WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

East Midlands Network

Nottingham University Hospitals NHS Trust

Visit Date: 10th November 2015 Report Date: March 2016

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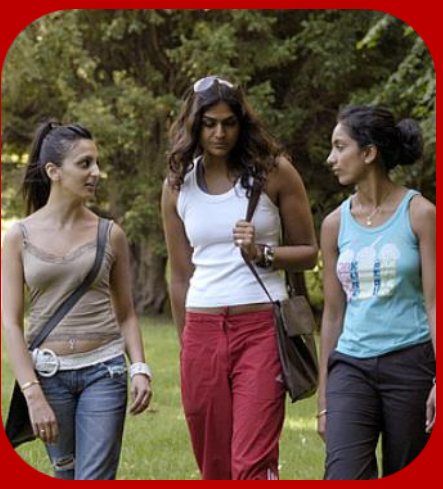

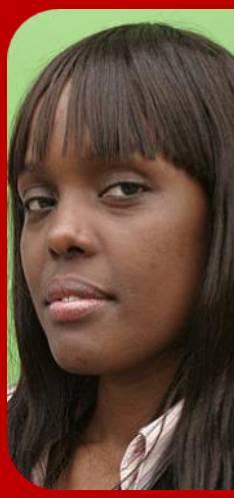
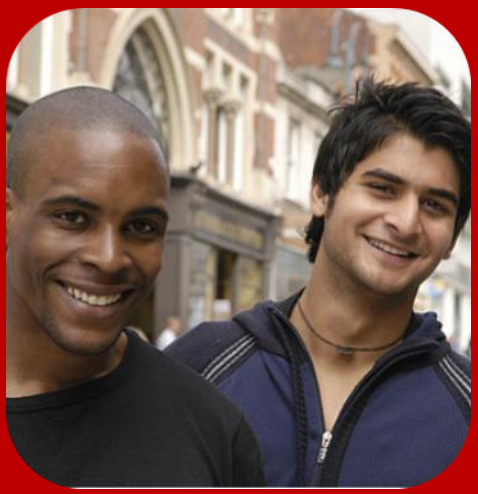
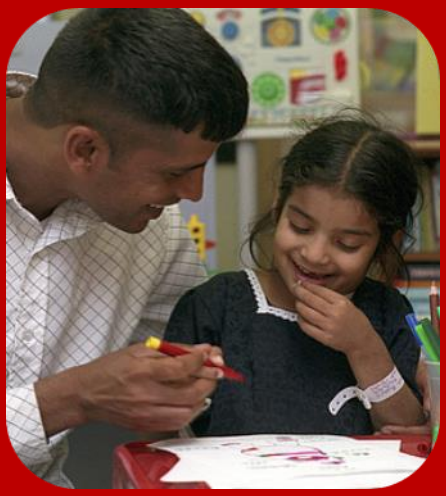

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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Nottingham University Hospitals NHS Trust (part of the East Midlands Network), which took place on 10th November 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:

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

About West Midlands Quality Review Service

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

HAEMOGLOBIN DISORDERS SERVICES IN EAST MIDLANDS NETWORK

At the time of the visit Nottingham University Hospitals NHS Trust was part of the East Midlands Network which also included University Hospitals of Leicester NHS Trust. Both of the Trusts were Specialist Haemoglobinopathy Centres.

Adults

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long term red cell transfusions
Nottingham University Hospitals NHS Trust	SHT	97	9	17
Derby Teaching Hospitals NHS Foundation Trust	LHT	23	<5	<5

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
Nottingham University Hospitals NHS Trust – Nottingham Children's Hospital	SHT	50	<5	6
Derby Teaching Hospitals NHS Foundation Trust – Derby Children's Hospital	LHT	10	5	5

ADULT SERVICES – NOTTINGHAM CITY HOSPITAL

Nottingham University Hospitals NHS Trust (NUH) consisted of City Hospital and the Queen's Medical Centre (QMC) which included the Emergency Department (ED) and the Children's Hospital. The Centre for Clinical Haematology was based at City Hospital. At the time of the visit this facility had 40 in-patient beds, a bone marrow transplant unit, a general haematology ward and a Day Case Unit. The Centre provided in-patient, out-patient and day case care for patients with haemoglobin disorders.

