WM QRS West Midlands Quality Review Service

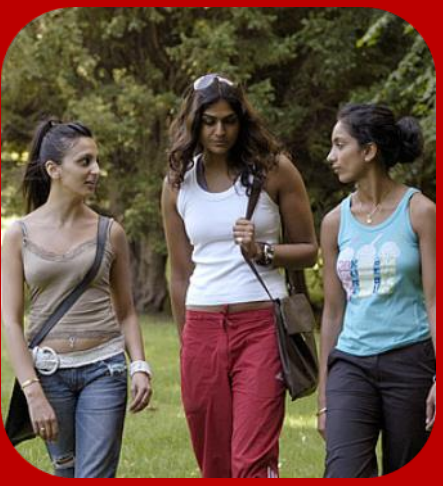
UK Forum on Haemoglobin Disorders

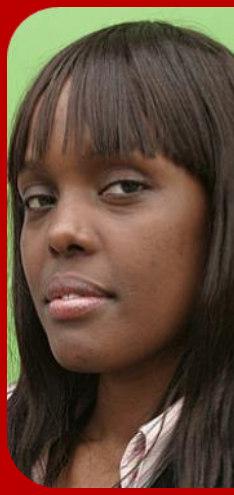
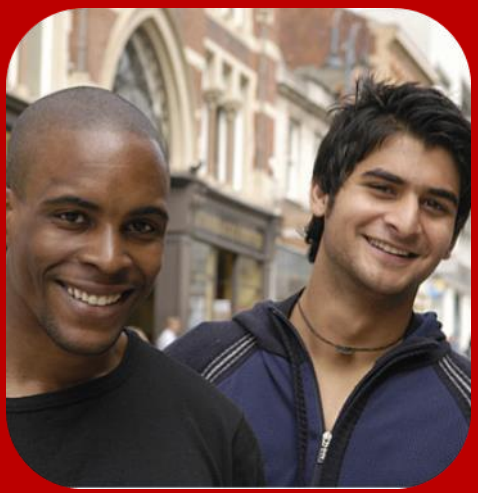
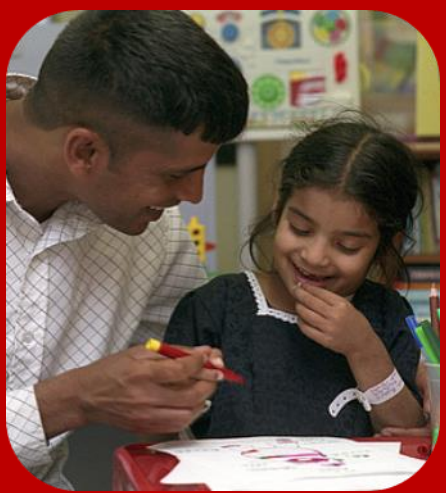
Health Services for People with Haemoglobin Disorders

East London Network

Homerton University Hospital NHS Foundation Trust

Visit Date: 20th January 2015 Report Date: April 2015



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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Homerton University Hospital NHS Foundation Trust (part of the East London Network), which took place on 20th January 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014 which were developed by the UK Forum on Haemoglobin Disorders working with the West 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:

- Homerton University Hospital NHS Foundation Trust
- NHS England: Specialised Cancer and Blood
- City and Hackney Clinical Commissioning Group

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

Acknowledgements

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

About West Midlands Quality Review Service

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

HAEMOGLOBIN DISORDERS SERVICES IN EAST LONDON NETWORK

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long term red cell transfusions
Homerton University Hospital NHS Foundation Trust	SHC	322	21	46

At the time of the review Homerton University Hospital NHS Foundation Trust was part of the East London Network with Barts Health NHS Trust and Barking, Havering and Redbridge University Hospitals NHS Trust. The Trust provided services for adults with haemoglobin disorders.

