WM QRS West Midlands Quality Review Service

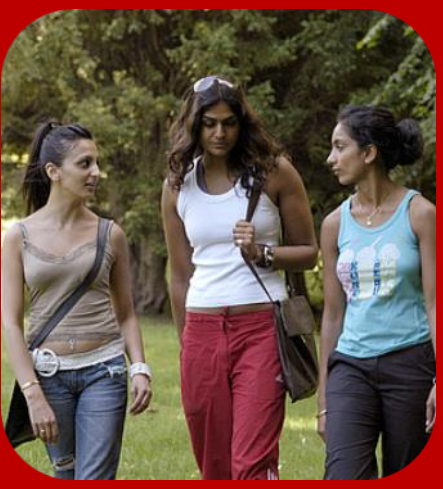
UK Forum on Haemoglobin Disorders

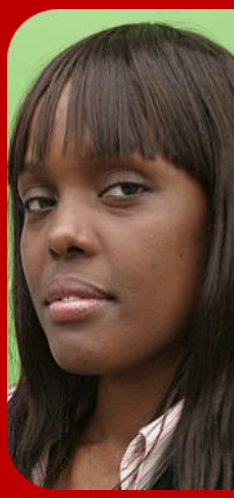
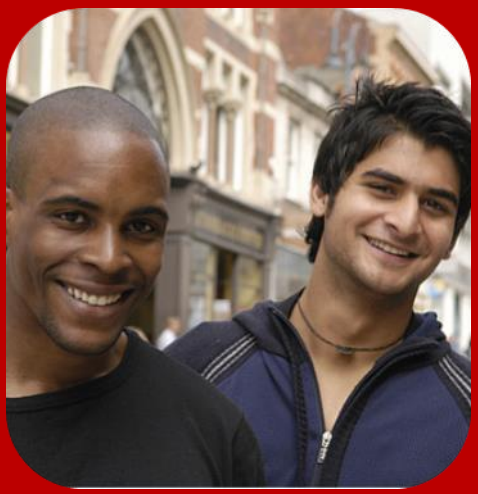
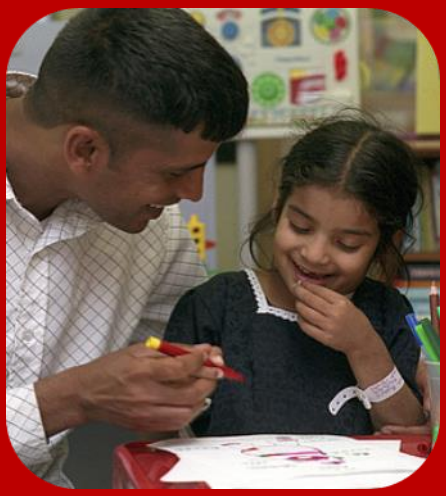
Health Services for People with Haemoglobin Disorders

North West England Network

The Royal Liverpool & Broadgreen University Hospitals NHS Trust
Alder Hey Children's NHS Foundation Trust

Visit Date: 24th September 2015 Report Date: January 2016



NHS

INDEX

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in The Royal Liverpool and Broadgreen University Hospitals NHS Trust and Alder Hey Children's NHS Foundation Trust (part of the North West England Network), which took place on 24th September 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014 which were developed by the UK Forum on Haemoglobin Disorders working with the West Midland Quality Review Service (WMQRS). The peer review visit was organised by WMQRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

Specialist Haemoglobinopathy Centre (SHC)
Accredited Local Haemoglobinopathy Team (A-LHT): A Local Team to which the Specialist Centre has delegated the responsibility for carrying out annual reviews
Local Haemoglobinopathy Teams (LHT): These are sometimes also called 'Linked Providers'

The aim of the Standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Appendix 1 lists the visiting team and Appendix 2 gives details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- The Royal Liverpool and Broadgreen University Hospitals NHS Trust
- Alder Hey Children's NHS Foundation Trust
- NHS England Specialised Commissioning
- Liverpool Clinical Commissioning Group

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

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

About West Midlands Quality Review Service
WMQRS is a collaborative venture 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 Return to *Index*

HAEMOGLOBIN DISORDERS SERVICES IN NORTH WEST ENGLAND NETWORK

The Royal Liverpool and Broadgreen University Hospitals NHS Trust and Alder Hey Children's Hospital NHS Foundation Trust, together with Central Manchester University Hospitals NHS Foundation Trust were part of North West England network.

The Royal Liverpool & Broadgreen University Hospitals NHS Trust (RLBUH) was the provider of adult Haemoglobinopathy Services to the population of Merseyside and Cheshire and the patient population was based mainly in the City of Liverpool. Established close links were in place with services at Alder Hey Children's NHS Foundation Trust (AHCH) which had an increasing patient population ready for transition in the forthcoming years.

