

Health Services for People with Haemoglobin Disorders

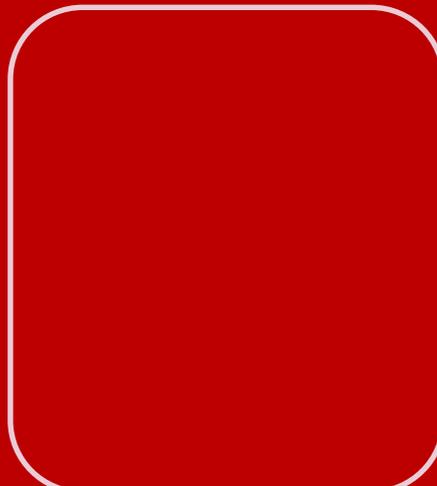
North West London Network

London North West Healthcare NHS Trust

Visit Date: 15th October 2015

Report Date: V2 June 2016

Images courtesy of NHS Photo Library



INDEX

Introduction	3
Haemoglobin Disorders Services in North West London Network	4
Review Visit Findings.....	6
Network	6
Specialist Team: London North West Healthcare NHS Trust Services for Adults, Children and Young People	8
Commissioning	10
Appendix 1 Membership of Visiting Team.....	11
Appendix 2 Compliance with the Quality Standards.....	12
Specialist Services for People with Haemoglobin Disorders	13
Haemoglobin Disorders Clinical Network.....	39
Commissioning	43

Document Control:		
No.	Date	Change
V1	21.4.2016	N/A
V2	8.6.2016	Revised document issued correcting some inaccuracies in V1.

Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in London North West Healthcare NHS Trust (part of the North West London Network), which took place on 15th October 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 Midlands 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:

- London North West Healthcare NHS Trust
- NHS England Specialised Commissioning
- NHS West London, Central London, Ealing, Hounslow, Hillingdon, Brent, Harrow and Luton Clinical Commissioning Groups

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

About West Midlands Quality Review Service

WMQRS is a collaborative venture between 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 NORTH WEST LONDON NETWORK

At the time of the visit London North West Healthcare NHS Trust was part of the North West London Network which also included Imperial College Healthcare NHS Trust both of which were Specialist Haemoglobinopathy Centres.

Adults

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
London North West Healthcare NHS Trust (Central Middlesex Hospital, Ealing Hospital and Northwick Park Hospital)	SHT	266	19	32

Children and Young People

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
London North West Healthcare NHS Trust (Central Middlesex Hospital, Ealing Hospital and Northwick Park Hospital)	SHT	170	15	21

EMERGENCY CARE

All adult acute reviews were organised through the refurbished Emergency Department (ED) at Northwick Park Hospital (NPH). These facilities were of a high standard. Following initial triage patients were fast-tracked for review by the ED medical team. The haematology team was primarily responsible for patient care but were supported by the general medical teams. The out of hours haematology specialist registrar, who was resident until 9pm, was called to assess and admit the patient if necessary. Sometimes patients were fast-tracked to the medical admissions unit on Carroll Ward where initial management commenced. The day unit area at Central Middlesex Hospital (CMH) had the facility to see the patients in pain and some of these patients were managed as day cases. The distance between the hospitals meant that unless patients presented early and settled rapidly this facility was of limited use. Only a small number of patients had their pain managed in this way.

Acute reviews of children were organised through the refurbished dedicated paediatric ED at NPH. These facilities were of a high standard. Following initial triage children were seen by the paediatric team in ED. There was paediatric consultant presence on site until 10pm. The attending paediatric team was primarily responsible for patient care but the haematology specialist registrar or the consultant haematologist was available for consultation and would review patients as required.

IN-PATIENT CARE

Adults requiring admission were preferentially admitted to the acute admissions unit, Carroll Ward, at NPH. This was designed as a short-stay acute general ward with 22 beds in use at the time of the review. Many nurses with experience in managing acute sickle cell disease complications who had worked at CMH previously had relocated to this ward. Patients were reviewed by the haematology specialist registrar or a red cell

consultant haematologist daily. Medical support out of hours was provided by the haematology specialist registrar who was resident until 9pm. Out of hours specialist support was provided by the haematology consultants on a non-malignant haematology 1:4 on call rota.

