WM QRS West Midlands Quality Review Service

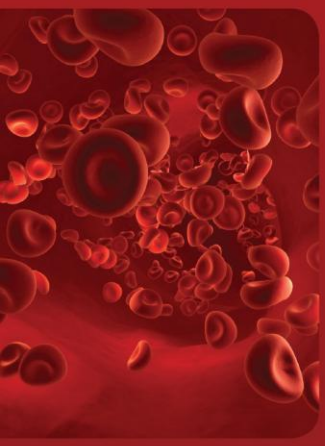
UK Forum on Haemoglobin Disorders

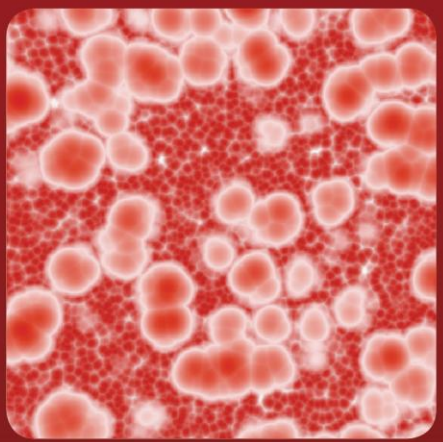
Health Services Caring for Adults with Haemoglobin Disorders

North Middlesex

North Middlesex University Hospital NHS Trust

Visit date: November 21st 2012 Report Date: April 2013




NHS

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INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia the North Middlesex Network, in particular the North Middlesex University Hospital NHS Trust, which took place on November 21st 2012. The purpose of the visit was to review compliance with the '*Quality Standards for Health Services Caring for Adults with Haemoglobinopathies',* 2011. The visit was organised by the West Midland Quality Review Service and supported by the UK Forum on Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Programme.

ACKNOWLEDGEMENTS

We would like to thank the staff of North Middlesex University Hospital 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.

ADULT HAEMOGLOBIN DISORDERS SERVICES IN NORTH MIDDLESEX NETWORK

Trust Name	Hospital/s	Abbrev-iation	Reviewed as:	Abbrev-iation
North Middlesex University Hospital NHS Trust	-	NMUH	Specialist Haemoglobinopathy Team (SHT)	SHT
Cambridge University Hospitals NHS Foundation Trust	Addenbrooke's Hospital, Cambridge	-	Local Haemogobinopathy team	LHT
Norfolk and Norwich University Hospitals NHS Foundation Trust	-	-	Local Haemoglobinopathy team	LHT
Barnet and Chase Farm Hospitals NHS Trust	-	-	Linked hospital	
Princess Alexandra Hospital NHS Trust	-	-	Linked hospital	
East and North Hertfordshire NHS Trust	The QEII Hospital, Welwyn Garden City	QEII	Linked hospital	

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
North Middlesex University Hospital NHS Trust	SHT	650	38	30 thalassaemia major 25 sickle cell disease
*Cambridge University Hospitals NHS Foundation Trust	LHT	31	<5	
*Norfolk and Norwich University Hospitals NHS Foundation Trust	LHT	20	<5	

* these clinics included small numbers of patients from each of Bedford, King's Lynn, Ipswich, West Suffolk, Great Yarmouth

NETWORK

The specialist team at North Middlesex University Hospital NHS Trust (NMUH) supported clinical activities at a number of linked hospitals over a wide geographical area, including Barnet and Chase Farm Hospitals NHS Trust in North London and the Princess Alexandra Hospital NHS Trust in Harlow. Other Trusts in the East of England linked to NMUH were Cambridge University Hospitals NHS Foundation Trust (which included patients sent from Bedford) and Norfolk and Norwich University Hospitals Foundation Trust (which included patients from Ipswich and King's Lynn). The Specialist Haemoglobinopathy Team (SHT) at NMUH also worked with East and North Hertfordshire NHS Trust predominantly with children with haemoglobinopathy disorders.

The consultants at NMUH held honorary contracts with Addenbrooke's Hospital which covered the quarterly adult and paediatric outreach clinics that were established there for the care of approximately 30 patients.

