WM QRS West Midlands Quality Review Service

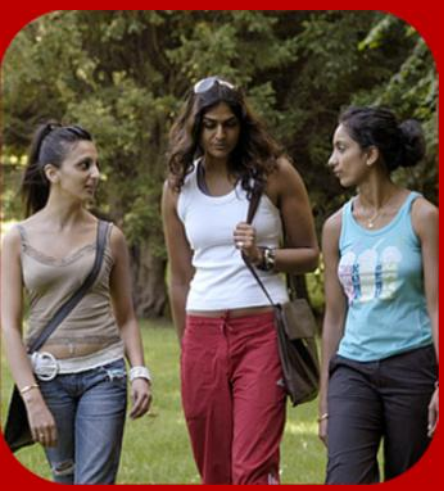
UK Forum on Haemoglobin Disorders

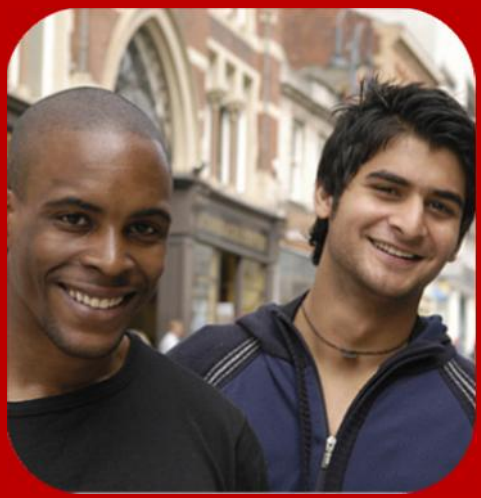
Health Services for People with Haemoglobin Disorders

North West Network

Central Manchester University Hospitals NHS Foundation Trust

Visit Date: 29th September 2015 Report Date: January 2016

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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Central Manchester University Hospitals NHS Foundation Trust (part of the North West England Network), which took place on 29th 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:

- Central Manchester University Hospitals NHS Foundation Trust
- NHS England Specialised Commissioning
- NHS Manchester 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 Central Manchester University Hospitals 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 THE NORTH WEST NETWORK

Central Manchester University Hospitals NHS Foundation Trust together with The Royal Liverpool and Broadgreen University Hospitals NHS Trust and Alder Hey Children's NHS Foundation Trust were reviewed as part of North West England network. A formal network had not yet been established. At the time of the visit Central Manchester University Hospitals NHS Foundation Trust (CMFT) offered comprehensive services for patients with haemoglobinopathies.

Adults were managed at the Manchester Royal Infirmary (MRI) exclusively or by shared care with other hospitals. The majority of adult patients with sickle cell disease and thalassaemia in the north west of England were known to MRI and attended clinics there at least once a year for review. Shared care arrangements were in place with local hospitals for patients outside Greater Manchester for routine care and some common protocols and guidelines were used. Specialist care was offered at CMFT for pregnancy, red cell exchange and those undergoing surgical procedures. Specialist nursing and medical advice was given on an informal basis across the region.

Children and young people were managed at Royal Manchester Children's Hospital (RMCH) in central Manchester which had a catchment area of almost 1,000,000 children up to 16 years old. RMCH was mainly a tertiary children's facility but also included a large secondary care unit for children living in central Manchester. A close working relationship existed between the adult and children teams with joint weekly laboratory meetings and a transition clinic every three months.