Children requiring admission were admitted to the refurbished children's ward, Jack's Place, at NPH. This was an acute general paediatric ward that had a 24-bed capacity, though plans were in place to expand to 27 beds. Consultant paediatrician support was available every day with the attending paediatric team primarily responsible for patient care. The lead paediatric consultant and lead haematologist were available for consultation and reviewed the patient as required. In-patient activity was low although some patients attended St Mary's Hospital for acute care but remained at Central Middlesex for out-patient care. The play room was of an exceptional standard and the needs of adolescents were met with a dedicated room. A play specialist was available from Monday to Friday between 9am and 5pm. Out of hours specialist support was provided by the haematology consultants on a non-malignant haematology 1:4 on call rota.

DAY UNIT

Adult patients used the Medical Day Care Unit at Central Middlesex Hospital which was modern and spacious with adequate provision for transfusions and day case pain management. Patients reported no concerns accessing the day unit facility.

A well-established paediatric day care service for children on long-term transfusions was provided. A play specialist was available from Monday to Friday between 9am and 5pm. Daily paediatric medical cover was in place with access to specialist haemoglobinopathy advice and review as required.

OUT-PATIENT CARE

Adult out-patient clinics were run weekly from the Haematology Department at CMH. Three clinical rooms and an office used by the clinical psychologist were available for the consultations. Clinics were attended by the multi-disciplinary team consisting of a clinical psychologist, a consultant haematologist, a specialist registrar and a specialist nurse, a consultant paediatrician and a paediatric registrar. Support from a social worker was available if required.

Paediatric out-patient clinics were run from the Rainbow Children's Unit at CMH. Four clinical rooms were available for the consultations. Clinics were attended by the multi-disciplinary team consisting of a clinical psychologist, a consultant haematologist, a specialist registrar and a specialist nurse. Support from a social worker was available if required. A multi-disciplinary outreach clinic was held at Bedford Hospital twice a year.

COMMUNITY-BASED CARE

The Brent Sickle Cell and Thalassaemia Centre was integrated within the Central Middlesex Hospital site and provided support for children and adults with haemoglobin disorders. Family counselling; neonatal screening and antenatal services were provided. Plans were in place to move the centre to a more accessible venue in the community.

VIEWS OF SERVICE USERS AND CARERS

The visiting team met a small number of patients and carers with sickle cell disease and thalassaemia and received feedback from them. They received no responses to questionnaires.

Common themes raised by patients and carers were:

Paediatrics:

- Patients generally felt supported by the services and were appreciative of the care they received
- Psychology support was embedded in the haemoglobinopathy services but many patients were unaware of these services
- Many patients were unaware of the transition services and support groups

- They had not been able to access written information

Adults:

- Patients generally felt supported by the services and were appreciative of the care they received
- Psychology support was embedded in the haemoglobinopathy services which some patients highly valued although other patients were not aware of the service
- There were some concerns about care in the Emergency Department (ED). Some patients indicated that they avoided admission through the ED because of the limited expertise and understanding they felt ED staff had in relation to managing patients with haemoglobinopathies. Patients felt they would benefit from an alert system to improve efficiency of management. They were not aware of care plans and were keen to explore individualised pain protocols. Some were confused about the admissions pathway following closure of the CMH ED
- On the whole they were pleased with the transfer of the in-patient services as the nursing staff from CMH had moved to the new location.
- Patients highlighted difficulty accessing the specialist nurse
- They welcomed the drop-in service on the day unit at CMH
- They were not aware of support groups
- Adults were keen to be more proactively involved including via a mentoring scheme.
- Patients did not feel that there was the opportunity regularly to feedback about the service and were not aware of how feedback was used or what actions were taken by the service following patient feedback.

Return to [Index](#)

REVIEW VISIT FINDINGS

NETWORK

General Comments

Adults

The North West London Network was one of the first to be established. Specialist care was provided by two large Trusts, Imperial College Healthcare NHS Trust and London North West Healthcare NHS Trust. Significant reconfiguration of services had taken place across the region including the closure of the Emergency Department at Hammersmith and Central Middlesex Hospitals. Since the previous peer review visits Central Middlesex, Ealing and Northwick Park Hospitals had successfully merged and the closure of the ED at Ealing Hospital was planned.

As a consequence of ongoing regional changes, funding for the network coordinator had been lost and the activity of the Network had been constrained. At the time of the visit Network meetings were being re-established.