Norfolk and Norwich Hospital had around 20 patients and a formal adult outreach clinic was in place that had run twice yearly since April 2012. A bi-monthly paediatrics clinic was held at The QEII Hospital, Welwyn Garden City. Paediatric and adult outreach clinics at Princess Alexandra Hospital NHS Trust, Harlow were planned but at the time of the visit patients were seen at NMUH. Network patients were seen at least annually for their review, and at other times according to clinical needs.

All the linked hospitals had shared clinical guidelines and access to the specialist haemoglobinopathy team for clinical advice at all times – by telephone for urgent matters and e-mail for less urgent enquiries. Guidelines included a list of clinical indications for contacting NMUH.

SPECIALIST TEAM: NORTH MIDDLESEX UNIVERSITY HOSPITAL NHS TRUST

North Middlesex University Hospital was a 400 bedded acute hospital in Edmonton. North London. It had a large and comprehensive specialist service for people with sickle cell disease or thalassaemia, which had grown and developed over more than 25 years. The centre provided all aspects of care except fertility, bone marrow transplant and certain clinical specialty appointments or investigations which were provided elsewhere in London.

The team had two consultant haematologists with an interest in haemoglobinopathy disorders, one of whom was predominantly paediatric but provided transitional care and cover for adult patients. They were supported by a transfusion practitioner, a clinical nurse specialist (CNS) and the community team based at the George Marsh Centre. A clinical psychologist also provided support. The laboratory lead provided support for data management.

At the time of the visit 450 children and adult patients had been entered into the National Haemoglobinopathy Registry (NHR). In 2011/12, there were 979 non-elective admissions with an average length of stay of 2.9 days.

Accident and Emergency

Patients with acute sickle cell disease or thalassaemia complications attended the Accident and Emergency Department (A&E) initially with the exception of a small cohort of patients who attended the Ambulatory Care Centre. Individualised care plans for pain management were available for most patients and were held on the hospital patient information system (CIP). Those without plans were managed according to their choice of the options listed in a generic protocol. All patients were admitted straight to the care of the haematology team. In normal working hours, patients were admitted by the haematology trainees. Out of hours, they were admitted by a specialist medicine trainee covering Haematology, Oncology and HIV. Haematology trainees and a haematology consultant were available at all times on call. The red cell consultants did not take leave at the same time, so that one was always available to advise on patients locally and across the network.

An Ambulatory Care Unit opened in April 2012 for a small cohort of frequent attenders to A&E. Patients attended directly avoiding the need to go to A&E and remained in this facility for up to eight hours.

Out-patient and Day Case Facilities

Clinics were held in the new out-patients department. Two dedicated adult red cell clinics were held per week on Tuesdays, running continuously from 2 pm to 8 pm or later. Approximately 25 patients usually booked for the afternoon, and up to 10 for the evening clinic.

The clinic was staffed by the consultant and supported by a haematology trainee and the acute clinical nurse specialist (CNS). The Transfusion Practitioner also attended this clinic and saw regularly-transfused patients on the months they did not require a clinical review . Other medical staff were encouraged to attend for training

purposes. Teenagers and young adults up to the age to 25 years had priority booking once a month, in an afternoon and evening clinic run by the paediatric haematology consultant.

Annual reviews were undertaken in the clinic, following a pre-printed proforma, National Haemoglobinopathy Registry consent and entry were also undertaken. Clinic letters were copied to all patients and to linked hospital consultants if applicable.

Once every three months, there was a 'family clinic', held in paediatric out-patients, at which parents and children who have sickle cell disease attended together to save multiple visits.

A seven-station dedicated Red Cell Day Unit was staffed by an experienced lead nurse and a regular healthcare support worker. The unit opened every Thursday and Friday 9 am to 9 pm with some flexibility for finishing times and alternate Saturdays 9 am to 5 pm. Additional elective or semi-elective red cell exchange transfusions, immunisations, and bisphosphonate infusions were also undertaken on this Unit. The lead nurse undertook manual exchange transfusion but automated transfusion for NMUH patients was performed by the apheresis service at University College London Hospitals NHS Foundation Trust (UCLH).

A home transfusion service was available for a few patients and it operated from the Red Cell Day Unit.

A multi-disciplinary meeting was held monthly. One hour was spent discussing any patients of concern to any of the team followed by two individual case conferences to which the patient and carers were invited, which lasted for an hour each.