Adult Haemoglobinopathy Services within the last three years had moved to sit within the Roald Dahl Centre, which also provided specialist services for Haemostasis and Thrombosis, including Haemophilia Services as a Comprehensive Care Centre & super-regional services for Thrombotic Thrombocytopenic Purpura (TTP). A significant remodelling of the service had taken place, including the appointment of a Lead Consultant within the last year.

Paediatric services were provided by Alder Hey Children's Hospital Foundation Trust.

Discussions were ongoing with NHS England and providers in Manchester regarding formalising the Haemoglobinopathy network in the North West.

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
The Royal Liverpool and Broadgreen University Hospitals NHS Trust	SHC	36	6(HbH)	<5

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
Alder Hey Children's Hospital NHS Foundation Trust	SHC	70	8	<5

ADULT SERVICES – THE ROYAL LIVERPOOL UNIVERSITY HOSPITAL

Emergency Care

During normal working hours patients contacted the haemoglobinopathy nurse specialist who arranged a review to take place in the Roald Dahl Centre. Alternatively patients presented to the Emergency Department (ED) where they were reviewed either by the clinical nurse specialist (CNS) or haematology registrar.

Outside normal working hours patients contacted the Haematology Ward for advice, which included liaison with the on-call haematology consultant or registrar, or self-presented to the Emergency Department.

Patients had patient-held Acute Care Plans, which were also recorded in the clinical notes and on the E-correspondence system. This included a plan of care and the contact details for the service.

In-Patient Care

Patients were admitted to a 20 bedded Haematology Ward housing malignant and non-malignant haematology patients. A daily ward round was undertaken by one of the non-malignant haematology consultants. There had been 47 in-patients admissions in the year before the review visit.

Day Care

Day care was provided on the Haematology Day Unit which housed malignant and non-malignant haematology patients, in addition to those needing immunology infusions. There were two areas, one for chemotherapy and a day ward for other activity including transfusions. The apheresis unit was adjacent to this unit.

Out-Patient Care

Out-patient care was provided in the Roald Dahl Centre where three consultation rooms and a treatment area with two beds/two chairs available. This was the centre for haemostasis, thrombosis and haemoglobinopathy out-patients. A weekly haemoglobinopathy clinic was run by the lead consultant and lead nurse. An additional weekly clinic was run by the lead nurse.

Community Based Care

At the time of the visit no community facility was provided but a business case had been developed for a Community Nurse Specialist (CNS).

Return to *Index*

CHILDREN AND YOUNG PEOPLE – ALDER HEY CHILDREN'S HOSPITAL

Emergency Care

At the time of the visit all patients needing acute admissions were admitted via the Haematology Treatment Centre (HTC) between 9am and 5pm and via the children's Emergency Department (ED) at all other times. Reviewers were told that few haemoglobinopathy-related admissions occurred, possibly related to the high usage of hydroxycarbamide (68% of all patients with sickle cell disease). Children with moderate or severe pain were given oral morphine but parenteral morphine and patient or nurse controlled analgesia could be organised if required. The paediatric ED and paediatric haematology team were responsible for managing the patient. The acute nurse specialist was able to assess and prescribe if necessary. The ED team and nurse specialist were supported by the paediatric haematology consultants on a 1:3 on-call rota. Input from other specialties was available if required.

All emergency assessments would take place in the ED when the service moved to the new hospital. Following initial triage, patients requiring admission would be moved to 3B ward (haematology and oncology) or admitted to the short stay facility within the ED for ambulatory management. Education and training for implementation of the new pathway was planned.

In-Patient Care

The new in-patient facility was co-located with the out-patient clinics and day care facilities on ward 3B. This was a large 19 bedded dedicated haematology / oncology unit. It contained a modern teenage and young persons' room and a school room with term time school teacher support. In addition, on-site kitchen facilities were available with a resident chef to allow for freshly-prepared food. Junior staff were ward-based. Few of the ward-based staff had been formally trained in the care of children with haemoglobinopathies.

Day Care

The new day care facilities were located on ward 3B. This unit was open Monday to Friday from 9am to 5pm. Routine phlebotomy including pre-transfusion testing was organised by trained health care assistants. Transfusions were planned here. There was no provision for out of hours transfusion.

Out-Patient Care

A dedicated haemoglobinopathy out-patient clinic was run fortnightly on a Thursday afternoon. A joint sickle cell disease / respiratory clinic was held every month. The new out-patients facility was housed within the ward 3B complex.

Community Based Care

Following retirement of the community-based Clinical Nurse Specialist in 2013, funding for the community service was withdrawn. The acute nurse specialist was responsible for community visits, if urgently required but routine provision was not available. Genetic counselling and initial newborn assessments were organised by the hospital-based team.