Services for children and young people

Specialist care for paediatric haemoglobinopathy patients was provided by St Mary's Hospital, Imperial College Healthcare NHS Trust and Central Middlesex/Northwick Park Hospitals (London North West Healthcare NHS Trust). The specialist centres supported a number of local hospitals in the region and were responsible for

annual reviews. St Mary’s Hospital provided high dependency in-patient care for children and young people. Children requiring high dependency care were transferred there from Northwick Park Hospital. Some children who lived near Central Middlesex also tended to go to St Mary’s for their in-patient care.

The North West London Network held educational events and hosted paediatric guidelines on the website. Both centres engaged with these educational events but there was no evidence of them working together clinically.

An annual network educational meeting for health care professionals, voluntary sector organisations and patients had been running since 2003.

Immediate Risks: No immediate risks were identified.

Good Practice

- 1 Outreach clinics were established although data for local haemoglobinopathy teams were not reviewed.

Immediate Risks: No immediate risks were identified.

Concerns

- 1 Community nursing time across the region was insufficient and community-based services provided in some areas should be reviewed.
- 2 It was not clear that patients in the network were receiving reviews by a specialist SHC. Reviewers were particularly concerned that paediatric patients from Ealing Hospital may not have been having annual reviews with a SHC. Access to automated apheresis was also variable.

Further Consideration

- 1 At the time of the visit interactions between the regional SHCs were limited, reviewers suggested that closer cooperation between the centres would be helpful to the effective functioning of the network.

NETWORK CONFIGURATION

It was noted that adult patients from the LHTs listed for Imperial attended either University College London Hospitals NHS Trust or Guy’s and St Thomas’ NHS Foundation Trust.

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

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
Imperial College Healthcare NHS Trust (Hammersmith Hospital, St Mary’s Hospital)	<ul style="list-style-type: none"> • Luton & Dunstable University Hospital NHS Foundation Trust (Luton & Dunstable Hospital) - paediatric only
	<ul style="list-style-type: none"> • West Hertfordshire Hospitals NHS Trust (Watford General Hospital) - paediatric only
	<ul style="list-style-type: none"> • Chelsea and Westminster Hospital NHS Foundation Trust (West Middlesex University Hospital)
	<ul style="list-style-type: none"> • The Hillingdon Hospitals NHS Foundation Trust (Hillingdon Hospital)
London North West Healthcare NHS Trust (Central Middlesex, Ealing and Northwick Park Hospitals)	<ul style="list-style-type: none"> • Bedford Hospital NHS Trust

Return to [Index](#)

SPECIALIST TEAM: LONDON NORTH WEST HEALTHCARE NHS TRUST SERVICES FOR ADULTS, CHILDREN AND YOUNG PEOPLE

General Comments and Achievements

This was a well-established and integrated clinical service with close working relationships between the paediatric, adult and community services. Members of the team were highly committed and the close collaboration had helped facilitate effective transition from paediatric to adult services. Strong psychology support for the service was delivered by a dedicated psychologist with expertise in haemoglobin disorders. Support from Brent CCG for a community based social project and the longstanding close interaction with the Sickle Cell Society were highly commendable.

Progress since Last Visit

Since the last review visits which took place in 2010 for the paediatric service and 2012 for the adult service, there had been a significant infrastructural change within the Trust with the closure of the CMH ED and acute wards and subsequent relocation of these services to NPH. The team had met the challenges of these changes exceptionally well. The reviewers noted that the new facilities were of a very high standard, particularly the ED and the paediatric ward (Jack's Place). Additionally a successful paediatric multi-disciplinary outreach clinic had been established at Bedford Hospital. The provision of a Saturday service was appreciated by carers.

Good Practice

- 1 An electronic elective transfusion recording system at NPH allowed for detailed documentation of transfusion information including time of arrival, time to initiation of transfusion and cannulation attempts.
- 2 Good multi-disciplinary working was in place involving all members of the team. Formal meetings were clearly recorded.
- 3 A healthcare assistant based within the CMH out-patient clinic supported consistency and continuity in patient care.
- 4 An annual community nursing review was undertaken and documented in a standardised letter.

Immediate Risks: No immediate risks were identified.

Concerns

- 1 The provision of acute hospital-based paediatric specialist nursing was insufficient to meet the needs of the population.
- 2 The reviewers considered that a single acute adult nurse specialist to support a split-site service model was insufficient for the needs of the population and had restricted the expansion of the acute nursing role that could have been possible.
- 3 The TCD screening service, although led by a highly enthusiastic sonographer, had no mechanism for an internal quality assurance and a robust plan to develop and sustain this service was not yet in place. Cover for absence was not available.