In-Patient Facilities

In-patients were admitted to Medical 1, the haematology ward. An average of approximately ten adults with haemoglobin disorders were in-patients at any one time and admission to outlying wards was common, due to bed pressures. All in-patient were managed by the haematology team wherever they were in the hospital.

The five consultant haematologists at NMUH practiced a bi-monthly rotating 'ward attending system'. Ward rounds were held twice weekly and were preceded by a meeting in which all the patients were discussed with the whole team, so that the red cell specialist consultants were available to advise on the care of all in-patients with these disorders, seeing them as necessary for complicated presentations. Between ward round days, the attending consultant saw any patients who were 'sick', and any new admissions; a local standard was for all admission patients to be seen by a consultant within 24 hours of arrival.

A Critical Care Outreach Team covered 8 am to 8 pm Monday to Friday but it was planned to increase to a 24 hour service, with an eleven bedded Progressive Care Unit and nine bedded Intensive Care Unit.

Any deaths and critical care episodes were discussed at morbidity and mortality sessions, which formed part of the weekly departmental teaching schedule. Mortality review sheets were submitted centrally to the Medical Directors office to allow any learning from the reviews to be communicated across other clinical teams.

Community Services

A team of five whole time equivalent nurse specialists were employed by NMUH and worked from the George Marsh Centre, which was based three miles away at St Anne's Hospital. They offered an outreach home pain assessment and treatment service which was available five days a week. Plans were in place for a daily service when the team was fully staffed. The service was also able to give ongoing medication to patients after discharge, thereby reducing hospital stays. At the time of the review visit this service had approximately 100 registered patients, about a quarter of whom were frequent users. A comprehensive operating policy for this service was in place that had been approved by the Care Quality Commission. The Centre also provided support for patients within the community.

The service did not have an allocated social worker and patients were signposted to Haringey social services.

The George Marsh Centre also offered specialist antenatal genetic counselling for North Middlesex, Chase Farm, and Barnet. It managed the results of the newborn screening programme. There was an active programme of teaching and training.

User Feedback

The review team met with a group of patients with sickle cell disease and thalassaemia.

LOCAL TEAMS

A member of the team spoke to a haematology consultant from Cambridge University Hospitals NHS Foundation Trust, Addenbrooke's Hospital, Cambridge and one from Norfolk and Norwich University Hospitals NHS Foundation Trust.

REVIEW VISIT FINDINGS

NETWORK

General Comments

Good progress was being made towards a network with a designated specialist centre and common protocols. There was a comprehensive policy for referral to the specialist centre. The majority of patients were seen either at the centre or in outreach clinics. There was evidence of annual network meetings over the previous four years at which mortality and complex cases were reviewed as well as the outcomes of paediatric peer review. These were well attended and inclusive of the entire network.

SPECIALIST TEAM: NORTH MIDDLESEX UNIVERSITY HOSPITAL

General Comments / Achievements

NMUH had a large clinical workload particularly of patients with sickle cell disease. The red cell team appeared cohesive with committed and inspirational leadership. Patients were unanimous in their praise for the entire haematology team. The Red Cell Day Unit, in particular, was considered to be a great improvement and all members of the team were very much appreciated by the patients. The care given was patient-focused with individualised protocols for most patients and arrangements for transfusion and community pain management, which were responsive to patients' individual needs. Audit of pain management in the A&E showed that over 80% of the patients received analgesia within the target of 30 minutes recommended by NICE. The red cell facility was comfortable and transfusion arrangements were efficient with audit data showing that the majority of patients reached the target waiting time of less than 20 minutes.

Governance arrangements for the service were particularly strong with regular audits, multi-disciplinary team meetings as well as morbidity and mortality reviews. Patient feedback and involvement was taken seriously in the delivery of the service.

A cohort of patients with sickle cell disease had high levels of dependency on acute hospital services although representing less than 10% of all patients. The team had developed pragmatic ways to manage this with the recent employment of a psychologist, an acute CNS, a pilot ambulatory care service and a popular community outreach pain team. Some patients expressed a desire for the ambulatory care service to be made available to more patients, thereby avoiding the need to attend A&E.

There was a comprehensive training programme for all levels of staff.

Good progress had been made towards entry of patients into the National Haemoglobinopathy Register and formally documented annual reviews.