Return to *Index*

VIEWS OF SERVICE USERS AND CARERS

Adult Service

The visiting team met a number of representatives of patients and carers with sickle cell disease and received feedback from them. They received responses to 13 questionnaires from the adult service.

Common themes raised by patients and carers were:

- The feedback about the haemoglobinopathy service was very positive with patients remarking on significant improvements in the last two to three years.
- Patients were particularly pleased with the care they received from the clinical nurse specialist who was easy to contact and facilitated hospital admission.
- Several patients said that since their out-patient care had been moved to the Roald Dahl centre (in 2013/4) it was much improved stating 'I actually look forward to my clinic appointments now'.
- Patients felt that the hospital really cared about them and appreciated the attention they received, for example, texts to remind them to wrap up warm as the weather was changing.
- Experiences in the Emergency Department were good if they were known to the department and if they called the CNS to say they were coming but was not so good if patients were not known to the department when long waits for analgesia were experienced.
- Patients were very concerned about the lack of availability of community nursing support. This had been available previously but the post had not been replaced. Patients felt their complaints about this had not been heard and that they had been neglected.

Paediatric Service

The visiting team met a number of young people and carers with sickle cell disease and received feedback from them. They received responses to 13 questionnaires about the paediatric service.

Common themes raised by patients and carers were:

- Overall patients and carers were highly complementary of the service. They were particularly appreciative of the input provided by the lead nurse.
- The parents reported they were very happy with the staff and the service they provided.
- Most of the parents had children on hydroxyurea and they reported that their children's health had improved.
- Parents spoke highly of the CNS, particularly the visits she had made to their children's schools which had resulted in a greater understanding of sickle cell disease.
- Parents reported concern that, as part of the plans for the new hospital site, they will lose direct access to the ward. Although they had been told that they could still phone the ward for advice they were nervous of having to depend on the knowledge of ED staff rather than the ward staff who know

their children. They stated they had not been consulted about this significant change and would have welcomed an opportunity to give feedback. Letters had been sent to some parents about the changes to the service. The Specialist Nurse had planned to hold a meeting with carers three months after the move to determine patients' and carers' satisfaction with the new services.

- Concern was expressed that they had received no specialised haemoglobinopathy community support since the retirement of the previous community nurse as the post had not been replaced.

Return to *Index*

REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

Reviewers met with the Specialist Commissioner for the North West who reported that they had tried to set up network meetings.

The region had three Trusts which self-assessed as providing specialist services, Central Manchester University Hospitals Trusts (adult and paediatric services), Alder Hey Children's Hospital NHS Foundation Trust (paediatric services) and The Royal Liverpool & Broadgreen University Hospitals NHS Trust (adult services).

The network also included several linked hospitals. Hospitals linked with CMFT provided care for only a small number of haemoglobinopathy patients, the majority of whom had thalassaemia. Annual reviews were provided by the team at Manchester for most of these patients either at the Manchester Royal Infirmary (adults) or via outreach clinics (paediatrics).

Progress since Last Visit

Informal meetings and collaborative working for services for children and young people took place between the hospitals although there was still no formal haemoglobinopathy network in the North West.

Good Practice

1 The Northern Nurses learning and review meetings for children and young people were well attended and provided a useful forum for discussion.

Immediate Risks: No immediate risks were identified.

Concerns

1 Formal arrangements were not yet in place for the provision of specialist care for adults who attended linked hospitals, although hospitals contacted Manchester Royal Infirmary (MRI) for clinical advice on adult patients on an informal basis:

   a. Shared network guidelines were not available.

   b. Guidance on when patients managed by the local teams should be referred to the specialist centre had not been developed within the network.

   c. The consultant at MRI had no formal service level agreement for the provision of care for adult patients at linked hospitals.

2 The peer review team spoke to one of the clinicians based in Blackburn who could not see patients when they attended for transfusions, as these were provided at a different hospital site in Burnley. Also, these patients did not regularly attend appointments for review at Blackburn. The consultant indicated that this arrangement would be reviewed. The level of haemoglobinopathy training for staff at Burnley

was not known though patients attended MRI for annual review. Provision of this service as an outreach clinic may improve the patient experience.

3 At the time of the visit, Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUH) cared for a small number of adult patients with sickle cell disease and a very small number of patients with thalassaemia major. Whilst the quality of medical care appeared excellent and showed marked improvement, the peer review team was concerned that the service as a whole saw insufficient patient numbers to provide specialist care for thalassaemia major patients, patients with iron overload and complex sickle cell disease.

4 Shared guidelines for the management of children and young people were used however formal shared care arrangements between the specialist centres and local hospitals were not in place. A clear escalation policy for the management of unwell children was not in place.