Emergency Care

Patients with haemoglobinopathies presenting with acute disease complications were encouraged to call the dedicated haematology triage nurse via a 24 hour helpline. The triage nurse used the sickle cell disease rapid assessment toolkit to direct the patient to the day case unit or Specialist Receiving Unit (SRU). This pathway ensured that patients were navigated directly to City Hospital campus rather than going to the Emergency Department(ED). Patients not known to the service were directed to the Queen's Medical Centre (QMC) ED and patients new to the area would also access emergency care via this route.

In-Patient Care

The majority of acute haemoglobinopathy admissions were to the SRU, either directly or from the Haematology Day Unit or ED. The main specialty users of the SRU were oncology, haematology, renal and

diabetes/endocrinology. Patients were admitted for a maximum of 18 hours. If the patient required ongoing care they would be admitted to another in-patient ward.

The main haematology ward was Toghill which was situated within the Centre for Clinical Haematology. It had 22 beds with six 'two-bedded' areas and ten single rooms which were used primarily for patients requiring protective isolation or barrier nursing. Patients were also housed on other cancer directorate wards (Gillies, Burns and Loxley) or other outlying wards, predominantly surgical wards Barclay, Harvey and Winifred 1 and 2 as patient-controlled analgesia was available on these wards. All admitted patients with sickle cell disease were reviewed daily by the ward-attending haematology team and were looked after by the 'hospital at night, team out of hours.

Day Care

The Day Care Unit consisted of 20 workstations including a stem cell/apheresis service and was adjacent to a large out-patients department. It provided a blood transfusion service and a service for management of acute painful crises and was open Monday to Friday 9am to 5pm and Saturday mornings (transfusion only). Sickle cell and thalassaemia patients attended the unit for blood transfusions (including exchange). Patients who were on hydroxycarbamide could attend for blood tests and adjustment of medication by arrangement, if needed.

Out-Patient Care

The dedicated out-patient suite was on the ground floor at the Centre for Clinical Haematology adjacent to the day unit. It had its own phlebotomy area and Sysmex blood analyser for processing blood counts. Eight consulting rooms and a quiet room were available. Adult Specialist Sickle Cell and Thalassaemia clinics were run every Wednesday and on the second and fourth Friday of each month.

Community Based Care

A nurse-led service was based at the Mary Potter Centre which was available between 9am and 5pm, from Monday to Friday. Patients had direct access to this service and could attend as a drop-in patient or make an appointment. Other services located there included the City Council - Children's and Adult Services, Occupational Therapy, Physiotherapy and a leg ulcer clinic. The psychologist could see patients at the Mary Potter Centre or in the hospital.

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Children and Young People – Nottingham Children's Hospital (Queen's Medical Centre)

Emergency Care

All children with sickle cell disease and thalassaemia attended children's ED for emergency care. If they needed a period of observation they were admitted to the 12-bedded children's assessment unit (E38) where they could stay for up to 12 hours before being discharged or transferred to a paediatric ward. The preferred ward for admission for children and young people was the 15 bedded haematology/oncology ward and included the newly built Teenage and Young Adult unit (E39). If admission to ward E39 was not possible then a bed on one of the other children's wards was found. Guidelines for emergency care of children with haemoglobinopathy were available on the Trust intranet and a version was also available in hard copy in the ED. On admission to the ward, an electronic clinical alert was issued to the specialist haemoglobinopathy clinical team, including the Trust- based acute CNS and the community CNS. The clinical care of the patients was led by the attending haemato/oncology team. During working hours the paediatric haematology registrar was present in ED to assess patients that required admission or emergency care.

In-Patient Care

Whenever possible, children with red cell disorders were admitted to ward E39, the designated haematology/oncology ward. When beds were not available on ward E39, children with red cell disorders were admitted to one of the other children's wards and all patients on outlying wards were reviewed as part of the daily ward round.