Adults

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long term red cell transfusions
Central Manchester University Hospitals NHS Foundation Trust (Manchester Royal Infirmary and Trafford General Hospital)	SHC	258	34	41
East Lancashire Hospitals NHS Trust Lancashire Teaching Hospitals NHS Foundation Trust The Pennine Acute Hospitals NHS Trust Wrightington Wigan and Leigh NHS Foundation Trust	LHT	-	24	18

Children and Young People

Trust	Reviewed as:	No. children with sickle cell disease	No. children with thalassaemia	No. children on long term red cell transfusions
Central Manchester University Hospitals NHS Foundation Trust (Royal Manchester Children's Hospital)	SHC	268	49	54
East Lancashire Hospitals NHS Trust (Royal Blackburn Hospital)	LHT	7	21	18

ADULT SERVICES – MANCHESTER ROYAL INFIRMARY

Emergency Care

Patients with sickle crises or acute complications of sickle cell disease or thalassaemia were advised to attend the Emergency Department (ED) for initial assessment by ED staff using a clinical protocol called 'Pink Pathway'. During working hours adult patients were referred from the ED directly to the haematology team and were seen by the haemoglobinopathy specialist nurse together with the red cell registrar. Patients were either admitted directly to the haematology team or to the medical team 'on take' according to the clinical problem. Out of hours patients were admitted by the medical team and transferred to the haematology team the next working day. A haematology registrar and /or consultant were available for advice regarding haemoglobinopathy patients at all times. Patients with acute sickle cell crisis were managed according to the Trust protocol for painful sickle cell crisis. Those requiring alternative analgesia from the protocol had individualised care plans which were held by the patient and also available in the ED on the electronic patient record (Symphony).

Patients with acute sickle cell pain crises or other complications admitted to linked hospitals were discussed with the haemoglobinopathy team on an *ad hoc* basis. Patients were transferred to MRI depending on severity of their illness and bed availability. A formal service level agreement between MRI and linked hospitals for acute in-patient management was not yet in place.

In-Patient Care

Patients were admitted to medical wards depending on bed availability (in practice this was the Acute Medical Unit or AM3/AM4 wards). Due to capacity issues it was unusual for patients to be admitted to the haematology ward (ward 44). Painful crisis in patients with sickle cell disease was managed according to protocols. Patient controlled analgesia (PCA) was routine for analgesic management although increasing numbers were managed with oral opiate analgesia. Nursing staff on the Acute Medical Unit or AM3/4 and ward 44 were trained to use PCAs. In 2014 to 15 the non-elective/ emergency admissions numbered 164, the mean length of stay was 3.6 days and 50 patients had 70 re-admissions within 30 days.

Day Care

The haematology Day Unit was open on Mondays to Fridays between 8.30am and 7pm for transfusions and apheresis. Automated red cell exchange was available on the day unit and by the bedside for acutely unwell patients. Patients requiring transfusion out of hours were sometimes accommodated on the ward, although this was usually not possible. A plan had been developed for moving to seven day working by October 2015. In 2014-2015 there were approximately 425 episodes of day care for transfusions (sickle cell disease, thalassaemia and inherited anaemias).

Out-Patient Care

Clinics were held every Thursday afternoon from 1.30pm to 5pm for patients with sickle cell disease and other general haemoglobinopathies. Thalassaemia clinics were held twice a month on Tuesdays. Specialist counsellors and clinical nurse specialists (CNS) attended these clinics. A combined haematology/cardiology clinic was held quarterly with a cardiologist, and a clinic for teenagers was held quarterly at RMCH with the paediatric haematologist. All patients were offered annual review at the clinic and by the sickle cell community team at the Sickle Cell and Thalassaemia Centre (SCTC). Thalassaemia patients transfused elsewhere attended for specialist review every three to six months. Chelation management was overseen by MRI. Patients on infusions received supplies through the 'hospital at home' service. The haematology CNS had undergone clinical skills training and was able independently to perform annual reviews. Specialist imaging slots for iron overload (Cardiac T2* and Ferriscan) were available weekly at MRI.

Community Based Care

At the time of the visit community-based care was delivered by the counselling team at Manchester Sickle Cell and Thalassaemia Centre. The centre had three full-time nurse counsellors, one paediatric nurse, 0.6 w.t.e. specialist midwife and one full-time service manager. All patients were offered an annual review and a specialist counsellor attended the sickle cell disease and thalassaemia clinics.

