated as a 'teenage and young person's area' but neither day unit nursing staff or patients seemed aware of it and it was therefore underutilised.

8 Out of hours transfusions were not available for adult patients, although this was on the work plan of the department.

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SERVICES FOR CHILDREN AND YOUNG PEOPLE

General Comments and Achievements

The Haemoglobinopathy Team had strong medical and nursing leadership. Considerable investment in the service had taken place since the 2013 peer review visit with expansion of nursing, medical and psychology staff. There was also evidence of improvement in 'Did Not Attend' rates, re-admission rates, time to analgesia and registration on the National Haemoglobinopathy Registry.

Patient feedback about the Sickle Cell Disease team was very positive and patients were aware of service improvements in the two years preceding the review visit, coinciding with expansion of the team. Patients and carers interviewed were particularly positive about the contribution of the medical and nursing leads. Patients and carers had also noticed an increased awareness of their needs and improved care in the Emergency Department. Positive comments were also made about the impact of training.

All members of the Haemoglobinopathy Team had relevant and up to date training. There was also some evidence of training packs and training slides for non-haematology staff.

Engagement and collaborative working with the attending paediatricians and their junior team was clearly evident despite the lead link paediatrician post being a locum appointment at the time of the review.

Progress since Last Visit

Service for children and young people with haemoglobin disorders were previously reviewed as part of the Royal London Hospital (now part of Barts Health NHS Trust) in May 2010. Since the last visit a comprehensive transition programme has been introduced. The amount of specialist nurse support available had increased and a 0.4 wte psychologist had been employed. The lack of community staff highlighted as an issue at the time of the previous visit had also been addressed.

Good Practice

1 A comprehensive transition programme from paediatric to adult care had recently been introduced. A transition co-ordinator was in place and all patients were followed up throughout the transition process.

2 Training of medical and nursing staff on the haematology ward and on the day unit was comprehensive, including thorough induction training and a rolling programme of ongoing training.

3 School care plans were of a high standard, linked into the training delivered to the school staff and updated each term. Parents who met the visiting team said that they felt reassured that their child's illness would be taken seriously and that school staff would be able to provide appropriate support and help.

4 Staff delivering the paediatric transfusions on Tropical Bay used a good 'Paediatric Transfusion Pathway' booklet to document all aspects of their care.

Immediate Risks: No immediate risks were identified

Concerns

1 **Trans Cranial Doppler Scans (TCD)**

a. An annual Trans Cranial Doppler Scan (TCD) was offered to most children but the clinic had a DNA (did not attend) rate of 42% over the last 12 months including 25% over the last two months.

b. At the time of the visit documented evidence of scanning competences was not available. The log book of scans was not available and there did not appear to be a clear procedure for quality assurance. Training of two additional radiographers to support TCD scanning was in progress.

2 **Clinical Guidelines**

a. The wording of the acute care guidelines indicated an expectation that the lead consultant would be called to guide management in many circumstances. In the absence of the lead consultant the paediatric team contacted the specialist centre for guidance which could delay acute management in the emergency setting. The role of the non-expert in the emergency pathways of care, particularly in the absence or non-availability of the lead consultant, should be clarified in order to ensure timely care was available in the hospital.

b. The manual exchange protocol contained little practical detail on the how to set up and complete an exchange. Staff were reliant on either calling the lead clinician or transferring the patient, which could lead to inappropriate delays if the patient was particularly unwell.

c. Several other acute care protocols (acute chest syndrome, priapism, fever and sepsis and stroke) were brief and/or inaccurate. The priapism protocol contained procedures which should be carried out only by a urologist.

3 **Psychology Staffing**

A 0.4 w.t.e psychologist was in post but was only able to provide basic psychology support, primarily to adults. This level of staffing was insufficient to provide adequate time for neuropsychological evaluation and support for all patients.

4 **Cover for Clinical Lead and Lead Nurse**

The haemoglobinopathy service was heavily reliant on the clinical lead and lead nurse. It was not clear that the quality of care provided was the same when they were away, as robust arrangements for cover for absences were not yet in place. Reviewers suggested that the potential for delegation or sharing some responsibilities with other staff within the team should be explored.