Patients reported that the patient focus group, held at the hospital, was effective and they felt they were involved in planning the service.

Good Practice

There were many examples of good practice:

1 The sticker system in the notes acted as an easily accessible reminder of annual review dates, immunisations and National Haemoglobinopathy Registry (NHR) entry.

2 Thalassaemia summary sheets were comprehensive.

3 The outreach pain service was a good model of community care and was delivered by a highly experienced team of nurses who ensured that the service was safe and sensitive to patient needs.

4 A specific clinic was held for patients in the 15 to 25 year age group.

5 The transfusion practitioner and Day Unit lead nurse ensured a highly efficient service for regularly-transfused patients with flexible arrangements. A home transfusion service was also offered though only a few patients had elected to use this.

6 The day care team was able to offer immunisations.

7 Some patient information leaflets were particularly good:

   a. Leaflet for questions before an outpatient appointment (Generic NHS)

   b. Teens in hospital leaflet

8 A regular focus group for patients was held.

Immediate Risk: No immediate risks were identified.

Concerns

1 There was no dedicated social worker support for the service. This was particularly important for this group of patients with complex medical and social needs who were high 'consumers' of hospital services in an area of social deprivation.

2 Demand for the community pain management service appeared to have outgrown capacity so that access was sometimes limited to existing patients and new patients could not be accommodated.

Further Consideration

1 The community model of increased home care had to compete with other aspects of community care, for example, screening and general patient counselling and support.

2 It may be helpful to review the community outreach pain service in light of increasing demand and to define the aims of the service. Consideration could be given to the quality, convenience and impact on hospital attendances compared with the costs and use of resources.

3 Although there was a good level of NHR entry and support for audits, much of this was done by medical staff assisted by laboratory senior staff. Consideration could be given to providing more data management support.

4 The team could explore alternative ways of working in partnership with primary care and other community services to manage the group of patients with complex care needs who were high users of acute hospital based care at the time of the visit.

5 The sickle cell patients who met the visiting team reported some concerns about the A&E department relating to a lack of privacy on occasions. They reported a variable attitude amongst some of the A&E staff with stigmatisation as drug seeking, a view that was expressed directly to them on occasions. The individual pain protocol was not always followed with some doctors unwilling to prescribe second doses of analgesia without haematology approval. This sometimes led to patients experiencing unacceptable delays. Pathways of management of patients in acute crises should be reviewed to address concerns expressed by patients. This might include exploring expanding day care assessment and treatment to a larger number of patients.

6 Although the clinical protocols were comprehensive in relation to medical care, consideration should be given to incorporating more guidance for nursing staff.

LOCAL TEAMS

General Comment

The consultants from Cambridge University Hospitals NHS Foundation Trust, Addenbrooke's Hospital, Cambridge and Norfolk and Norwich University Hospitals NHS Foundation Trust were very positive about the level of support provided by the specialist haemoglobinopathy team at NMUH. Both hospitals shared clinical guidelines with NMUH and there was a policy in place for discussion and/or transfer of patients to NMUH.

COMMISSIONING

Members of the review team met with a GP commissioner and the London commissioner for haemoglobinopathy services.

The GP considered that NMUH met the needs of the local sickle cell and thalassaemia population and there was prompt follow-up of patients. GPs were given good information from the hospital. The Clinical Commissioning Group would be keen to review the pathway, particularly to try and identify patients who were infrequent attenders to the hospital or those not accessing care.

London Commissioner

The London commissioners were aware of the relatively high rate of admissions for NMUH relative to the total population and the fact that a significant component reflected a very small number of very frequent attenders,

in common with other London services. A project was in place to identify an integrated pathway across a number of disciplines for this group of highly dependent patients.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Kate Ryan	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Central Manchester University Hospital NHS Foundation Trust.
Dr Banu Kaya	Consultant Haematologist	Royal London Hospital
Verna Davis	Nurse Manager	Central Manchester University Hospital NHS Foundation Trust.
Sekayi Tangayi	Service Manager / Nurse Lead and Specialist Nurse	East London NHS Foundation Trust
Ravinder Raj	Information Officer	Sickle Cell and Thalassaemia Support Project,
Patrick Ojeer	Carer Representative	London
Jacqueline Simpson	Service User	Croydon
Elaine Miller	Volunteer Representative	UK Thalassaemia Society
Pip Maskell	Quality Manager	Haemoglobin Disorders Review on behalf of WMQRS

APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

The Quality Standards are in the following sections:

HN - Services for Adults with Haemoglobin Disorders

HY - Haemoglobin Disorders Network (Adults):
Quality Standards for Haemoglobin Disorders Clinical Networks are given separately from those for Specialist Haemoglobinopathy Teams. These Standards are the responsibility of Specialist Haemoglobinopathy Teams but, by agreement, the functions may be delegated to other organisations or coordinating groups.

HZ - Haemoglobin Disorders – Commissioning
These Quality Standards are the responsibility of commissioners.

Each section covers the following topics:

100 - Support for Service Users and their Carers
200 - Staffing
300 - Support Services
400 - Facilities and Equipment
500 - Guidelines and Protocols
600 - Service Organisation and Liaison with Other Services
700 - Governance

NOTE. Different Quality Standards (QSs) are not comparable in terms of their importance or likely impact on the quality or outcomes of the service, and a figure summarising the number of QS's met cannot be used to assess the overall standard of the services provided or to compare this Trust's services with others.

SERVICES FOR ADULTS WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Met Y/N	Comment
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y	However, access to British Sign Language was not specified. See main report for comment on access to social workers.
HN-102 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 and transfusion services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. How to contact the service for help and advice, including out of hours e. Staff of the service f. Community services and their contact numbers h. Relevant support groups g. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns h. How to get involved in improving services (QS HN-199)	Y	A good leaflet regarding hospital appointments was available. Patient information contained explanations that enhanced understanding but 'e' could be clearer.

Ref	Quality Standard	Met Y/N	Comment
HN-103 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, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	Y	However, the evidence for 'a' was brief and there was no travel advice for thalassaemia.
HN-104 All	**Information for Primary Health Care Team** Written information for the patient's primary health care team should be available covering their roles and responsibilities, including: a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Information covering side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on shared care for hydroxycarbamide and iron chelation therapy (if being prescribed by GPs).	Y	
HN-105 All	**Care Plan** All patients should be offered: a. An individual care plan or a written summary of their annual review b. A permanent record of consultations at which changes to their care are discussed	Y	
HN-106 SHT A-LHT	**Transition Information** Information should be available for young people covering arrangements for transition to adult care. This information should cover all aspects of QS HN-501.	Y	The information was commendable, including a specific clinic for teenagers.

Ref	Quality Standard	Met Y/N	Comment
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	Y	All aspects of the service were monitored.
HN-201 All	**Lead Consultant** A nominated lead consultant haematologist 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	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHTs this should be a named deputy within the SHT with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHT. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHT advice and support.	Y	
HN-203 All	**Lead Nurse** A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders.	Y	
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-205 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 b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available.	Y	The evidence presented was comprehensive, however services were fully booked by high dependency patients. The community services were not clear if the role was to avoid hospital admissions only or provide a genuine alternative model. A service review may help clarify the model and whether the staffing levels are adequate.
HN-206 All	**Training Plan** 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-205).	Y	
HN-207 All	**Training Plan – Other Staff** A programme of induction and training covering the care of patients with haemoglobin disorders should be run for: a. Clinical staff in the Emergency Department b. Non-consultant medical staff c. Allied health professionals working with the SHT / LHT (QS HN-301).	Y	
HN-298 All	**Administrative and Clerical Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	Clinical staff provided administrative support. The clerical support was insufficient.
HN-301 All	**Support Services** Timely access to the following services should be available: a. Dietetics b. Physiotherapy c. Occupational therapy d. Leg ulcer service	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-302 All	**Specialist Services** Access to the following specialist staff and services should be available: a. Erythrocytopheresis or manual exchange transfusion (24/7) b. Acute and chronic pain team c. Pulmonary hypertension team d. Consultant obstetrician e. Fertility services f. Consultant cardiologist g. Consultant endocrinologist h. Consultant hepatologist i. Consultant ophthalmologist j. Consultant nephrologist k. Consultant urologist with expertise in managing priapism and erectile dysfunction l. Orthopaedic service m. Psychologist with an interest in haemoglobinopathies n. Specialist imaging o. DNA studies	Y	
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	N	The laboratory services were not CPA accredited according to the evidence seen by reviewers. The hospital's phlebotomy service, which was managed by haematology, had been judged to be too crowded and unsuitable for children. Other services used were satisfactory.
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.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-501 SHT A-LHT	**Transition Guidelines** 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. 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)	Y	
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First out-patient appointment b. Annual review for both sickle cell disease and thalassaemia	Y	
HN-503 All	**Clinical Guidelines: Routine Monitoring** Clinical guidelines on routine out-patient monitoring and management between annual reviews should be in use. Local Haemoglobinopathy Team guidelines should specify the indications for early referral to the Specialist Haemoglobinopathy Team.	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. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-505 All	**Chelation Therapy** Clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. 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 / SHT.	Y	'f' was not applicable.
HN-506 All	**Clinical Guidelines: Acute Complications** 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 **For patients with thalassaemia:** k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	Y	However, the guidelines were medically orientated and had no nursing focus.
HN-507 All	**Emergency Department Guidelines** Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department.	Y	Comprehensive acute pain guidelines were in place but lacked enough direction to A&E staff for patients unknown to the system.