Paediatric haematologists and oncologists operated a 'hot week' system for care of in-patients and provided senior review for all newly admitted patients. The haemoglobinopathy lead consultant aimed to review or discuss every patient within 24 hours of admission even when not on 'hot week' service and additionally undertook twice weekly formal ward rounds. Senior review during weekends was undertaken by the on-call consultant haematologist or oncologist, who shared an on call rota. Paediatric oncologists were familiar with the acute management of children with haemoglobinopathies and if needed, they were able to contact either the on-call adult haematology consultant or one of the two paediatric haematologists for advice.

The children's pain team comprised two WTE nurses and provided input into the management of the children with painful crises. They carried out daily ward rounds and reviewed children on patient-controlled analgesia as well as those on oral opiates. They supported the clinical haemoglobinopathy team to write pain plans for patients with complex pain issues.

Surgical management of haemoglobinopathy patients took place in one of the two surgical wards in the children's hospital. Procedures that required short anaesthetics were undertaken in the day unit where anaesthesia was provided in a dedicated list. MRI scans under general anaesthesia were undertaken in the day surgery ward.

For children and young people requiring higher degree of intervention there was an 11-bedded paediatric critical care unit situated within the children's hospital.

Day Care

The haematology day care area was shared with paediatric oncology and other haematology services as well as rheumatology and was adjacent to the in-patient ward, allowing easy access to the facilities. It was open from 8am to 8pm. Monday to Friday. Once a month it opened until 10pm enabling the provision of after-school blood transfusions and blood tests. Clinic rooms attached to the area were used for patient review. Notes for the children on transfusion programmes, plus other frequent attenders, were kept in the day care area. Some children had indwelling port devices for venous access and the nursing staff accessed these. Some nurses on the unit could perform venepuncture and cannulation. If they were not available then the day care clinical fellow would site intravenous access.

Out-Patient Care

The paediatric department had two large children's out-patient areas situated within NUH providing general paediatric clinics as well as a wide range of subspecialty clinics. The children's out-patient department (COPD) was open between 9am and 6pm, Monday to Friday. The clinics were held on the second, fourth and fifth Thursday morning of the month in COPD South. The paediatric haematology consultants, specialist registrar and CNS attended every clinic. The fifth week Thursday clinic, which took place four times per year, was an annual review clinic. These clinics had longer appointment slots and were attended by the adult haemoglobinopathy consultant, community CNS and clinical psychologist. The presence of the adult haematologist facilitated smooth transition. The clinical psychologist was allocated a room and could see clients and their families alongside or independently from clinic.

Within the clinic area there was a phlebotomy department with a nurse and play specialist allocated for each shift. The older children could use the hospital phlebotomy department if they wished after a clinic appointment or for blood tests at any other time.

Trans-Cranial Dopplers (TCD) were performed within NUH, if possible on the same day as the child's out-patient appointment. Endocrinology review for the young people requiring monitoring was offered during the annual review clinic in October each year.

Located within the children's out-patients was the sleep study service. On most occasions, if an overnight oximetry study was required it could be performed on the same day was requested from clinic.

Separate out-patient facilities were available within NUH for routine monitoring of audiology, ENT and ophthalmology, when required.

Community Based Care

The nurse-led sickle cell disease and thalassaemia service was based at the Mary Potter Centre. Among other services the team offered new-born counselling, emotional support, school visits, advice and transitional care. The service was available from 9am to 5pm, Monday to Friday and patients had direct access to the service by either dropping in or by appointment. Interview rooms were available to see the patients for private consultations.

The clinical psychologist who was based at Nottingham City Hospital was able to see some of the children and young people at the Mary Potter Centre if it was more convenient for families. Other services located at Mary Potter included City Council adult and child services and a leg ulcer clinic.

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VIEWS OF SERVICE USERS AND CARERS

Adult Services

The visiting team was not able to meet any patients or carers. Eighteen patients had been invited to the review and six had responded. A patient survey had been performed and they had received responses to 30 questionnaires.