5 **Out of hours advice**

At the time of the visit, the lead nurse was providing a single-handed, specialist telephone on-call service which was operating out-of-hours and over weekends. The Trust and commissioners had a plans to develop a 1:5 on call rota by January 2015.

Further Consideration

1 At the time of the review visit a business case for apheresis machines was under consideration by the Trust Board. Reviewers supported this development as it would be of considerable benefit to patients who were travelling out of the area to receive erythrocytopheresis.

2 Enrolment to the National Haemoglobinopathy Registry and annual reviews/adverse event reporting had been hindered by a lack of administrative and data collection support. A significant proportion (67%) of patients was entered on to the Registry but this may not be sustainable without additional support.

3 Some patients were not aware of the National Haemoglobinopathy Registry. It was not clear if they had been given patient information or had previously consented. It may be beneficial to review this process.

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5 Document control was not evident on all documents with some guidelines lacking dates for release and updates.

6 Although induction training was very good, the pocket guide to haematology used by junior doctors and shown to the team on the visit did not contain information about haemoglobinopathies and may benefit from this addition.

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COMMISSIONING

General Comments and Achievements

Local commissioners were fully engaged with the service and were very supportive of service developments. A comprehensive population health needs assessment had been carried out and there was good awareness of the specific needs of haemoglobinopathy patients, including the need for high quality community support.

Progress since Last Visit

The previous peer review visit reports had highlighted the need for commissioners to clarify the services commissioned across the network and progress had been made on this.

Good Practice

1 The haematology team met regularly with local commissioners and had developed a close and constructive working relationship with them. There was clear recognition that the care of people with haemoglobinopathies was a local priority and the local Clinical Commissioning Group and GP leads had been instrumental in supporting the infrastructure development for hospital and community services.

Immediate Risks: No immediate risks were identified.

Concerns: No concerns were identified.

Further Consideration

1 A review of commissioning arrangements, including specialist and co-commissioned services, should be considered as this was a very large local service providing many functions of a Specialised Haemoglobinopathy Centre, including initiation of transfusion, annual reviews and the initiation and amendment of chelation. Some patients with complex needs were referred to the specialist centre for review but the referral pathways were not always clear. There was no formal agreement between the specialist centre and the Trust as to which specialist functions were delegated and how data would be reported to the specialist centre.

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APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Clinical Leads:

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

Assistant Clinical Lead (part):

Dr Subarna Chakravorty	Consultant Paediatric Haematologist	Imperial College Healthcare NHS Trust

Visiting team:

Dr Michele Afif	Consultant Paediatrician	London North West Hospitals NHS Trust
Nkechi Anyanwu	Clinical Nurse Manager (Haemoglobinopathies)	Guy's and St Thomas' NHS Foundation Trust
Dr Asa'ah Nkohkwo	Patients & Public (PPE) Advocate	Independent Adviser
Giselle Padmore - Payne	Senior CNS for Paediatric and Adolescent Haemoglobinopathies	University College London Hospitals NHS Foundation Trust
Jacqueline Simpson	Service User	
Dr Tullie Yeghen	Consultant Haematologist	Lewisham and Greenwich NHS Trust

WMQRS:

Sarah Broomhead	Assistant Director	West Midlands Quality Review Service

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APPENDIX 2: COMPLIANCE WITH 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

Health Services for People with Haemoglobin Disorders:	Number of Applicable QS	Number of QS Met	% met
Adult Service	43	36	84
Service for Children and Young People	49	41	84
Clinical Network: Adult	9	3	33
Clinical Network: Children and Young People	9	3	33
Commissioning: Adult	3	2	67
Commissioning: Children and Young People	3	2	67
Total	**116**	**87**	**75**

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

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-101 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199)	Y		Y	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-102 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	Y	Patient information leaflets were comprehensive and well written. They were available in the outpatient clinics and the wards.	Y	
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		Y	

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	Paper versions of Individual Care Plans were readily available in the Emergency Department. They were updated once a year at the annual review and patients were given copies of them. There was a plan to have electronic versions of the Care Plans in the future.	Y	
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	See main report.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	See main report.	Y	See main report.
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	This standard was met even though the Trust was not a specialist centre.