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CHILDREN AND YOUNG PEOPLE – ROYAL MANCHESTER CHILDREN'S HOSPITAL

The Paediatric Haemoglobinopathy Unit was part of the paediatric haematology/oncology unit, situated on Ward 84. It consisted of a large in-patient unit, a dedicated paediatric bone marrow transplant unit, a day case ward, a comprehensive care centre for bleeding disorders and an out-patient facility with out-patient clinics held in the consultants' offices on the ward complex. There were four consultant paediatric haematologists; one was an honorary Professor of paediatric haematology bone marrow transplant (BMT). Close liaison with colleagues at the Manchester Sickle Cell and Thalassaemia Centre, which was situated across the road from the Trust, was in place.

Paediatric laboratory medicine was split with paediatric histopathology situated in RMCH and other paediatric laboratory sub-specialities in the clinical science buildings that served the multi-hospital complex. Molecular biology facilities were shared.

Emergency Care

All patients had direct access to the Paediatric Emergency Department (PED) which was open 24/7. During normal working hours a proportion of patients were 'expected arrivals' as parents were encouraged initially to contact the haematology nurse specialist who notified the ED team. Patient records were accessible electronically and, in most cases, there was easy access to the hospital notes. Guidelines for the care of children with sickle cell disease and thalassaemia were located in PED, Ward 84 doctor's office, Ward 84 and haematology consultant offices. These could also be accessed electronically. The haematology team was primarily responsible for managing the patient but support was provided by the ED team. The ED consultant was available for most of the evening. The paediatric haematology consultants operated a 1:4 on-call rota and were available to see patients as required.

In-Patient Care

Ward 84 was a dedicated 25 bedded unit for haematology/oncology admissions. Patients were admitted to outlying wards when beds were not available on ward 84. The haematology team remained responsible for the care of these patients. The bone marrow transplant unit, which consisted of seven in-patient beds, was also co-located. Good facilities for adolescents and a school room were available.

Day Care

Day care was based within the ward 84 haematology/oncology complex and consisted of six beds and seven chairs for day case admissions. Three beds were available for routine transfusions. The unit was open from 8am until 5pm. Ward 76 day care also had two beds per week available for elective transfusions. All nurses were competent in cannulation and the transfusion process was primarily nurse-led.

Out-Patient Care

The haematology/oncology out-patient clinic was held weekly in the consultant's office on ward 84. The psychologist and one of the nurse specialists normally attended this clinic together with the consultant. Transcranial Doppler scans were organised on the same day in the radiology department. An adolescent clinic was run four times a year and attended by the lead consultants. An outreach clinic was attended by the lead consultant and the lead paediatrician at the Royal Blackburn Hospital. This was organised three to four times a

year. Ferriscans took place at the Royal Blackburn Hospital and RMCH but T2* cardiac MRI scans were only available at RMCH. Children from other local hospitals in the region attended RMCH for their annual review.

Community-Based Care

Manchester Sickle Cell & Thalassaemia centre was situated across the road from MCH. The centre had three full time nurse counsellors, one paediatric nurse, 0.6 w.t.e. specialist midwife, one full time service manager and one psychologist. New patients were initially seen in the community clinic and the patient support groups were organised from there. The service was also responsible for genetic counselling and general support.

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VIEWS OF SERVICE USERS AND CARERS

The visiting team met a large number of **adult** patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They received responses to 44 questionnaires.

Common themes raised by patients and carers were:

- Care from lead clinician and lead nurse was praised.
- Initial analgesia was usually received in a timely fashion but sometimes delays occurred in receiving subsequent doses of analgesia.
- Care in centres outside MRI was reported as not being as good as care within the MRI. Analgesia was not always given in a timely fashion and caregivers in the local teams did not seem to know much about haemoglobinopathies.
- Follow-up was provided by the lead nurse not by a community nurse.
- Care was good on many wards but variable.
- Maintaining access to comprehensive support and advice in a clinic setting was appreciated.
- Inclusion in service development was requested.