Further Consideration

- 1 Consideration should be given to reviewing the patient information as some of this was outdated. Although an excellent TCD information booklet was available there was an error with regard to the management of abnormal TCDs that needed amending.
- 2 In general, the clinical guidelines may benefit from being more concise to improve ease of use by junior staff particularly in the ED. Reviewers suggested that the pain protocols for adults, could be developed

further, particularly with additional practical detail to enable the Emergency Department staff to manage patients more efficiently.

- 3 Care planning for both adult and paediatric patients was inconsistent. Some patients were unaware of care plans and accessibility in the Emergency Department was limited. This may have been one contributory factor to the non-compliance with NICE guidance on 'time to first dose' analgesia.
- 4 Paediatric clinical guidelines on the management of chronic complications were incomplete and may benefit from review.
- 5 At the time of the visit the apheresis service was dependent on one registered nurse. Twenty-four hour cover was not available. Reviewers suggested that a review of the nursing skill mix within the service may be appropriate to address the acute nursing need within the hospital, including for the apheresis service.
- 6 Reviewers suggested that the service would benefit from additional administrative support to facilitate data entry and data collection, including with data entry onto the National Haemoglobinopathy Registry.
- 7 Junior doctor training within the Trust could be reviewed to ensure adequate exposure to the care of patients with haemoglobinopathies as changes to working patterns have limited attachment to the red cell service.
- 8 Attention to workforce requirements and succession planning may help to ensure the service is sustainable in the longer term.
- 9 The format of the information provided in clinic letters could be standardised.
- 10 Reviewers suggested that mechanisms for patient involvement and engagement should be reviewed. Although North West London patient consortium meetings and new patient support groups were in place, some patients and carers expressed concerns around the accessibility of members of the team and demonstrated a lack of awareness of services provided.
- 11 Local access to MR imaging for iron monitoring purposes was not available at the time of the visit and local provision would be beneficial. The reviewers noted that the Trust had plans to commence this service.
- 12 At the time of the visit elective out of hours transfusion was not provided.
- 13 The service had not completed all the recommended audits.

Return to [Index](#)

COMMISSIONING

General Comments and Achievements

The visiting team met with a commissioner from Brent Clinical Commissioning Group during the visit. Also, during the visit to London North West Healthcare NHS Trust (LNWH), reviewers were informed that there had been meetings with the specialised commissioners over the previous 12 months.

From the perspective of LNWH local commissioned services, Brent CCG had supported the community sickle cell disease service for many years and had funded a support service for recently discharged patients in conjunction with the Sickle Cell Society. There appeared to be little contact between the CCG and the specialist commissioner in relation to the care of people with haemoglobin disorders.

Immediate Risks: No immediate risks were identified.

Concern

- 1 Evidence of engagement by specialised commissioners about services for people with haemoglobin disorders across both specialist haemoglobinopathy centres in the network was not presented to the review team.
- 2 The reviewers were concerned that not all patients were benefitting from access to a specialist centre for annual review and automated exchange, it is important for commissioners to clarify the arrangements for equitable access to services.

Further Consideration

- 1 Community services were under resourced for adult and paediatric patients within parts of the network.

Return to [Index](#)

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Leads

Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust

Visiting Team

Dr Moira Dick	Consultant Paediatrician	Kings College Hospital NHS Foundation Trust
Dr Shivan Pancham	Consultant Haematologist	Sandwell & West Birmingham Hospitals NHS Trust
Dr Tullie Yeghen	Consultant Haematologist	Lewisham and Greenwich NHS Trust
Nkechi Anyanwu	Clinical Nurse Manager	Guy's and St Thomas' NHS Foundation Trust
Natasha Lewis	Clinical Nurse Specialist	Homerton University Hospital NHS Foundation Trust
Edith Aimiwu	Clinical Nurse Specialist	Whittington Health NHS Trust
Helen De Marco	Senior Clinical Psychologist	University College London Hospitals NHS Foundation Trust
Cly Mensah	User Representative	Not applicable

Return to [Index](#)

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 Services	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	45	34	76
Haemoglobin Disorders Clinical Network	9	8	89
Commissioning	3	1	33
Total	57	43	75

Services for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	49	34	69
Haemoglobin Disorders Clinical Network	9	7	78
Commissioning	3	1	33
Total	61	42	69

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

Return to [Index](#)

SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-101 All	<p>Haemoglobin Disorder Service Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199) 	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-102 All	<p>Information about Haemoglobin Disorders</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions 	Y	The information pack seen by the review team included cassette tapes which were no longer useable.	Y	The information pack seen by the review team included cassette tapes which were no longer useable.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-103 All	<p>Information for Primary Health Care Team</p> <p>Written information should be sent to the patient's primary health care team covering available local services and</p> <ol style="list-style-type: none"> a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service 	Y		Y	
HN-104 All	<p>Care Plan</p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> 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 <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p>	Y	The care plan was provided in the form of letters.	Y	The care plan was provided in the form of letters.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-105 All	<p>School Care Plan (Paediatric Services Only)</p> <p>A School Care Plan should be agreed for each child or young person covering, at least:</p> <ol style="list-style-type: none"> School attended Medication, including arrangements for giving / supervising medication by school staff What to do in an emergency whilst in school Arrangements for liaison with the school 	Y		Y	
HN-106 SHC (A-LHT)	<p>Transition to Adult Services</p> <p>Young people transferring to the care of adult services should be offered written information covering at least:</p> <ol style="list-style-type: none"> Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer A joint meeting between children's and adult services to plan the transfer A named coordinator for the transfer of care A preparation period prior to transfer Arrangements for monitoring during the time immediately after transfer 	Y	Paediatric and adult staff held joint clinics for teenage patients.	Y	Paediatric and adult staff held joint clinics for teenage patients.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-107 SHC	<p>Information about Trans-Cranial Doppler Ultrasound</p> <p>Written information should be offered to patients and their carers covering:</p> <ol style="list-style-type: none"> Reason for the scan and information about the procedure Details of where and when the scan will take place and how to change an appointment Staff who will be present and will perform the scan Any side effects Informing staff if the child is unwell or has been unwell in the last week How, when and by whom results will be communicated 	N/A		Y	Although an excellent TCD information booklet was available there was an error with regard to the management of abnormal TCDs that needed amending.
HN-199 All	<p>Involving Patients and Carers</p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> Mechanisms for receiving feedback from patients and carers An annual patient survey (or equivalent) Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service Examples of changes made as a result of feedback and involvement of patients and carers 	N	See further consideration section of the main report.	N	See further consideration section of the main report.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-201 All	<p>Lead Consultant</p> <p>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.</p>	Y		Y	
HN-202 All	<p>Cover for Lead Consultant</p> <p>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.</p>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-203 All	<p>Lead Nurse</p> <p>A lead nurse should have appropriate time available for their leadership role and:</p> <ul style="list-style-type: none"> a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) 	Y		Y	However the post for the paediatric acute care CNS was vacant.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-204 All	<p>Staffing Levels and Competences</p> <p>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> Medical staffing for clinics and regular reviews Medical staffing for emergency care, in and out of hours Nurse staffing on the ward and day unit Clinical nurse specialist/s with responsibility for the acute service Clinical nurse specialist/s with responsibility for the community service Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. Clinical or health psychologist with an interest in haemoglobin disorders <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT).</p> <p>Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders.</p> <p>Cover for absences should be available.</p>	Y	However the adult community nurse post was vacant.	Y	However the post for the paediatric acute care CNS was vacant.
HN-205 All	<p>Competences and Training</p> <p>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).</p>	Y	Adult patients noted the improved levels of knowledge amongst ward staff.	Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-206 SHC	Specialist Advice During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		Y	
HN-207 All	Training for Emergency Department Staff The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	Y	Adult patients noted the improved levels of knowledge amongst ED staff.	N	No evidence was provided for the formal education of ED doctors although it was accepted that informal education occurred in all areas.
HN-208 All	Safeguarding Training All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	Doctors in Training The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-210 SHC	<p>Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)</p> <p>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.</p>	N/A		N	<p>Only one member of staff was available with no cover for absences.</p> <p>See concerns section of the main report.</p>
HN-299 All	<p>Administrative, Clerical and Data Collection Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p>	N	No data management support was provided and senior clinical staff were spending valuable time on data entry.	N	No data management support was provided and senior clinical staff were spending valuable time on data entry.
HN-301 All	<p>Support Services</p> <p>Timely access to the following services should be available:</p> <ol style="list-style-type: none"> Psychologist with an interest in haemoglobinopathies Social worker Leg ulcer service Play specialist (children's services only) Chronic pain team Dietetics Physiotherapy Occupational therapy Mental health services (adult and CAMHS) <p>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.</p>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-302 SHC	<p>Specialist On-site Support</p> <p>Access to the following specialist staff and services should be available on the same hospital site as the specialist team:</p> <ul style="list-style-type: none"> 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		N	No paediatric critical care was provided on site.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-303 SHC A-LHT	<p>Specialist Services - Network</p> <p>Access to the following specialist staff and services should be available:</p> <ul style="list-style-type: none"> a. Erythrocytapheresis 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 <ul style="list-style-type: none"> 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 <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p>	Y	<p>However provision of urological services out of hours was insufficient.</p> <p>T2* was provided at Brompton Hospital but the facility for hepatic R2 was not available.</p>	Y	<p>No evidence of paediatric nephrology was provided.</p>