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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	Mechanisms were in place to receive feedback from patients but examples of changes made as a result of the feedback were not always clear, although some patients said that they had seen changes made as a result of feedback. The service could consider a formal feedback of survey findings to parents and carers.	Y	Mechanisms were in place to receive feedback from patients but examples of changes made as a result of the feedback were not always clear, although some patients said that they had seen changes made as a result of feedback. The service could consider a formal feedback of survey findings to parents and carers.
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	A second consultant with responsibility for haemoglobinopathy was in post.	Y	A locum consultant with responsibility for paediatric haemoglobinopathy was in post.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	Y		Y	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-204 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	Insufficient psychologist support was available. A 0.4 w.t.e. psychologist had recently been appointed and was carrying out a service evaluation. Additional psychology time will be needed to provide comprehensive psychology support and a neuropsychological service. Effective cover for the lead nurse was not yet in place.	N	Insufficient psychologist support was available. A 0.4 w.t.e. psychologist had recently been appointed and was carrying out a service evaluation. Additional psychology time will be needed to provide comprehensive psychology support and a neuropsychological service. Effective cover for the lead nurse was not yet in place.
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 clear training plan was available for both medical and nursing staff working on the haematology ward and day unit.	Y	
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	This standard was met even though the Trust was not a specialist centre.	Y	This standard was met even though the Trust was not a specialist centre.

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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	
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) *b.* Equality and diversity	Y		Y	
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	The Haematology Trainee booklet did not contain information on haemoglobinopathies. This standard was met even though the Trust was not a specialist centre.	Y	This standard was met even though the Trust was not a specialist centre.
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	Although the Trust was not an SHC at the time of the visit, this Quality Standard was applicable as they did carry out Trans-Cranial Doppler ultrasound. Documentary evidence was not available to reviewers.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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.	N	Insufficient support was available for data collection and audit. Clinical staff were therefore spending time which could have been used for clinical work on data collection and data entry.	N	Insufficient support was available for data collection and audit. Clinical staff were therefore spending time which could have been used for clinical work on data collection and data entry.
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	0.4 w.t.e psychology support was in place but the service would benefit from additional support.	Y	0.4 w.t.e psychology support was in place but the service would benefit from additional support.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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/A		N/A	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	Y	Erythrocytopheresis was available at the Homerton University Hospital NHS Foundation Trust and University College Hospitals NHS Foundation Trust and small numbers of local patients attended for erythrocytopheresis at other sites. These sites were generally not easy to access and there was no clear route of referral. A business case for apheresis machines was with the Trust Board. 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	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	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	The adult day unit was well-organised (see main report). The 'teenagers' and young adults' area' was not well used and staff did not seem to be aware of it.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Saturday transfusions were planned but at the time of the visit were not yet available.	Y	Transfusions were available 8am to 8pm, Monday to Friday, on the Day Unit.
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	See main report.	Y	See main report.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	The checklist for first out-patient appointment was more suitable for children and young people than adults. Recording of vaccinations given and dates could be clearer.	Y	
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.	Y		Y	
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. 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	The exchange transfusion protocol was not very clear. In practice the consultant was usually called. The protocol could be clarified and made more 'user-friendly'. The hospital transfusion policy required the addition of special blood requirements for haemoglobinopathies and massive blood loss.	Y	