The visiting team also met a small number of **children and young people** and their carers with both sickle cell disease and thalassaemia and received feedback from them. They received responses to 30 questionnaires.

Common themes raised by patients and carers were:

- The feedback about the haemoglobinopathy service was very positive and parents reported receiving a consistently high quality service.
- Care from the lead clinician and lead nurse was praised and thalassaemia patients had sometimes opted to use RMCH rather than their local hospital.
- Haematology nurses on the ward 84 had a good understanding, tried to form good relationships and listened to feedback.
- Some parents were uncertain if they had been offered care plans. They were generally very pleased with school care plans.
- Direct ward access was not possible but would be appreciated. Admission to any ward other than ward 84 on occasion could be problematic. For example, staff elsewhere did not have as good an understanding of haemoglobin disorders or the requirements for pain relief.
- Information on ward 84 was noted to be more oncology or haemophilia-orientated and more haemoglobinopathy-specific age-related information was requested. The suggestion was made for a pack containing information leaflets on haemoglobin disorders, treatment options including bone marrow transplantation and alternate therapies.

- It was felt that evening or weekend transfusions would be preferable. Transfusion at home was suggested or more hospital school support to ensure children were adequately catching up on missed lessons, although transfusion dates were accommodated to fit with exams.
- A lack of awareness in the ED of haemoglobinopathies and the pain management protocols could result in delayed analgesia administration.

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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 NHS Foundation Trust (adult and paediatric services), Alder Hey Children's 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 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: CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST ADULT SERVICES

General Comments and Achievements

This was an effective team with strong leadership from the lead consultant and lead nurse. The team received positive feedback from service users and other clinical staff within the hospital. The visiting team saw evidence of good team-working with the community team.

Progress since Last Visit

Since the last review a data administrator (0.4w.t.e.) had been appointed which had led to improved data input to the National Haemoglobinopathy Registry (NHR). Weekly scheduled appointments for MRI Cardiac T2* and Ferriscan were available in MRI and a combined haematology cardiology clinic was held quarterly. The frequency of thalassaemia clinics had increased to fortnightly. In addition, participation in phase 1 clinical trials was taking place.

Several concerns raised in the last peer review had still not been addressed. The clinical lead had, however, produced a detailed service plan which had been approved and was ready for implementation. It listed requirements for service improvements including:

- Additional four consultant Programmed Activities
- Additional CNS post (30 hours per week)
- Psychology support
- Improved in-patient and day unit capacity

Good Practice

1 The documentation of both clinical guidelines and patient information was of high quality and well presented. The reviewers highlighted the obstetric guideline, the transition guideline and patient information, the detailed patient information for patients with thalassaemia and the information leaflets for teenagers and students.

2 The audits were detailed and of high quality. The pain audit against NICE standards was well-presented and included a detailed action plan. Students and the lead clinician had produced excellent audits of iron overload and efficacy of apheresis.

3 The multidisciplinary team structure was robust. Meetings were held fortnightly, outcomes were well-documented and there was a detailed standard operating procedure.

Immediate Risks: No immediate risks were identified.

Concerns

1 The staffing levels for the service were not adequate to provide safe care on an ongoing basis. Although a plan had been approved that addressed this concern (see above) at the time of the visit it remained a concern for a variety of reasons:

   a. Inadequacy of cover for absence of the lead consultant.

   b. Insufficient nursing time and lack of cover for absence had led to inadequate training plans.

   c. A psychologist with a special interest in haemoglobinopathy was not in post.

   d. Lack of social work or benefits advice.

2 Concerns were also raised about service capacity:

a. In-patients were usually not cared for on the haematology ward but on acute medical wards and patients may benefit from 'cohorting' on a single ward.

b. Lack of capacity for expansion in numbers of patients on red cell apheresis, although there was a plan to perform weekend red cell exchange.

c. Lack of capacity in the day unit meant that the service could not offer day unit review for treatment of acute pain episodes.