Common themes raised by patients and carers in the survey were:

- Patients gave very positive feedback about the medical and nursing members of the sickle cell team who they felt gave very good care and were readily available.
- Several patients raised concerns about being housed on many different medical wards when they were admitted to hospital. They felt that nursing and medical staff were often not well informed about sickle cell disease and would benefit from additional training.
- Patients felt that initial analgesia was usually given in a timely fashion, but there were often delays in obtaining subsequent doses of analgesia.

Services for Children and Young People

The visiting team met a small number of patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They received responses to 15 questionnaires.

Common themes raised by patients and carers were:

- Overall they were very appreciative of the service and the CNS and consultant were highly praised
- CNS could be contacted any day of the working week
- Transition was working well, there was good planning, including meetings with the adult team and adult service users
- Long waiting times in the ED

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REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

The East Midlands had a strong well-developed and established haemoglobinopathy network which had been running for many years. The funding of network posts, particularly a data manager, had enabled excellent engagement with the National Haemoglobinopathy Registry (NHR), good data collection and the setting up of a robust structure for regional meetings. The network consisted of two specialist centres, Nottingham and Leicester. The Nottingham team covered the north of the region including North Nottinghamshire, Derbyshire and Lincolnshire. The adults from Sherwood Forest Hospitals NHS Foundation Trust (King's Mill Hospital, Newark Hospital) and United Lincolnshire Hospitals NHS Trust attended Nottingham for annual reviews. The service ran educational meetings three times a year (one audit, one educational, one clinical) and was producing network guidelines.

Good Practice

1 The East Midlands Network was well established and regular business and educational meetings

2 The regional multi-disciplinary meeting was an excellent resource and ensured good patient care across the region

3 Data collection was good and the data manager post, which had previously been funded on a short-term basis, now had long-term funding. Clinical data were collected from all hospitals in the network. These data were available at the peer review visit in Leicester and were detailed and comprehensive. An annual report had been produced for two years which gave detailed data and was particularly useful for future service planning.

4 The pathways of care across the network had been well worked-out and were clearly presented

Immediate Risks: No immediate risks were identified.

Concerns

1 Long-term consultant support for the service was a concern. Both specialist centres (Leicester and Nottingham) had had experienced clinical leads but the Leicester lead had retired and the Nottingham lead was due to retire within the two years following the visit. Leicester had been unable to appoint a replacement clinical lead. Reviewers suggest that the network should consider succession planning for the services.

2 Adult patients attending Derby Hospital did not have an annual review at the specialist centre and did not have access to specialist services.

Further Consideration

1 The network had a small total number of thalassaemia patients at several centres. Concentrating expertise in one centre where specialist experience can be developed may be of benefit.

2 Guidelines for services for children and young people may benefit from being updated.

3 Although the data manager had spent time at all the sites and the quality of data collection was very good, the data collected from the local centres were not complete.

4 The network may benefit from the development of clearer guidelines particularly with reference to acute management of complications, who should be referred to the multi-disciplinary meetings and indications for transfusion

5 At the time of the visit CNS support for patients from Kettering and Northampton was not provided. Short-term funding for this post had been made available and the post had been advertised. Reviewers suggested that making this post permanent should be considered.

NETWORK CONFIRGURATION

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

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
Nottingham University Hospitals NHS Trust (Nottingham City Hospital)	• Derby Teaching Hospitals NHS Foundation Trust, Royal Derby Hospital • Sherwood Forest Hospitals NHS Foundation Trust, King's Mill Hospital • United Lincolnshire Hospitals NHS Trust, Grantham and District Hospital, Lincoln County Hospital, Pilgrim Hospital Boston
Nottingham University Hospitals NHS Trust (Nottingham Children's Hospital - Queens Medical Centre)	• Derby Teaching Hospitals NHS Foundation Trust, Royal Derby Hospital • Sherwood Forest Hospitals NHS Foundation Trust, King's Mill Hospital • United Lincolnshire Hospitals NHS Trust, Grantham and District Hospital, Lincoln County Hospital, Pilgrim Hospital Boston
University Hospitals of Leicester NHS Trust (Leicester Royal Infirmary)	• Kettering General Hospital NHS Foundation Trust, Kettering General Hospital • Northampton General Hospital NHS Trust, Northampton General Hospital