HOMERTON UNIVERSITY HOSPITAL NHS FOUNDATION TRUST

ACCESS TO ADVICE

Patients could access specialist advice during working hours from the community centre and medical day unit. Out of hours specialist advice for clinical staff was available via the on call haematology consultant between 5pm and 9am Monday to Friday and 24 hours a day on Bank Holidays and weekends. A 24 hour helpline for patients (funded by the Clinical Commissioning Group (CCG)) had commenced in January 2015. This was run by medical and nursing staff from the clinical team on a seven week rolling rota. Two planning and assessment nurses supported the helpline, undertaking patient follow up and homecare.

EMERGENCY DEPARTMENT

Emergency Department attendances by people with haemoglobin disorders averaged 49 attendances per month over the period January to November 2014, with a range from 62 in August 2014 down to 30 in October 2014.

IN-PATIENT CARE

In-patient facilities consisted of Lloyd Ward, a 28 bed acute medical ward shared with endocrinology and metabolic medicine, with patients admitted from either the Emergency Department (ED) or Medical Day Unit (MDU). If no beds were available on Lloyd Ward patients were admitted to the Acute Care Unit (ACU) and then transferred to Lloyd Ward as soon as possible. Nurses on both Lloyd Ward and the ACU were trained in the care of patients with haemoglobin disorders. In 2014 there were 428 in-patient episodes for patients with haemoglobin disorders with a mean length of stay of 6.8 days and a total of 2,899 bed days. Re-admission rates for January to November 2014 were 120 within 30 days (28%), 58 within seven days (13.5%) and eight within 24 hours (1.9%).

OUT-PATIENT CARE

Two consultant led out-patient clinics were held each week, a general haemoglobinopathy clinic on a Tuesday morning and an annual review clinic on a Friday afternoon. The 'did not attend' rate for the general clinic in January to November 2014 was 18% and 51% for the annual review clinic. Eighty eight annual reviews were carried out between January and November 2014, compared with 125 from January 2013 to December 2013. Only around 20 annual reviews had been entered onto the National Haemoglobinopathy Registry (NHR) between April 2014 and January 2015.

DAY UNIT CARE

The Medical Day Unit (MDU) had four beds and five chairs reserved for patients with sickle cell disease and other haemoglobin disorders. The MDU was open Monday to Friday 9.00am to 7.00pm and was staffed by five nurses. One of the doctors from the haemoglobinopathy team was assigned to the MDU at all times.

Patients could attend for a planned appointment or could 'drop-in' if they were feeling unwell. Patients could also either self-refer or request a GP referral for review by a member of the haemoglobinopathy team. Patients were also transferred to the MDU from the ED for assessment and management. In the period from January to November 2014 there were 2,496 attendances at the MDU by patients with haemoglobin disorders, an increase of 254 attendances from the previous year (January to November).

SUPPORT SERVICES

A range of support services was available including access to psychology (provided as part of the multi-disciplinary team) or via self-referral to community psychology services. Mental health services worked in collaboration with the psychology services and patients assessed by the team psychologist could be referred onwards if necessary.

Physiotherapy services were also provided as part of the multi-disciplinary team with patients able to self-refer to the Wednesday afternoon session and the specific programme 'Living well with sickle cell and thalassaemia'. Occupational therapy was also part of the 'living well' programme.

Educational sessions were run on alternate weeks covering topics such as food fortification, sleep workshops, employment and self-management. The service also provided alternative therapies such as massage, acupuncture and aromatherapy massage to help patients manage chronic and acute pain. The service had plans to expand this programme and to include patients under the age of 16 years.

TRANSFUSIONS

At the time of the visit 46 patients were on a regular blood transfusion programme. Six were receiving regular top-up transfusions and 39 were receiving regular exchange transfusions, nearly all of which were automated red blood cell exchange transfusions.

VIEWS OF SERVICE USERS AND CARERS

Service users' and carers' views were influencing the service in the following way:

a. The local Health Watch had run a survey, using a comprehensive questionnaire developed by the haemoglobinopathy service. Over 70 patients had responded.

b. The service had run a 'patient event' in 2014 and a further event was panned for 2015.

c. Reviewers met patients who were on the day unit for transfusions or pain relief on the day of the visit.