Further Consideration

1 The Trust should consider developing a robust plan for future service provision. Both the lead clinician and lead nurse were likely to retire in the next five years and service growth was greater than 20% per year.

2 The 'did not attend' rate was very high (at between 25% and 30%) and the Trust should consider measures to increase attendance.

3 The clarity of some of the patient documentation could be improved, for example, the GP/patient letters after annual review appointments were not always reported in a systematic manner. The documentation on transfused patients was not clear. In particular, information about indications for transfusion was lacking and the date when patients started transfusion was not clear from the patients' notes.

4 The community staff were carrying out very detailed annual reviews on some of the patients. This included medical information which was repeated in the medical annual review which took place in the hospital. Reviewers suggested that this practice should be reviewed as it appeared to be quite repetitive and the time spent doing this could be used in patient-related activity.

5 The social worker post was vacant at the time of the review and the community staff were providing social support and benefits advice. The funding for the social worker post was still available and the Trust were considering how it should be re-configured. The need for the post had been exacerbated by withdrawal of voluntary sector funding and limited availability of immigration advice services in Manchester.

6 The service had not completed all the recommended audits and did not have a rolling plan of audits.

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ACCREDITED LOCAL TEAM: EAST LANCASHIRE HOSPITALS NHS TRUST

General Comments and Achievements

The peer review team spoke via telephone to the lead clinician at the Royal Blackburn Hospital (part of the East Lancashire Hospitals NHS Trust). The clinician had taken on the role just before the review visit but was enthusiastic about working with the team at MRI to improve services for their local patient population, the majority of whom had thalassaemia major. All patients received their blood transfusions locally and had an annual review at MRI.

Immediate Risks: No immediate risk was identified.

Concerns

1 The lead consultant was based at the Royal Blackburn Hospital and was unable to see the patients when they attended for transfusions at Burnley General Hospital, (both hospitals were part of the East Lancashire Hospitals NHS Trust). The lead clinician was only able to review patients when they attended clinics at Blackburn, attendance at which was poor.

SPECIALIST TEAM: CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST PAEDIATRIC SERVICES

General Comments and Achievements

Overall this was an excellent service with strong medical and nursing leadership. It was clear that all members of the team were highly committed and enthusiastic. The positive patient feedback also reflected this. Senior management was particularly engaged and understood the needs of the population. The service had a very low out-patient 'did not attend' rate of only 6%. A good working relationship existed with the team at the Royal Blackburn Hospital where a significant number of children with thalassaemia were seen.

Progress since Last Visit

Since the last peer review visit in 2011, the team had worked hard to focus on the needs of adolescents. The adolescent transition package, which included education from a young age, was of a high standard. In addition to the transcranial Doppler service, access to radiological investigations was enhanced with the Trust able to provide Ferriscan liver MRI scans and cardiac T2* MRI examinations.

Good Practice

1 There were many areas of good practice including:

a. Failsafe arrangements for the transcranial Doppler (TCD) service were noteworthy with a formal action plan for all patients who 'did not attend'. A good internal quality assurance programme was in place. Clinicians providing the TCD were fully engaged with the care of children with haemoglobin disorders and were keen to be involved in a National QA scheme.

b. Access to dedicated social work support was provided which the patients found most beneficial.

c. An annual report was generated by the psychology team which documented their work.

d. An emergency ambulance register was available allowing for more appropriate transportation of patients.

e. A highly active support group was facilitated by the community service.

Immediate Risks: No immediate risks were identified.

Concerns

1 The region had a rapidly growing patient population. Medical and nursing time allocation to meet the needs of this growing population was insufficient.

2 Some components of the ED management pathway were not working well. The service was not meeting NICE (National Institute for Health and Care Excellence) guidance on the timeliness of first dose analgesia. Only 55% of patients received analgesia within the 30 minute target in 2012 and 53% in 2014. Patient experience in ED was reported as negative at times, with some patients reporting long waits for treatment. The reviewers noted, however, that there had been a recent modification of the pain management protocol utilising intranasal diamorphine which was expected to result in improvements.