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SPECIALIST HAEMOGLOBINOPATHY CENTRE ADULT SERVICE: CITY HOSPITAL

General Comments and Achievements

This was a small but high-quality service providing very good specialist care for local patients. Several improvements in the service had been made since the last visit. The service was well supported by its data manager and all patients who consented to this were registered on the National Haemoglobinopathy Registry (NHR). The Annual Review procedure was embedded in clinical practice with all patients having a comprehensive annual review, the outcome of which was copied to patients and entered onto the NHR.

A strong obstetric haematology service was in place and all pregnant haemoglobinopathy patients were reviewed regularly in this joint clinic. The first peer review visit took place in 2012 for adult services.

Progress since Last Visit:

The following progress had been made since the previous visit:

- Since February 2015, transfusions had been available for patients on the Haematology Day Unit during Saturday mornings

- Patients with haemoglobinopathies with acute complications were admitted under the care of the attending haematology consultant and reviewed by the haematology team on a daily basis, providing robust in-patient cover for the service
- Specialist MRI scans had become available (Ferriscan in Nottingham and T2* cardiac scan in Leicester)
- An integrated clinical nurse specialist had been introduced and provided hospital and community support for adult patients
- An additional community specialist nurse had been appointed who was responsible for 11to 24 year olds and also worked with the paediatric and adult clinical specialist nurse.
- A clinical psychologist post had been established within the team and worked one day in the adult service and one day in the paediatric service

Good Practice

1 The transition service was robust and well supported by the new clinical nurse specialist. The adult consultant attended the paediatric clinics four times a year and participated in the annual review appointments for several years prior to transition. The transition pathway and patient information leaflets were very clear and of high quality.

2 For both sickle cell disease and thalassaemia, the annual proforma was extremely clear and comprehensive.

3 Acute pain crises were well managed. A clear pathway of care 'the painful crisis flow chart' was used and the team had developed a unique triage tool for use by the triage nurse which was very useful in clinical practice. The majority of patients had direct admission to SRU which enabled them to bypass the ED and to receive rapid analgesia.

4 Patient information was of high quality and was comprehensive. The peer review team particularly noted patient information on exchange transfusion, the 'When to seek urgent medical care' booklet, the 'Keeping well with thalassaemia and sickle cell disease' booklets and the hydroxycarbamide information leaflet.

5 The team had developed good links with Nottingham Trent University because of the large numbers of university students with sickle cell disease. Reviewers suggested that the team may wish to consider extending this service to Nottingham University

Immediate Risks: No immediate risks were identified

Concern

1 In-patients with haemoglobinopathies were admitted to 13 different wards around the hospital. This meant that medical and nursing care could be inconsistent and was reported as a problem by several patients in the patient surveys.

Further Consideration

1 In view of the large number of wards providing medical care it was difficult to provide adequate nursing training to all the wards where patients with sickle cell disease could be placed. The sickle team were working on a system of linked nurses and an intranet training package to try and improve nursing training. Reviewers suggested that patient care would be improved by restricting haemoglobinopathy admissions to a small numbers of wards.

2 The 'hospital at night' team provided out of hours medical care for the haemoglobinopathy patients but there was no evidence of a comprehensive training programme for this group of doctors.

3 Whilst haematology specialist registrars received adequate training in looking after in-patients with sickle cell disease and were well supported educationally within a regular formal red cell teaching programme, they typically only attended one haemoglobinopathy clinic during their entire training. This was not sufficient to obtain adequate experience of management of chronic complications and the Trust should consider how they could be supported to attend additional clinics during their training.

4 The lead consultant worked three days per week and a formal arrangement for specialist advice at other times was not in place, although informal arrangements with other Trusts existed. The Trust should consider formalising links with other services to provide improved access to specialist advice. In addition the lead consultant was expecting to retire in 2017. In view of the difficulties in recruiting in this speciality and the lack of other specialists nearby the Trust should consider succession planning.