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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 reissued including final compliance with network Quality Standards and a section on network-related issues.

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SPECIALIST TEAM: HOMERTON UNIVERSITY HOSPITAL NHS FOUNDATION TRUST

General Comments and Achievements

This service demonstrated many improvements and developments since the previous peer review in January 2013 and had responded in a very positive and often innovative manner to the issues raised at that visit. The Lead Consultant and Lead Nurse were both dedicated to holistic care and were working well with the rest of the team to deliver service improvements.

A comprehensive patient survey had recently been developed and run by the local *Health Watch*. More than 70 patients had responded to the survey. At the time of the visit results had been analysed but a response had not been developed. The specialist team planned to review the results and feedback any actions taken via their regular monthly patient meetings and quarterly newsletter.

Nurse led clinics for patients on hydroxycarbamide and iron chelation therapy were available and effective use of automated exchange blood transfusion therapy had led to a decrease in hospital admissions. Comprehensive training programmes for both medical and nursing staff in the day unit, wards and Emergency Department were in place.

Social media, including active Facebook and Twitter accounts, was used to contact and update patients for such things as upcoming massage or training sessions and for sending reminders, such as about getting a flu jab.

Research output from the department included several recent papers and abstracts and engagement in international commercial trials was also being planned.

Progress Since the Last Visit

1 A multi-disciplinary approach had addressed the issue of multiple, unplanned attendances of patients with Sickle Cell Disease for management of chronic pain with parenteral opiates. This included a transitional programme of decreasing opiate use and restriction of day unit attendances.

2 A monthly haematology-obstetric clinic had been set up in 2014 and all pregnant women with sickle cell disease (SCD) were seen regularly in this clinic. There was also access to a renal clinic and a renal physician with an interest in SCD at Homerton University Hospital NHS Foundation Trust.

3 Referral guidelines and pathways had been improved and the link to Barts Health NHS Trust for supra-specialist care had been consolidated. This included the transition service and a regular transition clinic for young patients living locally to Homerton Hospital was held at The Royal London Hospital (Barts Health NHS Trust) and attended by one of the Homerton University Hospital NHS Foundation Trust consultants. These patients were then offered follow-up appointments in the adult service at Homerton Hospital. Transition leaflets and guidelines were available and were shared with Barts Health NHS Trust.

Good Practice

1 The 'Home Care Hospital Avoidance' strategy was an innovative way of supporting patients in the community. This included the 24 hour helpline, easy access to the day unit and a specialist team for hospital avoidance, implementation was helped by good engagement with the local Clinical Commissioning Group.

2 'Living Well with Sickle Cell Disease and Thalassaemia' sessions were run on a weekly basis and included physiotherapy, alternative therapies and educational sessions. This holistic approach to care was highly valued by patients.

3 Multi-disciplinary meetings were held fortnightly and included Emergency Department staff. They provided excellent governance and demonstrated thorough discussion of patient complaints.

4 Individualised care protocols were available for all patients and were easy to access in all areas of the hospital.

5 Engagement of local GPs with the service was actively encouraged. A recent survey of GPs had been completed and a GP with a Special Interest in Haemoglobinopathies (GPwSI) practised locally and was working with the specialist team to deliver education in the community.

Immediate Risks: No immediate risks were identified.

Concerns

1 Although guidelines for the management of thalassaemia had been developed since the last visit the review team was concerned about the following aspects of the care of patients with thalassaemia:

   a. The small number of transfusion dependent thalassaemia patients (<5) may benefit from annual review at a specialist thalassaemia centre.

   b. Guidelines for thalassaemia were brief and some aspects did not follow standard practice in other areas. Liaison with a specialist centre to standardise guidelines may be of benefit.

   c. Information leaflets for patients with thalassaemia were brief and some were out of date.

2 Patients with haemoglobinopathies were not reviewed by senior haematology decision makers over the weekend or Bank Holidays. Patients admitted on Friday evening were not seen by the haematology team until Monday morning.