Further Consideration

1 Reviewers suggested that adult patients from RLBUH should have an annual review with staff from a specialist centre (MRI). Closer working with MRI could also enable ongoing development of the skills of the clinical teams at RLBUH.

2 Reviewers suggested that formal multi-disciplinary network learning and review meetings would be beneficial.

NETWORK CONFIGURATION

The network configuration at the time of the review was as follows. East Lancashire Hospitals NHS Trust was the only Accredited Local Haemoglobinopathy Team.

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
Alder Hey Children's Hospital NHS Foundation Trust	• Aintree University Hospital NHS Foundation Trust • Countess of Chester Hospital NHS Foundation Trust • Southport and Ormskirk Hospital NHS Trust • St Helens and Knowsley Teaching Hospitals NHS Trust • Warrington and Halton Hospitals NHS Foundation Trust • Wirral University Teaching Hospital NHS Foundation Trust • Mid Cheshire Hospitals NHS Foundation Trust • Bangor Hospital • Glan Clwyd Hospital • Wrexham Maelor Hospital
Central Manchester University Hospitals NHS Foundation Trust	• Blackpool Teaching Hospitals NHS Foundation Trust • Bolton NHS Foundation Trust • East Cheshire NHS Trust • East Lancashire Hospitals NHS Trust • Lancashire Teaching Hospitals NHS Foundation Trust • University Hospitals of Morecambe Bay NHS Foundation Trust • Salford Royal NHS Foundation Trust • Stockport NHS Foundation Trust • Tameside General Hospital NHS Foundation Trust • The Pennine Acute Hospitals NHS Trust • University Hospital of South Manchester NHS Foundation Trust • Wrightington, Wigan and Leigh NHS Foundation Trust • Mid Cheshire Hospitals NHS Foundation Trust
The Royal Liverpool and Broadgreen University Hospitals NHS Trust	• Aintree University Hospital NHS Foundation Trust • Countess of Chester Hospital NHS Foundation Trust • Southport and Ormskirk Hospital NHS Trust • St Helens and Knowsley Teaching Hospitals NHS Trust • Warrington and Halton Hospitals NHS Foundation Trust • Wirral University Teaching Hospital NHS Foundation Trust

SPECIALIST TEAM (ADULT SERVICES): THE ROYAL LIVERPOOL & BROADGREEN UNIVERSITY HOSPITALS NHS TRUST (RLBUH)

General Comments and Achievements

The service benefitted from the strong leadership of the new lead nurse and lead consultant. Many changes and improvements had been made which was reflected in the positive feedback given by patients and staff, all of whom were very positive about the changes in the services over the previous two years.

The service was a good example of where a creative approach had been used to improve services despite small patient numbers. For example, the lead nurse also had a role in blood transfusion and the non-malignant haematology services worked closely together sharing facilities within the Roald Dahl Centre to provide comprehensive care for patients. The NHS Blood and Transplant Special Health Authority provided a 24/7 apheresis service which worked well and was supportive of the haemoglobinopathy patients. Despite the small patient numbers there was good engagement in research and patients had been entered into early phase drug trials. The centre was working to develop international collaborations with the Liverpool School of Tropical Medicine and via British Council funding on exchange visits to Ghana. The team worked closely with some of the other specialist teams, for example, the leg ulcer team and chronic pain team. Although there were no formal joint clinics, either the lead clinician or lead nurse would attend specialist clinic appointments with patients.

Progress since Last Visit

At the previous visit the Liverpool adult haemoglobinopathy service was reviewed as an accredited local team within the North West network with the Specialist Haemoglobinopathy Centre (SHC) in Manchester. A team of doctor, nurses and managers from RLBUH attended the visit and had partially completed their self-assessment.

Significant progress had been made since the first review report in 2012 and many of the issues raised at that time had been addressed.

- Patient leaflets had been updated and improved
- Guidelines had been updated and improved
- A lead consultant and lead nurse were in post
- Weekly haemoglobinopathy clinics had been introduced which included appointments for annual review

Good Practice

1 Acute clinical plans were available for all patients which were comprehensive and available in clinical areas. The plans were carried by patients.

2 The clinic proformas for routine and annual review appointments were comprehensive and easy to use.

Immediate Risks: No immediate risks were identified.

Concerns

1 Nursing capacity was insufficient to support the service which was a concern for service users. In particular;

a. Cover was not available for absences of the lead nurse.

b. Community nursing support was not available.

c. A robust training plan was not in place for nursing staff on the wards and in the Emergency Department and there was insufficient time in the nurse's job plan to fulfil training requirements.

The Trust had a plan to address this and had a job plan for a new post.