5 The service had not completed all the recommended audits and did not have a rolling programme of audit

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Specialist Haemoglobinopathy Centre Team: Services for Children and Young People, Nottingham Children's Hospital

General Comments and Achievements

This was an excellent, cohesive and well-led service. The lead nurse and lead consultant's commitment to the service was hugely appreciated by users. Evidence of forward planning to match local needs was provided together with several instances of good practice within the service. The first peer review visit took place in 2011 for children's services.

Progress since last visit

The following progress had been made since the previous visit:

- Employment of a 0.5 WTE regional clinical nurse specialist within paediatrics
- Employment of a WTE regional clinical psychologist
- Introduction of a transition programme and a clinical nurse specialist for the transition age group (11 to 24 year olds).
- Introduction of annual review clinics to include endocrinology.

Good Practice

1 The pain team was highly involved with the care of children with haemoglobin disorders and review of patients with chronic pain was available.

2 Excellent patient information leaflets were available, including a very good 'traffic light' leaflet regarding health promotion and age-specific leaflets about transfusion and chelation

3 The transition service was robust and well supported by the new clinical nurse specialist. The adult consultant attended the paediatric clinics four times a year and participated in the annual review appointments for several years prior to transition. The transition pathway and patient information leaflets were very clear and of high quality.

4 Easy access to youth workers was available. This was appreciated by users and referral to the service was likely to increase

Immediate Risks: No immediate risks were identified.

Concerns

1 Some clinical guidelines were not up to date and some guidelines had very long review dates (up to eight years). Some guidelines were not in a finalised Trust format and some still had tracked changes.

2 The workload of the lead nurse exceeded the time allocated in her job plan. Although there was a link-nurse in the day unit the review team considered that some delegation of roles to a ward link-nurse might improve the in-patient experience and allow time to develop for example, training opportunities. Identification of a ward link-nurse may also help communication with families in the lead nurse's absence.

Further Consideration

1 The third paediatric consultant role, though funded was not filled as the second substantive consultant was on maternity leave. The reviewers considered that this post was needed to support the clinical workload and retirement and should take place as soon as possible.

2 A review of the training programme for junior doctors in haematology and ED may be helpful.

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LOCAL HAEMOGLOBINOPATHY TEAM: DERBY TEACHING HOSPITALS NHS FOUNDATION TRUST

General Comments and Achievements

The peer review team spoke to the lead adult consultant at Derby Hospital. This team looked after 20 patients with sickle cell disease. The level of local care provided was reported as adequate and good continuity of care was provided by the lead consultant and clinical nurse specialist. Patients with complex needs were discussed at the regional MDT.

Immediate Risks: No immediate risks were identified.

Concern

1 Adult patients with sickle cell disease attending Derby Hospital did not have access to specialist annual reviews were. The Trust should consider developing formal links with Nottingham as its nearest specialist centre to ensure all patients receive specialist annual review.

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COMMISSIONING

General Comments and Achievements

Commissioners had been engaged with the service over many years which had enabled the development of a strong network. Additional support for the data collection post and nursing posts at the local centres had been identified.

Peterborough Hospital was not reviewed as part of the Leicester visit but the care of patients from Peterborough was discussed. It is situated only 35 miles away from Leicester but falls within East of England rather than the East Midlands commissioning area. At the time of the visit clinical links were being developed between Peterborough and Leicester but it was not clear where the haemoglobinopathy patients from Peterborough were receiving their specialist care.

Good Practice

1 The networks of care were clearly defined

2 Specialist commissioners were engaged with the service, attended network review and learning meetings and reviewed clinical quality data.

Immediate Risks: No immediate risks were identified

Concern

1 Arrangements for specialist care of patients with haemoglobin disorders from Peterborough were not clear.

Further Consideration

1 Commissioners should encourage discussion of consultant succession planning across the network. Reviewers suggested that this could include closer working between the haematology services at the two specialist centres.