Further Consideration

1 Reviewers suggested that additional workforce planning for future service need was required.

2 Nursing numbers should be brought in line with those of other long term conditions.

3 Guidance issued by the UK Forum on staffing levels for services for people with haemoglobin disorders should be considered.

4 A formal service operational policy outlining the haemoglobin disorders service structure and fail-safe arrangements may be of benefit. At the time of the review these arrangements were detailed in different policies.

5 The shared care arrangements should be formalised to clarify roles and responsibilities between the specialist and local centres. An escalation policy detailing the process for the management of unwell children at local centres may also be helpful.

6 The reviewers noted good communication between the hospital, community teams and the GP. Overall GP engagement was good however the role of the GP could be enhanced to support routine general health maintenance.

7 The annual review correspondence shared with the patient/parents and GP could be reviewed to include a more formal care plan. Likewise, school care plans may benefit from some simplification.

8 Availability and access to patient information in clinical areas could be reviewed. Patient feedback suggested this was not always easily accessible.

9 Most guidelines and policies had no formal ratification. Document control policies should be adopted.

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ACCREDITED LOCAL TEAM: EAST LANCASHIRE HOSPITALS NHS TRUST

General Comments and Achievements

The reviewers met with the lead paediatrician and lead nurse based at the Royal Blackburn Hospital. Children were primarily seen in the out-patient clinic at the Royal Blackburn Hospital but transfusions were organised at Burnley General Hospital. Good communication existed between these two units and there was evidence of a good working relationship with the specialist centre. Access to Ferriscan liver MRI scans was available at a local private clinic.

Good Practice

1 The nurse-led transfusion service was well-organised with excellent record keeping of transfusion schedules.

Immediate Risks: No immediate risks were identified.

Further Consideration

1 The shared care arrangements should be formalised to clarify roles and responsibilities between the specialist and local centres. An escalation policy detailing the process for management of unwell children at local centres may also be helpful.

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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.

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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:

Pauline Garnett	Haemoglobinopathy Genetic Counsellor	Bradford Teaching Hospitals NHS Foundation Trust
Sajid Hussain	Service User	Not applicable
Elaine Miller	Coordinator	UK Thalassaemia Society
Dr Lola Oni	Specialist Nurse Consultant & Professional Services Director	London North West Healthcare NHS Trust
Dr Jenny Welch	Consultant Paediatric Haematologist	Sheffield Children's NHS Foundation Trust
Dr Christine Wright	Consultant Haematologist	Sandwell & West Birmingham Hospitals NHS Trust
Siobhan Westfield	Service User	Not applicable
Cherryl Westfield	Carer	Not applicable

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

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

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	44	29	66
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	56	29	52

Paediatric Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	49	45	92
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	61	45	74

Pathway and Service Letters

HN-	Specialist services for People with Haemoglobin Disorders
HY-	Haemoglobin Disorders: Network
HZ-	Haemoglobin Disorders: Commissioning

Topic Sections

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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	Written information for patients was well presented and the 'My Team' leaflet was useful.	Y	Generally information was of good quality however there were references to oncology and haemophilia. This point was also reflected in patient feedback. See main report.

		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	Lots of good information was available. The information for thalassaemia and exchange transfusion was of particular note. Good health promotion and student/teenage guides were available.	Y	An excellent range of information was offered although 'g,i' and 'g,iv' could be enhanced. Information was good for the pregnancy section, enuresis and disease-specific aspects.

		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	Iron chelation was not prescribed by GPs.	Y	Information was available as a letter/care plan but generic information for GPs would be beneficial. It would also help with GP engagement to define the role of the GP. See main report.
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		Y	Although available as a letter/care plan consideration should be given to re-formatting, particularly for the annual review correspondence. Parents and carers were uncertain about care plans, See main report.