2 Patients were not able to access psychology services.

3 The lack of a functioning network was of concern for a variety of reasons;

   a. Formal links were not in place between RLBUH and local teams.

   b. In view of the small number of patients some of the specialist services, for example, cardiology and endocrinology, may not see sufficient haemoglobinopathy patients to gain the necessary specialist clinical experience. The service had no transfused thalassaemia major patients but some thalassaemia major patients were due to transition from paediatric services. The service may benefit from linking to another centre so that staff with more extensive experience in managing thalassaemia patients could offer annual reviews.

   c. The service may benefit from working with another specialist centre with experience of higher numbers of patients with haemoglobin disorders, for example, with Central Manchester University Hospitals NHS Foundation Trust who could provide specialist advice when the lead consultant was absent and for multidisciplinary discussion of complex cases.

4 A guideline for the management of obstetric patients was not available and regular in-patient haematology review was not available for obstetric patients whose in-patient obstetric care was provided in another Trust.

Further Consideration

1 Whilst there was a marked improvement in patient information, the thalassaemia information was brief and would benefit from updating.

2 Whilst most of the guidelines had been updated, this work was incomplete. In particular, the thalassaemia guidelines needed to be updated.

3 Completing outstanding audits would be beneficial.

4 The majority of patients had consented for their data to be collected for the National Haemoglobinopathy Registry (NHR) but annual reviews and adverse events were not being entered in a systematic way. The appointment of a data manager shortly before the review visit should address this issue.

5 It may be helpful to consider how multi-disciplinary meeting arrangements could be formalised.

Return to *Index*

Specialist Team (Children and Young People Services): Alder Hey Children's NHS Foundation Trust

General Comments and Achievements

This was a good, cohesive and rapidly growing service. Strong medical and nursing leadership was evident and it was clear that the team was highly committed and enthusiastic despite limited time allocated to care of patients with haemoglobin disorders in job plans. The reviewers recognised the additional challenges of the transition to new premises which was scheduled to occur two weeks after the review visit. Service users, carers and health professionals expressed a degree of apprehension around this move particularly as it involved a change to a number of policies and procedures.

Progress since last visit

The previous peer review took place in 2010 and there had been a number of improvements since then. The 'did not attend' rate had been significantly reduced, partly due to better patient engagement. The team had a proactive approach to management especially the use of hydroxycarbamide and this had had an impact in reducing the complication rate, including admissions to hospital. Parents felt listened to, and said that issues were addressed in a timely manner. The team had been awarded the 'Investors in Children' award for haemoglobinopathy services in 2012. The hours of the lead nurse for haemoglobinopathies had been increased from 18.75 hours to 30hours per week. She had gained additional competences in prescribing and independent assessment. Following retirement of the community nurse specialist, the post had not been replaced.

Good Practice

A number of areas of good practice were noteworthy including:

1 Guidelines' checklists for clinicians and management checklists for parents were helpful and laid out clearly.

2 The one-stop transcranial Doppler clinic had good internal quality assurance arrangements. The radiology team were very engaged with the service and this allowed for good communication and timely discussion of results.

3 The 'sickle kids club' included a regular newsletter and meetings. Families found this a very useful source of information and support.

4 Much of the age-specific patient information was excellent. The transcranial Doppler information for very young children was particularly good.

5 Close working relationships with the screening laboratory had helped to ensure timely diagnosis and early implementation of treatment.

6 Excellent working relationships with other services within the Trust were in place including paediatric respiratory and intensive care.

7 The team was proactive with research and development with good links to Liverpool John Moores University. Innovative projects included development of an IT support platform for hydroxycarbamide prescribing.

8 Food was freshly prepared on each ward by resident chefs allowing for good quality meal provision for children and families.

Immediate Risks: No immediate risks were identified.

Concerns

1 The lack of community care provision following the retirement of the community nurse specialist (CNS) in 2013 had resulted in the hospital-based acute CNS undertaking roles more suited to community based teams.

2 A robust training and development plan for ED and ward staff covering care of children and young people with haemoglobin disorders was not yet in place. This was particularly of concern as, following the planned move, the rapid access unit in the old facility would no longer be in operation.

3 Formal annual reviews were not carried out. Annual review of results and notes was undertaken by the nurse specialist and clearly documented but there was no formal annual review assessment by a consultant. Annuals reviews were not entered onto the NHR.

4 Psychology provision was limited. Access to health and neuro-psychology was available but under the plans to merge malignant and non-malignant haematology there was no formal identification of a designated psychologist with an interest in haemoglobinopathies who would be prepared routinely to accept referrals.

5 Administrative support was insufficient and this had impacted data entry to the NHR for recording of adverse events and annual reviews. Some patients who had given consent had not been registered onto the NHR.

6 The Emergency Department was using an out-dated pain scoring method, general awareness of haemoglobinopathies was limited and a programme of education of staff in the care of people with haemoglobin disorders was not yet in place.