2 CNS support for adult patients from Kettering and Northampton was not in place at the time of the review and commissioner support may be needed to ensure progress is made with a substantive appointment.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Leads:

Dr Subarna Chakravorty	Consultant Haematologist	Kings College Hospital NHS Foundation Trust
Dr Jo Howard	Consultant Haematologist	Guy's and St Thomas' NHS Foundation Trust

Visiting Team:

Baaba Davis	Service User	Not applicable
Claire Foreman	Senior Programme of Care Manager – Blood and Infection	Specialised Commissioning, NHS England
Pauline Garnett	Haemoglobinopathy Genetic Counsellor	Bradford Teaching Hospitals NHS Foundation Trust
Sajid Hussain	Service User	Not applicable
Dr Lola Oni	Specialist Nurse Consultant	London North West Healthcare NHS Trust
Dr Elizabeth Rhodes	Consultant Haematologist	St George's University Hospitals NHS Foundation Trust
Dr Kate Ryan	Consultant Haematologist	Central Manchester University Hospitals NHS Foundation Trust
Louise Smith	Sickle Cell Clinical Nurse Specialist	Alder Hey Children's NHS Foundation Trust

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

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

Table 1 - Percentage of Quality Standards met

Adult Services	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	43	32	74
Haemoglobin Disorders Clinical Network	9	5	56
Commissioning	3	3	100
Total	55	40	73

Services for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	49	38	78
Haemoglobin Disorders Clinical Network	9	6	67
Commissioning	3	3	100
Total	61	47	77

Pathway and Service Letters

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

Topic Sections

Each section covers the following topics:

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

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SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

		Adult Services		Services 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	Good leaflets were available on clinical psychology. Also good information about services was available in the community.

		Adult Services		Services 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	Good information was available on exchange transfusion and the leaflet 'keeping well with sickle cell disease' was very detailed and relevant. However ‘c’ was not clear and information for ‘g i ‘ was generic rather than specific to haemoglobin disorders.	Y	

		Adult Services		Services 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	N	Information covering 'e' was not sent to the primary care team.	Y	The GP letter was comprehensive.
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	A summary of their annual review was provided to patients. Some patients had a detailed care plan in the day service.	Y	

		Adult Services		Services 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	An in depth leaflet was available for schools.
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	Information for schools and teachers was good.	Y	

		Adult Services		Services 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	
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	Evidence from 'past, present and future events' was good. Thirty patient surveys and a summary sheet were provided.	y	

		Adult Services		Services 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	However more evidence of continuing professional development specifically linked to haemoglobin disorders would be useful.
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	Cover was provided by haematology -oncology colleagues but evidence of their continuing professional development for haemoglobin disorders was not provided. In the absence of the lead consultant specialist advice was accessed from elsewhere.	Y	Continuing professional development evidence was not seen for the deputy on maternity leave.

		Adult Services		Services 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	However evidence for the RCN competences was not present.

		Adult Services		Services 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	Evidence of training for non-haematology staff providing out of hours care was not available. Some difficulties in getting ward nursing staff to attend training was reported as a large number of wards were used for admission of patients with haemoglobin disorders.	Y	
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	A training plan was available but it had not yet been activated. Plans for linked nurse training and intranet training were under development.	Y	A formal training plan was not yet in place but training was undertaken with nurses in the ED and on the wards.

		Adult Services		Services 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 specialist consultant was only available three days per week and arrangements for cover were not clear.	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	Regular training for Emergency Department staff was not provided.	N	A rolling teaching programme for paediatric and Emergency Department nurses was being planned.
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.	N	Adequate in-patient training and good red cell training days were provided but no (or minimal) out-patient attendances were provided.	Y	

		Adult Services		Services 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	
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		Y	However some doubt was expressed about the future of the post.
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.	Y	Psychologist support was available one day per week.	Y	

		Adult Services		Services 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	

		Adult Services		Services 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.	Y	Services for 'b' were provided in Sheffield.	Y	

		Adult Services		Services 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.	N	Ward facilities were not adequate for the number of patients. Patients had been seen on 13 different wards over the last 12 months and were rarely admitted onto haematology ward.	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.	Y	Top up transfusions were available on Saturday mornings.	Y	

		Adult Services		Services 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	Documentation was still in progress but the intention was to adopt 'ready steady go'.
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 annual review proforma was in use.	Y	

		Adult Services		Services 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	See page 14 of the main report for reference to Derby Hospital.
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		N	However guidelines for 'b' were not present.

