

# Health Services for People with Haemoglobin Disorders

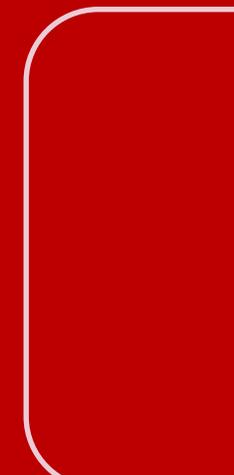
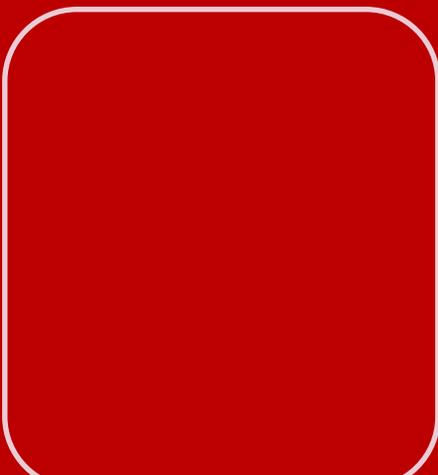
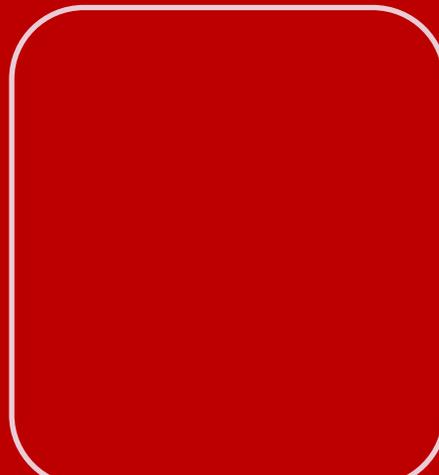
## East Midlands Network

### University Hospitals of Leicester NHS Trust

Visit Date: 11<sup>th</sup> February 2016

Report Date: June 2016

*Images courtesy of NHS Photo Library*



**INDEX**

- Introduction ..... 3**
- Haemoglobin Disorders Services in East Midlands Network ..... 4**
  - Adult Services – Leicester Royal Infirmary .....4
  - Children and Young People – Leicester Royal Infirmary.....5
- Review Visit Findings..... 7**
  - Network ..... 7
  - Specialist Team: University Hospitals of Leicester NHS Trust – Adult Services ..... 8
  - Local Haemoglobinopathy Team: Northampton General Hospital NHS Trust and Kettering General Hospital NHS Foundation Trust .....10
  - Specialist Team: University Hospitals of Leicester NHS Trust – Services for Children and Young People .....11
  - Commissioning .....12
- Appendix 1 Membership of Visiting Team..... 14**
- Appendix 2 Compliance with the Quality Standards..... 15**
  - Specialist Services for People with Haemoglobin Disorders .....16
  - Haemoglobin Disorders Clinical Network .....43
  - Commissioning .....47

## INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in University Hospitals of Leicester NHS Trust (part of the East Midlands network), which took place on 11<sup>th</sup> February 2016. 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:

- University Hospitals of Leicester NHS Trust
- NHS England Specialised Commissioning
- NHS Leicester 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 University Hospitals of Leicester 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](http://www.wmqrs.nhs.uk)

## HAEMOGLOBIN DISORDERS SERVICES IN EAST MIDLANDS NETWORK

### Adults

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
University Hospitals of Leicester NHS Trust	SHC	95/101	29/30	15
Kettering General Hospital NHS Foundation Trust	LHT	23	0	0
Northampton General Hospital NHS Trust	LHT	38	<5	0

### Children and Young People

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
University Hospitals of Leicester NHS Trust	SHC	41/45	<5	<5
Kettering General Hospital NHS Foundation Trust	LHT	25	<5	<5
Northampton General Hospital NHS Trust	LHT	50	<5	<5