Further Consideration

1 Consideration should be given to better primary care engagement to support routine health maintenance and accessing support for social needs.

2 Reviewers suggested that multi-disciplinary team arrangements and learning and review meetings should be formalised.

3 Care plans were in the process of review. Reviewers agreed that further development of care plans would be beneficial.

4 Formal ratification and approval of guidelines and policies was required as many were in draft format or lacked indication of document control.

5 Network links within the region were not clear (see network section of this report).

Return to *Index*

COMMISSIONING

General Comments and Achievements

The peer review team met the specialist commissioner for the North West as part of the Manchester visit. They had responsibility for the services for people with haemoglobin disorders across the North West and had a good understanding of the local services. An increase in the number of patients with haemoglobin disorders in the region had put a significant demand on resources. Prior to 2014 a regional group led by the specialist commissioner had met. The commissioner assigned to the North West region had gained a good understanding of haemoglobinopathies and further meetings were planned.

Immediate Risks: No immediate risks were identified.

Concerns

1 Clinical networks had not been agreed and specialist centres had not been designated. This led to variation in services across the region. Reviewers considered that, at the time of the review, only Central Manchester University Hospitals NHS Trust was providing an appropriate specialist service.

2 The quality of services for people with haemoglobin disorders was not being regularly reviewed by the commissioner.

3 Network meetings were not taking place and should be organised as a priority so that network guidelines can be agreed and progress made towards achieving other network standards.

Further Consideration

1 The Commissioner should consider how best to provide equitable care for all adult patients in the region. Reviewers suggested that patients with more complex needs should be managed at the MRI. At the time of the review, MRI was not resourced to provide an increase in support. (See network section of the report).

2 The Specialist Centres and commissioner should work together to clarify the network in the North West and could consider the provision of network educational events as well as producing network guidelines perhaps hosted on a website.

3 Formal agreement between the two hospitals in the region seeing the highest proportion of children was required on network roles and responsibilities. Reviewers suggested that a health needs assessment led by the specialist commissioner would be useful.

Return to *Index*

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead/s:

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

Visiting Team:

Lindy Defoe	Haemoglobinopathy Specialist Nurse	South Tees Hospitals NHS Foundation Trust
Dr Marie Donohue	Consultant Haematologist	Nottingham University Hospitals NHS Trust
Sajid Hussain	Service User	Not applicable
Dr Baba Inusa	Paediatric Haematologist	Guy's and St Thomas' NHS Foundation Trust
Natasha Lewis	Lead Nurse, Sickle Cell & Thalassemia	Homerton University Hospital NHS Foundation Trust
Karen Madgwick	Transfusion Practitioner	North Middlesex University Hospital NHS Trust
Cly Mensah	Service User	Not applicable
Elaine Miller	Coordinator	UK Thalassaemia Society
Aldine Thomas	Clinical Nurse Specialist, Haemoglobinopathies	Barts Health NHS Trust
Siobhan Westfield	Service User	Not applicable
Cherryl Westfield	Carer	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 Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	45	25	56
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	**57**	**25**	**44**

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	50	31	62
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	**62**	**31**	**50**