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-304 All	Laboratory Services UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	N	Laboratory services were provided by TDL and UKAS accreditation inspection was due early in 2016.	N	Laboratory services were provided by TDL and UKAS accreditation inspection was due early in 2016.
HN-401 All	Facilities Available The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y		Y	Facilities for children were of a very high quality.
HN-402 All	Facilities for Out of Hours Care Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Facilities were not available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Facilities were not available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-501 SHC A-LHT	<p>Transition Guidelines</p> <p>Network-agreed guidelines on transition to adult care should be in use covering at least:</p> <ul style="list-style-type: none"> a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams 	N	Although a transition process was in place the guidelines lacked specific detail.	N	Although a transition process was in place the guidelines lacked specific detail.
HN-502 All	<p>Monitoring Checklists</p> <p>Checklists should be in use for:</p> <ul style="list-style-type: none"> a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) <p>Use of the checklists should cover both clinical practice and information for patients and families.</p>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-503 LHT	<p>Clinical Guidelines: LHT Management and Referral</p> <p>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.</p>	N/A		N/A	
HN-504 All	<p>Transfusion Guidelines</p> <p>Transfusion guidelines should be in use covering:</p> <ol style="list-style-type: none"> Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion Offering access to exchange transfusion to patients on long-term transfusions Protocol for carrying out an exchange transfusion Hospital transfusion policy Investigations and vaccinations prior to first transfusion Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. Areas where transfusions will usually be given Recommended number of cannulation attempts 	Y	However 'a' and 'b' lacked detail for the adult service.	Y	However the guidelines were long and would benefit from review to become more concise and user-friendly.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-505 All	<p>Chelation Therapy</p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ul style="list-style-type: none"> 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. 	N	The available guidelines for adults lacked detail.	Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-506 All	<p>Clinical Guidelines: Acute Complications</p> <p>Network-agreed clinical guidelines on the management of acute complications should be in use covering at least:</p> <p>For patients with sickle cell disease:</p> <ol style="list-style-type: none"> Acute pain Fever, infection and overwhelming sepsis Acute chest syndrome Abdominal pain and jaundice Acute anaemia Stroke and other acute neurological events Priapism Acute renal failure Haematuria Acute changes in vision Acute splenic sequestration (children only) <p>For patients with thalassaemia:</p> <ol style="list-style-type: none"> Fever, infection and overwhelming sepsis Cardiac, hepatic or endocrine decompensation 	Y	However the acute pain section needed a little more clarity. A quick reference guide to acute management might make the guidelines more 'user-friendly'.	Y	However the acute pain section needed a little more clarity. The guidelines were lengthy making them difficult to navigate. More concise guidance on individual complications may be useful to a busy junior doctor.
HN-507 All	<p>Specialist Management Guidelines</p> <p>Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> During anaesthesia and surgery Who are pregnant Receiving hydroxycarbamide therapy 	Y	Local guidelines were in place but network guidelines were not yet agreed.	Y	Network guidelines were not yet agreed.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-508 All	<p>Clinical Guidelines: Chronic complications</p> <p>Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least:</p> <ul style="list-style-type: none"> a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only) 	Y	Local guidelines were in place but network guidelines were not yet agreed.	N	Guidelines were not yet in place for 'f', 'g', 'h', 'i', 'j' or 'k'.
HN-509 SHC	<p>Referral for Consideration of Bone Marrow Transplantation</p> <p>Guidelines for referral for consideration of bone marrow transplantation should be in use.</p>	Y		Y	
HN-510 All	<p>Thalassaemia Intermedia</p> <p>Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering:</p> <ul style="list-style-type: none"> a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy 	N	The local guidelines for adults lacked detail.	Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-511 All	<p>Clinical Guideline Availability</p> <p>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.</p>	Y	However guidelines lacked detail.	Y	However guidelines were too lengthy.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-512 SHC	<p>Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)</p> <p>Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least:</p> <ol style="list-style-type: none"> Identification of ultrasound equipment and maintenance arrangements Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound Ensuring all patients are given relevant information (QS HN-107) Use of an imaging consent procedure Guidelines on cleaning ultrasound probes Arrangements for recording and storing images and ensuring availability of images for subsequent review Reporting format, including whether mode performed was imaging or non-imaging Arrangements for documentation and communication of results Internal systems to assure quality, accuracy and verification of results Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established) 	N/A		N	<p>'j' was not yet in place.</p> <p>See concern section of the main report.</p>