Further Consideration

1 The Lead Consultant and deputy were both locum posts at the time of the visit. The Trust had advertised the posts but the recruitment process was on hold. These posts were essential for the long-term support and development of the service.

2 Automated red cell exchanges were not available outside normal working hours and emergency manual red cell exchanges could only be performed on the Intensive Therapy Unit.

3 Despite good engagement with Emergency Department (ED) staff and evidence of frequent staff training, the recent audit of 'time to analgesia' showed only 37% of patients received analgesia within 30 minutes. This was a recent audit and results had not yet been shared with ED staff at the time of the visit.

4 The majority of guidelines were in place and were readily accessible but some were in need of updating and described outdated practice. There were plans to update the Sickle Cell Handbook which contained most of the guidelines during 2015.

5 Data were routinely being collected by senior medical staff. This was not an appropriate use of their time and a data manager or further administrative support should be considered.

6 At the time of the visit care plans and annual reviews were not being shared with patients routinely. Reviewers suggested that further consideration should be given to how this could be done.

7 The pathway for 'did not attend' patients was not presented in the service organisation policy and may benefit from clarification.

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COMMISSIONING

General Comments and Achievements

The local Clinical Commissioning Group was involved with the service and had supported service developments including the 'Hospital Avoidance Team'. The specialist commissioner had commented on the relevant Standards but did not attend the peer review visit. It was therefore not possible to ask about network arrangements. The Trust was recognised as a Specialist Haemoglobinopathies Centre (SHC) but it was not clear if links with local district general hospitals or other SHCs were in place. At the time of the visit the Trust was part of the East London Network but there was a lack of clarity about how the network functioned and which local hospitals linked to the Trust.

Progress Since the Last Visit

The organisation and delivery of services within the East London network was under consideration at the time of the last review in January 2013. Progress had been made by Clinical Commissioning Group commissioners but not yet by specialist commissioners.

Concerns

1 None of the commissioning Standards were met at this visit and specialist commissioners did not appear to be engaged with this service or with others in the network.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead:

Dr Jo Howard	Consultant Haematologist	Guy's and St Thomas' NHS Foundation Trust

Visiting Team:

Dr Wale Atoyebi	Consultant Haematologist	Oxford University Hospitals NHS Trust
Verna Davis	Nurse Manager	Central Manchester University Hospitals NHS Foundation Trust
Roanna Maharaj	Service User	
Dr Asa'ah Nkohkwo	Patients & Public (PPE) Advocate	Independent Adviser
Barry O'Neill	Local Service Specialist, Specialised Commissioning – (East Midlands)	NHS England
Kalpna Sokhal	Service User	
Rhonda Skeete	Specialist Nurse	Croydon Health Services NHS Trust

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

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

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services	44	34	77
Network	9	4	44
Commissioning	3	0	0
Total	**56**	**38**	**68**

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	
Ref	**Quality Standard**	**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	Some of the information was several years old and out of date. There was minimal information for patients with thalassaemia.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
HN-102 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	Little up to date information was available for patients with thalassaemia.
HN-103 All	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service	N	Written information for 'b', 'c' (for hydroxycarbamide) and 'd' was not yet in place.

		Adult Service	
Ref	**Quality Standard**	**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).	N	Patients were not offered a copy of their care plan. The care plans were of a very high standard and easily accessible by clinical staff in the areas visited by reviewers.
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	
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	Excellent information (shared with Barts Health NHS Trust) was available.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
HN-107 SHC	**Information about Trans-Cranial Doppler Ultrasound** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated	N/A	
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	There was extremely good evidence of patient and carer involvement included a patient survey, patient conference and monthly support group meetings. The Chief Executive met sickle patient groups every six months and changes as a result of patient involvement were fed back to patients via the support group and a quarterly newsletter. See main report.
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	At the time of the visit this was a locum post. See main report.
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y	At the time of the visit this was a locum post. See main report.