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

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-101 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and 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	No community service was in place therefore 'e' was not relevant. Information relating to 'h,ii' and 'h,iii' was not easily available. Information relating to the new build was more extensive.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-102 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	Y	Information on thalassaemia was available but was brief. This reflected the low number of thalassaemia patients attending the service.	Y	Child-focussed and age-specific information was of good quality.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-103 All	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service	Y	All patient correspondence and care plans were copied to GPs. Iron chelation was not prescribed by primary care so no information was available.	Y	Written information was available as a comprehensive letter following initial diagnosis. Condition-specific information was also available.
HN-104 All	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	Y	Very good care plans outlining care in the Emergency Department were in notes given to patients and available on the electronic patient record. These included contact details for the Sickle Team. All letters were copied to patients.	Y	Plans were in place to revise and condense the care plans. See Further Consideration section in the report. Hand-held records were available.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-105 All	**School Care Plan (Paediatric Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school	N/A		Y	School care plans were of good quality. Parents reported this was functional and useful.
HN-106 SHC (A-LHT)	**Transition to Adult Services** Young people transferring to the care of adult services should be offered written information covering at least: a. Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer b. A joint meeting between children's and adult services to plan the transfer c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Arrangements for monitoring during the time immediately after transfer	Y		Y	Transition information was of a good standard and individualised to patient need. A survey was also incorporated.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-107 SHC	**Information about Trans-Cranial Doppler Ultrasound** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated	N/A		Y	Patient-friendly information was of good quality. See good practice section of the main report.
HN-199 All	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	Y	An annual patient survey was carried out and results were available.	N	Although a recent patient survey had been organised that had received 12 responses, a robust plan for regular user engagement was not in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-201 All	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	Y	Staff had been appointed since the last review visit with 3.5 PAs in their job plan.	Y	Insufficient time was identified in the job plan for the general needs of the population. This was particularly evident considering the high intensity of support required for the hydroxycarbamide programme. Guidance issued by the UK Forum on staffing levels for services for people with haemoglobin disorders should be considered.
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y	The previous lead on sickle cell disease provided cover for the lead consultant, including out-patient clinics.	Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	N	The lead nurse was 0.6 w.t.e. which was insufficient for all of the responsibilities. The Royal College of Nursing competences in caring for people with haemoglobin disorders had not been implemented.	Y	Insufficient time was allocated in the job plan for the needs of the population.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-204 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	'd': Inadequate time was allocated in the job plan and cover for absence was unavailable. No community nurse was in post to cover ('e') and there was no psychology support ('g').	N	Quality standards 'a', 'd', and 'e' were not met and although access to psychology was available there were concerns that rapid and timely access was not available for health and neuropsychology support.
HN-205 All	**Competences and Training** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).	N	Evidence of training of the haemoglobinopathy team was available but training for ward staff was not part of a formal training plan and evidence of how many of ward staff had received training was not seen.	N	A robust training plan for nursing and medical teams in the ED and ward 3B was not in place. Plans were in place to address this.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	N	The Trust may benefit from linking with another centre to provide specialist advice of complex cases to cover the lead consultant absence.	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	N	Whilst 'a' was offered for medical staff it was not available for nursing staff. 'b': A training plan was not formalised.	N	A robust programme of training was not in place. See 'concerns' section of the main report.
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	Adequate training for doctors in training was provided.	N	General awareness of haemoglobinopathies was limited and there was a clear need for education. See 'further concerns' section of the main report.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-210 SHC	**Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A		N	Meeting the need for two competent personnel with the required 40 annual scans was not possible because of the population size.
HN-299 All	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	A data manager shared with the haemophilia service had been appointed shortly before the review visit and had attended NHR training.	N	Lack of administrative support was compromising registration and data collection on the NHR.
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.	N	A psychologist with an interest in haemoglobinopathies was not available to patients. Good liaison with the leg ulcer service and chronic pain team was evident.	N	Services for 'a', 'b', and 'i' were not available. Access to Child and Adolescent Mental Health Services was available however staff did not have specific competences in the care of young people with haemoglobin disorders.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	Y	Obstetric services were based at another Trust but the lead clinician had an honorary contract there and attended clinics with the consultant obstetrician.	Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	N	Access to 'm' was not available. Named specialists for other services were listed although it was not clear if all specialist services had an appropriate level of specialist expertise in the care of people with haemoglobinopathies and accessing regional services may be helpful.	Y	Patients were referred to Manchester for bone marrow transplantation although patients were managed pre- and post-transplant at Alder Hey.
HN-304 All	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-401 All	**Facilities Available** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	Out-patient facilities were of high quality with good use of art work.	Y	The nurse specialist provided routine phlebotomy from laboratory facilities. However, once the new build was ready, the plan was for these duties to be undertaken by health care assistants who were undergoing training. See 'further consideration' section in the main report.
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	Access to Saturday transfusion was possible, if needed, and the day unit opened until 6pm.	N	Out of hours routine elective transfusion was not available.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-501 SHC A-LHT	**Transition Guidelines** Network-agreed guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y		Y	However no formal network agreement was in place. A clear plan for transition was available from age 12 and transfer was individualised between ages 16 and 18. Where necessary, special provision was arranged up to age 23. There was no dedicated transition practitioner.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	Y	Annual review and routine monitoring checklists were of a high quality.	N	Although regular clinic reviews were organised and review of the notes undertaken annually by the CNS. No formal annual review procedure was in place for monitoring checklists which included consultant input or patient presence. See 'concerns' section of the main report.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-503 LHT	**Clinical Guidelines: LHT Management and Referral** Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A		N/A	
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Offering access to exchange transfusion to patients on long-term transfusions c. Protocol for carrying out an exchange transfusion d. Hospital transfusion policy e. Investigations and vaccinations prior to first transfusion f. Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. g. Areas where transfusions will usually be given h. Recommended number of cannulation attempts	Y		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-505 All	**Chelation Therapy** Network-agreed clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y		Y	However network agreed guidelines were not available.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	N	Guidelines for 'd','l' and 'm' were not present.	Y	However network agreed guidelines and 'j' were not available.
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	N	Guidelines for 'b' were not present or the Royal College of Obstetricians and Gynaecologists guidelines used. The hydroxycarbamide guideline had been updated but it was not clear that monitoring guidelines were always being used.	Y	However network agreed guidelines on 'b' were not available. Hydroxycarbamide guidelines were good.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	N	Guidelines for 'e', 'f', 'h' and 'I' were not present.	Y	However network agreed guidelines were not available. The endocrine section was particularly comprehensive though awaiting formal endocrine approval.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N	Guidelines for referral for consideration of bone marrow transplantation were not in use.	Y	
HN-510 All	**Thalassaemia Intermedia** Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y		Y	Guidelines were comprehensive.
HN-511 All	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y	Although the guidelines were all available on the Trust intranet they were being updated and rationalised.	Y	Guidelines were available 'on line'.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-512 SHC	**Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)** Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least: a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)	N/A		Y	Guidelines were in place. Internal quality assurance was organised between the two practitioners. The team was keen to participate in a national assurance programme. The information for children was particularly good.