		Adult Services		Services 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 Services		Services 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	Although good pain guidelines were available, guidelines for 'h' 'i' and 'j' were not provided.	N	Including pain management and a summary of complication management for ED would be helpful. Guidelines for 'h', 'i', 'j', 'l' and 'm' were not present.
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	Good guidelines were available for hydroxycarbamide monitoring and pre-operative guidance.	N	Network-agreed clinical guidelines were not yet in use.

		Adult Services		Services 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)	Y		N	Network-agreed clinical guidelines on 'c', 'd', 'e', 'f', 'g', 'h' and 'i' were not covered.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y		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	However indications for splenectomy were out with national/international recommendations.	N	The guidelines needed to be revised.

		Adult Services		Services 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		N	Clinical guidelines for the monitoring and management of acute and chronic complications were not available.

		Adult Services		Services 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		N	Guidelines on Trans-Cranial Doppler ultrasound were not yet in use.

		Adult Services		Services 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' was not applicable.	Y	

		Adult Services		Services 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		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	Community services were part of the Trust.	N/A	Community services were part of the Trust.
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	
HN-605 SHC	**Neonatal screening programme review meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	N/A		N	Meetings with representatives of the neonatal screening programme were not yet in place.

		Adult Services		Services 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		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	Y	The interim report was very good.	Y	

		Adult Services		Services 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	Y	The annual report was very good.	Y	The annual report was very good.

		Adult Services		Services 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	An audit had shown that whilst the 30 minute target was met in 82% of the cases some of the other standards were not met for example, oxygen was not always given and follow up pain assessment was not done.	Y	

		Adult Services		Services 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 yet have a rolling programme of audit.	Y	
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N	The SHC did not participate in research relating to the care of patients with haemoglobin disorders.	N	The SHC did not participate in research relating to the care of patients with haemoglobin disorders.
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	

		Adult Services		Services 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		N	No evidence was seen of multi-disciplinary review and learning.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adult Services		Services 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	The network did not yet have mechanisms for involving patients and their carers from all services in the work of the network. Patient events were held in the Nottingham part of the network.	N	The network aspiration was to engage patients but this had not yet been achieved in the network.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	Y	A good flow chart of who did what in network was seen.	Y	Insufficient time was allocated in the job plan of network 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.	Y	A well-established programme of education and training was in place across the network.	Y	A well-established programme of education and training was in place across the network.

		Adult Services		Services for Children and Young People	
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-wide guidelines were not yet in place, both SHCs in the network used their own local guidelines.	N	Network-wide guidelines were not yet in place, both SHCs in the network used their own local guidelines.

		Adult Services		Services 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-wide guidelines were not yet in place, both SHCs in the network used their own local guidelines.	N	Network-wide guidelines were not yet in place, both SHCs in the network used their own local guidelines.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	Y	Monitoring was done systematically by the data manager.	Y	Monitoring was done systematically by the data manager.

		Adult Services		Services 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.	Y	Network-wide audits were in place covering NICE compliance.	Y	
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		Y	However the network needed to facilitate trials.
HY-798	**Network Review and Learning** The SHC should meet at least twice a year with its referring LHT teams to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from any positive feedback or complaints involving liaison between teams d. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams e. Consider the content of future training and awareness programmes (QS HY-202)	Y	The evidence of business and educational meetings was good.	Y	

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COMMISSIONING

		Adult Services		Services 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	Y	Arrangements for annual reviews of patients at Derby Hospital were not yet in place. Commissioners may want to review whether a single centre for care of patients with thalassaemia may be helpful.	Y	
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	Y		Y	

		Adult Services		Services 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.	Y		Y	

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