		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	Further consideration should be given to simplifying the School Care Plan though the 'flags of good practice' highlighted in the plans were very 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	The transition process was patient-led and thorough. A good 'age specific checklist' was in use.	Y	Audit checklist and targeted information was focussed on education. A list of specialist centres was included.

		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	However 'e' and 'f' need to be clarified.
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	Forty-four patient surveys had been completed.	Y	A number of sessions were organised. The 'parent power' support group was particularly good. See good practice 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-201 All	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	Y		Y	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	N	However a new post with four PAs for the care of people with haemoglobin disorders was being advertised at the time of the visit.	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)	Y		Y	

		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	No cover was available for the acute nurse although a post (30 hours per week) was being advertised at the time of the visit. A psychologist 'g' was not available, although this post was also identified in the business plan 'g'.	Y	Additional nursing time would be beneficial. See main report.
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	No training plan was in place.	Y	

		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	No specialist cover was available.	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	Training took place on an *ad hoc* basis.	Y	A robust training schedule was in place however staffing pressure within the ED had meant that some nurses had not been able to attend planned sessions.
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	

		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		Y	Good internal quality assurance arrangements and fail safe arrangements were in place.
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	The team had appointed an administrator (0.4 w.t.e.) after the review visit in 2012.	Y	
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	Services for 'a' and 'b' were not available, 'd' was not applicable and 'e'- 'l' were Trust-wide.	Y	Although no leg ulcer service was in place the large plastic surgery unit on site was able to provide support as required.

		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		Y	

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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 a specialist neuropsychologist was not available.	Y	However automated exchange 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-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	
HN-401 All	**Facilities Available** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	The community space was good.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	However, starting in October, the day unit was expected to open every day for transfusions.	N	At the time of the review the Trust policies adopted the UK Serious Hazards of Transfusion (SHOT) guidance recommending avoidance of out of hours transfusions.

		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	See main report.	Y	Good quality guidelines were in place. See 'good practice' section of the main report.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	Y	A good patient checklist was being used.	Y	

		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	'b' could be clearer.

		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	

		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	Y		Y	
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y	The obstetric haematology guidelines were good and the admission plan was in place.	Y	

		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	The majority of the guidelines for chronic complications were not adequately covered and could be pulled into one document. 'd' was not covered. In practice, patients were referred to an appropriate clinician with relevant experience and patients were managed jointly.	Y	
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 yet in place.	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	

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-511 All	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y		Y	

		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	This was well organised, with good internal quality assurance arrangements.

		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	Y	A clear operational policy was in place.	Y	A single formal service policy was not in place but arrangements were covered in different Trust policies. See main report.

		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).	Y	Well documented, clear guidelines for the multi-disciplinary meetings were available.	Y	
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A		N/A	
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	N	Network meetings had not yet taken place.	Y	The Northern nurses network was well-attended but there were no formal network meetings for all MDT (multi-disciplinary team) members.
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.	Y	More than 80% of patient data were entered onto the registry, including adverse events. Since April, all annual reviews were being prospectively entered and 92 were complete.	Y	
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	N	No evidence was available on ED attendances or 'did not attend' rates.	Y	The 'did not attend' rate was low at 6%

		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	Data were not collected for 'b', 'c', 'h', 'i' or 'j'.	Y	

		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	The audits which were undertaken were excellent, in particular for pain and iron overload. However audits had not been carried out for 'g', 'j' or 'k'.	N	Audits were unavailable for 'h' 'i' 'ii', 'j' and 'k'. Data for 'g' was submitted to a recent national audit.

		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	A rolling programme of audit for guidelines was not yet in place.	N	A rolling programme of audit for guidelines was not yet in place.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		Y	
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	See main report.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-798 All	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility	Y		Y	No significant events had been reported but audit actions were in progress.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		N	Document control procedures were not used.

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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.
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.

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Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	Network guidelines for transition were not yet in place.	N	Network guidelines for transition were not yet in place.

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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.

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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.

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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.

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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.

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