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

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	N	Weekly informal joint meetings of non-malignant staff took place but the Lead Clinician only attended on alternate weeks. These meetings were not documented.	N	Some evidence of multi-disciplinary working was available but formal arrangements were not yet in place.
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	Community services were not available.	N	Community services were not available
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS **Error! Reference source not found.**).	N	Formal network meetings were not in operation.	N	Formal network meetings were not in place.
HN-605 SHC	**Neonatal screening programme review meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	Y		Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	N	The majority of patients were not enrolled on the NHR. Annual reviews and adverse events were not being entered onto NHR in a systematic way. The data manager appointed shortly before the visit should address this issue	N	Partial data were entered but this was limited by lack of administrative support.
HN-702 All	**Annual Data Collection - Activity** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y	It would be helpful to see mean length of stay as well as total length of stay	Y	Evidence of data collection was provided although no formal review of data had been undertaken.

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

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	N	Good audit data were available for 'd', 'e' and 'f'. 'g' and 'k' were not available. 'l' and 'k' were not applicable as there were no thalassaemia major patients.	Y	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-705 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	The service did not have a rolling programme of audit for guidelines.	N	Limited evidence of a rolling programme of audit was available.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	An impressive level of engagement in research was evident.	Y	The department was engaged in innovative research projects.
HN-707 SHC	**Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required	N/A		Y	An internal quality assurance scheme was in place.
HN-798 All	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility	Y	Monthly morbidity and mortality meetings were part of directorate governance arrangements.	N	The reviewers did not see evidence of formal review meetings. There had been no serious events or deaths in the previous five years.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		N	Many documents were in draft format and had not been formally ratified.

Return to *Index*

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Mechanisms were not yet in place.	N	Formal network mechanisms were not yet in place although the community teams and local centres organised annual meetings for users. In addition a highly active support group was facilitated by the community team.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	N	The network had not yet nominated any leads.	N	The network had not yet nominated any leads.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-204 and HN-205.	N	The network had not agreed a programme of education.	N	Although the network had not agreed a formal programme of education for all staff, the north nurses met as a group.
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	Network guidelines for transition were not yet in place.	N	Network guidelines for transition were not yet in place.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-502	**Clinical Guidelines** Network guidelines should have been agreed covering: a. Annual review (QS HN-502) b. Routine monitoring (QS HN-503) c. Transfusion (QS HN-504) d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303) g. Specialist management (QS HN-507) h. Thalassaemia intermedia (QS HN-510) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.	N	Network clinical guidelines were not yet in place.	N	Guidelines were not yet in place across the Network although local centres jointly developed and shared guidelines with the specialist centre.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	N	Ongoing monitoring was not yet being undertaken.	N	Ongoing monitoring was not yet being undertaken.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QSs HN-703, HN-704, HN-705 and HN-707.	N	An agreed programme of audit was not yet in place.	N	An agreed programme of audit was not yet in place.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	A research policy was not yet in place.	N	A research policy was not yet in place.
HY-798	**Network Review and Learning** The SHC should meet at least twice a year with its referring LHT teams to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from any positive feedback or complaints involving liaison between teams d. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams e. Consider the content of future training and awareness programmes (QS HY-202)	N	Network review and learning was not yet in place.	N	Network review and learning was not yet in place.

Return to *Index*

COMMISSIONING

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular: a. Designated SHC/s for the care of people with with sickle cell disease b. Designated SHC/s for the care of adults with thalassaemia c. Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia d. Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	N	Commissioners had not agreed the configuration of the clinical network.	N	Commissioners had not agreed the configuration of the clinical network.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, in particular QS HN-703 b. Each network, in particular, achievement of QS HY-702 and QS HY-798. c. Service and network achievement of relevant QSs	N	Commissioners did not regularly review the quality of care provided for people with haemoglobin disorders.	N	Commissioners did not regularly review the quality of care provided for people with haemoglobin disorders.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	Network review and learning meetings were not in place.	N	Network review and learning meetings were not in place.

Return to *Index*