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-601 All	<p>Service Organisation</p> <p>A service organisation policy should be in use covering arrangements for:</p> <ol style="list-style-type: none"> '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) Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission Patient discussion at multi-disciplinary team meetings (QS HN-602) Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population Arrangements for liaison with community paediatricians and with schools (children's services only) 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated Follow up of patients who do not attend 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. Accessing specialist advice (QS HN-206) Two-way communication of patient information between SHC and LHTs If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together 	N	A service organisation policy was not yet in use.	N	A service organisation policy was not yet in use.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-602 All	<p>Multi-Disciplinary Meetings</p> <p>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).</p>	Y		Y	
HN-603 All	<p>Service Level Agreement with Community Services</p> <p>A service level agreement for support from community services should be in place covering, at least:</p> <ol style="list-style-type: none"> 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 Trust had an integrated community service.	N/A	The Trust had an integrated community service.
HN-604 All	<p>Network Review and Learning Meetings</p> <p>At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).</p>	Y		Y	
HN-605 SHC	<p>Neonatal screening programme review meetings</p> <p>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.</p>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-701 SHC	<p>Data Collection</p> <p>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.</p>	N	Formal data management support was not available.	N	Formal data management support was not available.
HN-702 All	<p>Annual Data Collection - Activity</p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances Length of in-patient stays Re-admission rate 'Did not attend' rate for out-patient appointments 	Y	Reports up to 2014 were available but the merger shortly before the visit may make further data collection difficult. Collection of these by clinical staff may not be the best use of time which could be used for clinical care.	Y	Reports up to 2014 were available but the merger shortly before the visit may make further data collection difficult. Collection of these by clinical staff may not be the best use of time which could be used for clinical care.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-703 SHC	<p>Annual Data Collection – Network Patient Data</p> <p>The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: <ol style="list-style-type: none"> i. Date seen in clinic ii. Date offered and prescribed penicillin d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year e. Number of network patients on long-term transfusion f. Number of network patients on chelation therapy g. Number of network patients on hydroxycarbamide h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients j. Number of network patients whose care was transferred to another service during the year k. Number of network patients who died during the year l. Number of network patients lost to follow up during the year 	N	Annual monitoring was not undertaken.	N	Annual monitoring was not undertaken.

<p>HN-704 All</p>	<p>Audit Clinical audits covering the following areas should have been undertaken within the last two years: Achievement of screening follow-up standards:</p> <ul style="list-style-type: none"> 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 <p>For patients with sickle cell disease:</p> <ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke <p>For patients with thalassaemia:</p> <ul style="list-style-type: none"> 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 <p>All patients:</p> <ul style="list-style-type: none"> k. Waiting times for transfusion 	<p>N</p>	<p>Partial compliance was achieved. The pain audit demonstrated delays in analgesia for adults and children. The vaccination audit demonstrated problems accessing five yearly boosters.</p>	<p>N</p>	<p>Partial compliance was achieved. The pain audit demonstrated delays in analgesia for adults and children. The vaccination audit demonstrated problems accessing five yearly boosters.</p>
-----------------------	---	----------	--	----------	--

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-705 All	<p>Guidelines Audit</p> <p>The service should have a rolling programme of audit, including:</p> <p>a. Audit of implementation of clinical guidelines (QS HN-500s).</p> <p>b. Participation in agreed network-wide audits.</p>	Y		Y	
HN-706 SHC	<p>Research</p> <p>The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.</p>	Y		Y	
HN-707 SHC	<p>Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)</p> <p>The service should monitor and review at least annually:</p> <p>a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512)</p> <p>b. Results of internal quality assurance systems (QS HN-512)</p> <p>c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)</p> <p>d. Results of 'fail-safe' arrangements and any action required</p>	N/A		N	There was a single sonographer for the service with no robust mechanisms for internal quality assurance.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-798 All	<p>Review and Learning</p> <p>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:</p> <p>a. Review of any patient with a serious adverse event or who died</p> <p>b. Review of any patients requiring admission to a critical care facility</p>	Y		Y	
HN-799 All	<p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p>	Y		Y	