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

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	N	Point 'b', specifically fever, was not covered in the guidelines. Guidelines for points 'c' and 'f', acute chest syndrome and stroke and other neurological events, were brief and inadequate. Guidelines for point 'g', priapism required clarification about the referral pathway for specialist care. Referrals to other specialities lacked clarity.	N	Points 'b', fever, and 'h', acute renal failure, were not included in the guidelines. Guidelines for points 'c' and 'g', acute chest syndrome and priapism, required clarification about referral pathways for specialist care. Guidelines for points 'b' and 'f' were very brief (infection and overwhelming sepsis and stroke and other neurological events) were very brief.
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	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y	Guidelines for pulmonary hypertension and endocrinology could be clearer.	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	This standard was met even though the Trust was not a specialist centre.	Y	This standard was met even though the Trust was not a specialist centre.
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	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-512 SHC	**Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)** Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least: a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)	N/A		N	Although the Trust was not an SHC at the time of the visit, this Quality Standard was applicable as they did carry out Trans-Cranial Doppler ultrasound. Point 'g' was not met as images were not recorded and stored and were not available for review. Point 'j' was not met as there were no systems to ensure quality and accuracy of results. The accreditation log was not seen during the visit although reviewers were told that it was in place.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-601 All	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	Y		Y	The policy included point 'b' but it was not clear if arrangements over the weekend were robust as reviewers were told that it was often difficult to speak to a haematology consultant and in these cases the Royal London Hospital was contacted. Arrangements for liaison with community paediatricians and schools were not explicit in the policy but in practice good liaison was in place. Some patients reported issues around point 'j' with scans not being available for review when they attended a SHC.

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	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	A service level agreement was not required as community staff were employed by the Trust.	N/A	A service level agreement was not required as 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	This standard was met even though the Trust was not a specialist centre.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	N	Although the Trust was not an SHC at the time of the visit, this Quality Standard was applicable as they did enter patient's details onto the National Haemoglobinopathy Register (NHR). 63% of patients were registered on the NHR with 53 annual reviews completed and five adverse events reported. Some of the patients who were interviewed during the visit were not aware of the National Haemoglobinopathy Registry. It was not clear if these patients had consented and had forgotten or if they had not been made aware of the Registry.	N	Although the Trust was not an SHC at the time of the visit, this Quality Standard was applicable as they did enter patient's details onto the National Haemoglobinopathy Register (NHR). Some of the patients who were interviewed during the visit were not aware of the National Haemoglobinopathy Registry. It was not clear if these patients had consented and had forgotten or if they had not been made aware of the Registry.
HN-702 All	**Annual Data Collection - Activity** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y	Good work was being done on 'Did Not Attend' rates.	Y	

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

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	N	Audits were not available for points 'l' and 'i'.	Y	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-705 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	Y	Two network audits had been undertaken.	Y	
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	This standard was met even though the Trust was not a specialist centre.	Y	This standard was met even though the Trust was not a specialist centre.
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	Although the Trust was not an SHC at the time of the visit, this Quality Standard was applicable as they did carry out Trans-Cranial Doppler ultrasound. The QS was not met ('b' and 'd' were not met) but the Trust had plans in place to improve compliance.
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	

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Document control was not evident on all documents and some guidelines lacked dates for release and expected updates.	N	Document control was not evident on all documents and some guidelines lacked dates for release and expected updates.

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Compliance with network Quality Standards is as found at this Trust review visit. The report will be re-issued with final network compliance when all SHCs and A-LHTs in the network have been reviewed.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Network mechanisms for involving patients and carers were not yet in place.	N	Network mechanisms for involving patients and carers were not yet in place.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	N	Network leads had not yet been identified.	N	Network leads had not yet been identified.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-204 and HN-205.	N	A network programme of education and training was not yet in place.	N	A network programme of education and training was not yet in place.
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		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	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.
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.	Y		Y	
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.	Y		Y	

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	A policy was not yet in place and a list of research trials was not available to patients.	N	A policy was not yet in place and a list of research trials was not available to patients.
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

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular: a. Designated SHC/s for the care of people with with sickle cell disease b. Designated SHC/s for the care of adults with thalassaemia c. Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia d. Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	Y	Points 'a' and 'b' were not applicable as the Trust was not a SHC.	Y	Points 'a' and 'b' were not applicable as the Trust was not a 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	Y		Y	

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	Commissioner's attendance at the network review and learning meetings was not yet in place. Commissioners had attended the annual service user's conference.	N	Commissioner's attendance at the network review and learning meetings was not yet in place. Commissioners had attended the annual service user's conference.

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