		Adult Service	
Ref	**Quality Standard**	**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	
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 Clinical Psychologist had recently left but a replacement has been appointed and there were adequate arrangements for cover.
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 comprehensive training plan was in place which included haemoglobinopathy training on induction for ward nurses.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**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	
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	Documentation was not clear but staff in the Emergency Department described a comprehensive training plan.
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	
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	Although the haematology Specialist Registrar did not attend haemoglobinopathy outpatient clinics, they gained plentiful inpatient and day unit experience. They also gained outpatient haemoglobinopathy experience elsewhere in the rotation.
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	
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	Medical staff collected the majority of data and entered data into the National Haemoglobinopathy Registry (NHR).

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.	Y	There were very good links with the leg ulcer service. Physiotherapy was an integral part of the 'Living Well' programme.
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	

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	N	There was no access to pre-implantation genetic diagnosis. In view of the small numbers of transfusion dependent thalassaemia patients the service should consider referring thalassaemic patients to specialist cardiology and endocrinology clinics.
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	
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	Facilities were good, especially in the day unit.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	Extended hour access to the day unit was available and a 24 hour helpline was in place. There was no weekend availability of transfusion although clinicians said the local population did not request this. Reviewers suggested it may be helpful specifically to discuss this issue with the patient group.
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	Good guidelines were available. See main report.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	N	The National Haemoglobinopathy Registry (NHR) checklist was used for annual review.
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	

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
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 Sickle Handbook was out of date. The protocol for automated exchange was separate to this. The recommendations for haemoglobin targets in thalassaemia required clarification.
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	Guidelines were available but some of the recommendations were outside standard practice in other units and required updating.

		Adult Service	
Ref	**Quality Standard**	**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	Y	Some of these guidelines were out of date. For example the acute pain guideline was written before the National Institute for Health and Care Excellence (NICE) guideline so this was not included. The sickle cell handbook contained an acute pain crises guideline which fulfilled the NICE acute pain crises recommendations. Reviewers suggested that the guidelines should also include references and contact details for specialist services.
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	
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 were not in place for endocrinopathies ('f'), neurological complications ('g') or liver disease ('l'). Others guidelines were in place although some were out of date. The guidelines should also include references and contact details for specialist services.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y	

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
HN-510 All	**Thalassaemia Intermedia** Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	N	Guidelines were not in place for 'c'.
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	The handbook and other guidelines were easily available on line or as paper copies throughout the Trust.
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	

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

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
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	
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	
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	Almost all patients were registered on the National Haemoglobinopathy Registry (NHR) and adverse events were also being entered. Small numbers of annual reviews had been done previously. At the time of the visit these were being done systematically and this practice appeared to be embedded.
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	

		Adult Service	
Ref	**Quality Standard**	**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	Data were collected separately at each site and discussed at network meetings.

		Adult Service	
Ref	**Quality Standard**	**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 for points 'i', 'j' and 'k' were not yet undertaken and there was no evidence for 'd' and 'e' after 2012.
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 audits had only recently been discussed.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
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	
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	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	Some guidelines were still going through the governance process. There had been no meeting for the previous two months.

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adult Service	
Ref	**Quality Standard**	**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	No mechanisms for the involvement of patients and carers were in place.

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

		Adult Service	
Ref	**Quality Standard**	**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 wide 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	
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	There was no rolling programme of audit in place.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	There was no agreed policy on access to research in place.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
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	

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COMMISSIONING

		Adult Service	
Ref	**Quality Standard**	**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 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 information available relating to the Trust's Specialist Haemoglobinopathy Centre (SHC) designation. It was not clear who were the other local teams and linked providers to the Trust. The local commissioners were very engaged with the service and had funded outreach posts, undertaken a GP survey looking at the care and management of pain for patients, appointed a GP with Special Interest for haemoglobinopathies and helped to put an admissions avoidance scheme in place.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**
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	Quarterly meetings with clinical staff from the staff were in place but not any formal clinical quality review meetings.
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	The commissioner did not attend these meetings.

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