Return to [Index](#)

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-199	<p>Involving Patients and Carers</p> <p>The network should have mechanisms for involving patients and their carers from all services in the work of the network.</p>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-201	<p>Network Leads</p> <p>The network should have a nominated:</p> <ul style="list-style-type: none"> 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		N	However network leads had been agreed for the Imperial College Paediatric Red Cell Disorders Network.
HY-202	<p>Education and Training</p> <p>The network should have agreed a programme of education and training to help services achieve compliance with Qs HN-204 and HN-205.</p>	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-501	<p>Transition Guidelnes</p> <p>Network guidelines on transition to adult care should have been agreed covering:</p> <ol style="list-style-type: none"> Age guidelines for timing of the transfer Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer Allocation of a named coordinator for the transfer of care Communication of clinical information from paediatric to adult services Arrangements for monitoring during the time immediately after transfer to adult care Arrangements for communication with Local Haemoglobinopathy Team (if applicable) <p>Guidelines should be explicit about transition directly to any accredited LHTs.</p>	Y	The clinical guidelines for adults and children with haemoglobin disorders produced by both SHCs within North West London had been reviewed and ratified by the protocol sub-group of the managed clinical network.	Y	Transition guidelines were available for both the Imperial College Paediatric Red Cell Disorders Network and North West London Haemoglobinopathy Managed Clinical Network.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-502	<p>Clinical Guidelines</p> <p>Network guidelines should have been agreed covering:</p> <ul style="list-style-type: none"> 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) <p>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.</p>	Y	The clinical guidelines for adults and children with haemoglobin disorders produced by both SHCs within North West London had been reviewed and ratified by the protocol sub-group of the managed clinical network.	Y	All Imperial College Paediatric Red Cell Network guidelines were agreed and utilised by clinical teams at LHTs within the network.
HY-701	<p>Ongoing Monitoring</p> <p>The network should monitor on a regular basis:</p> <ul style="list-style-type: none"> a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year. 	Y		Y	

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-702	<p>Audit</p> <p>The network should have an agreed programme of audit and review covering network-wide achievement of Qs HN-703, HN-704, HN-705 and HN-707.</p>	Y		Y	
HY-703	<p>Research</p> <p>The network should have agreed:</p> <ol style="list-style-type: none"> A policy on access to research relating to the care of patients with haemoglobin disorders A list of research trials available to all patients within the network. 	N	A network research policy was not yet in place.	N	A network research policy was not yet in place.
HY-798	<p>Network Review and Learning</p> <p>The SHC should meet at least twice a year with its referring LHT teams to:</p> <ol style="list-style-type: none"> Identify any changes needed to network-wide policies, procedures and guidelines Review results of audits undertaken and agree action plans Review and agree learning from any positive feedback or complaints involving liaison between teams Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams Consider the content of future training and awareness programmes (QS HY-202) 	Y		Y	

Return to [Index](#)

COMMISSIONING

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HZ-601	<p>Commissioning of Services</p> <p>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:</p> <ol style="list-style-type: none"> Designated SHC/s for the care of people with sickle cell disease Designated SHC/s for the care of adults with thalassaemia Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia Community care providers 	N	Documentation on the formal commissioning arrangement was not seen as this work had not yet been undertaken.	N	Documentation on the formal commissioning arrangement was not seen as this work had not yet been undertaken.
HZ-701	<p>Clinical Quality Review Meetings</p> <p>Commissioners should regularly review the quality of care provided by:</p> <ol style="list-style-type: none"> Each service, in particular QS HN-703 Each network, in particular, achievement of QS HY-702 and QS HY-798. Service and network achievement of relevant Qs 	N	Regular clinical quality review meetings for services for people with haemoglobin disorders were not yet in place. However commissioners were engaged with the service through regular Commissioner-Clinician meetings.	N	Regular clinical quality review meetings for services for people with haemoglobin disorders were not yet in place. However commissioners were engaged with the service through regular commissioner-clinician meetings.

Ref	Quality Standard	Adult Services		Services for Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HZ-798	<p>Network Review and Learning</p> <p>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.</p>	Y		Y	

Return to [Index](#)