Ref	Quality Standard	Met Y/N	Comment
HN-508 All	**Clinical Guidelines: Chronic complications** 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 Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team.	Y	
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	N/A	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	Y	
HN-511 All	**Thalassaemia Intermedia** 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	

Ref	Quality Standard	Met Y/N	Comment
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	Y	
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 (QS HN-205) and representatives of support services (QS HN-301).	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	The service had an integrated team.
HN-701 SHT A-LHT	**Data Collection** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-702 All	**Ongoing Monitoring** The service should monitor on an ongoing basis: a. Number of patients having acute admission, day unit admission or A&E attendances b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year c. Length of in-patient stays d. Re-admission rate e. DNA rate f. Waiting times for transfusion	Y	
HN-703 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **For patients with sickle cell disease:** a. Proportion of patients with recommended immunisations up to date b. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required c. 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. This audit should cover all hospitals where patients with sickle cell disease may attend. **For patients with thalassaemia:** d. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) e. Proportion of patients who have developed new iron-related complications in the preceding 12 months	Y	
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	Y	
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	

Ref	Quality Standard	Met Y/N	Comment
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months	Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

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	There were no mechanisms for involving patients and their carers from all services in the work of the network.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	Y	
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-205 and HN-206.	Y	

Ref	Quality Standard	Met Y/N	Comments
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	Y	
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-302) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-302) g. Transfer for critical care (QS HN-509) h. Specialist management (QS HN-510) i. Thalassaemia intermedia (QS HN-511) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHTs.	Y	
HY-701	**Annual Meeting** The network should hold a meeting at least annually involving network leads (QS HY-201) and lead consultants and lead nurses for each LHT / SHT in the network (QSs HN-201 and HN-203) to review the network's progress towards achievement of Quality Standards and its implementation of agreed service development plans.	Y	

Ref	Quality Standard	Met Y/N	Comments
HY-702	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Register (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	Y	
HY-703	**Audit** The network should have an agreed programme of audit and review covering, over the whole programme, network-wide achievement of QSs HN-702, HN-703 and HN-704.	N	However, an audit was planned.
HY-704	**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	No discussions had taken place regarding patients and clinical trials.
HY-798	**Review and Learning** The network should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses', especially those involving more than one service within the network.	Y	

COMMISSIONING

Ref	Quality Standard	Met Y/N	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks and, within each network, the configuration of services for people with haemoglobin disorders across each network, in particular: a. Designated SHT/s for the care of adults with sickle cell disease b. Designated SHT/s for the care of adults with thalassaemia c. Accredited LHTs for care of adults 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	Specialised Commissioners were engaged with services across London and were working towards the development of both an acute provider network and a fully integrated pathway of care.

Ref	Quality Standard	Met Y/N	Comments
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by each network, in particular, achievement of QS HY-702 and HY-798.	Y	Clinician and commissioner meetings were established to review care and to support service improvements. Minimum data sets were established for the collection of data to enable monitoring of outcomes across London providers. Minutes of these meetings were available.