## ADULT SERVICES – LEICESTER ROYAL INFIRMARY

### Emergency Care

Patients requiring emergency hospital admission were encouraged to call the dedicated triage nurse on a 24 hour helpline. This triage nurse was not specific to haemoglobinopathy and used a generic triage tool to direct the patients to the day care unit or assessment unit based in Osborne Building. This ensured direct admission to the care of the haematology 'blue' team rather than going to the Emergency Department. If beds were not available on the assessment unit patients were directed to the Emergency Department, but this was a rare occurrence and staff could not remember the last time they had not been able to accept a patient. The assessment unit was shared between oncology and haematology. Patients not known to the service would be admitted via the Emergency Department where they had specific guidelines on treating patients with sickle cell disease in crisis who would then be referred straight to the assessment unit.

### In-Patient Care

All patients with haemoglobinopathy were admitted to the haematology wards 41, 40 and 39 under the care of the 'blue team' which was staffed by the haemoglobinopathy lead or deputy and a specialist registrar. Junior doctors were ward-based and not team-based. Out of hours care was provided by a haematology consultant and specialist registrar.

## **Day Care**

The day care unit was open from Monday to Saturday between 8am and 6pm. Patients with sickle cell disease and thalassaemia attended the unit for blood transfusion and red cell exchanges. Saturday transfusions could be accommodated.

## **Out-Patient Care**

The dedicated out-patient clinic area was on the ground floor of Osborne Building. Patients with haemoglobinopathies were seen in a designated clinic on Tuesday afternoon. This was a multi-disciplinary clinic attended by the Clinical Nurse Specialist and Clinical Psychologist in addition to the consultant haematologist. Annual reviews were performed as part of the clinic.

In order to give flexibility to patients, the lead consultant had provided a monthly Saturday whole-day clinic since November 2015. Positive feedback was received from patients and the 'did not attend' rate was negligible.

## **Community-Based Care**

Community care was provided in the Merlyn Vaz Health and Social Care Centre which was open from Monday to Friday, between 8.30am and 5.00pm. It was staffed by two w.t.e registered nurses and one w.t.e support worker. They supported patients with haemoglobinopathies and their families and undertook school and home visits if needed. In the previous year they had carried out 900 pre-conception tests, antenatal counselling with 230 couples and post-natal counselling with 150 couples.

At the time of the visit this team was situated in a large GP practice but plans were in place to move the service into the hospital. This would allow closer working between the community services and secondary care and would encourage 'seamless' transition between the two teams.

Return to [Index](#)

## **CHILDREN AND YOUNG PEOPLE – LEICESTER ROYAL INFIRMARY**

### **Emergency Care**

Paediatric patients had direct access to the Children's Admissions Unit (CAU) on the 3rd Floor, Balmoral Building. They were advised to call ahead of arrival. Patients brought in by ambulance were also directed to CAU unless the patient was critically ill, in which case they were taken directly to the Paediatric Emergency Department.

### **In-Patient Care**

Care for malignant haematology, oncology and haemoglobinopathy patients was provided in ward 27. The ward had five beds for teenagers and young adults and seven paediatric beds. Patients had access to the ward chef. If older than 13 years, they had access to an adolescent 'chill out' room. If beds were unavailable in Ward 27, patients were admitted to the adjacent general paediatric ward. A Paediatric High Dependency Unit with six beds and a Paediatric Intensive Care Unit with nine beds were available on-site.

### **Day Care**

Services were provided in the oncology day care area of Ward 27 which opened between 8.00am and 6.30pm from Monday to Friday and between 8.00am and 4.00pm on Saturdays. All weekend transfusions took place in the Ward 27 day care unit.

### **Out-Patient Care**

A monthly multi-disciplinary team clinic took place in the Children's Out-patient Department where patients underwent their Transcranial Doppler scanning and also met the psychologist and the clinical nurse specialist (CNS) if needed.

### **Community Based Care**

The community service was in the process of being merged with the acute hospital service but at the time of the visit, the team was based in the Mervyn Vaz Health Centre, located in Leicester city centre.

Return to [Index](#)

## **VIEWS OF SERVICE USERS AND CARERS**

### **Adult Services**

The visiting team met a small number of patients and carers with sickle cell disease and thalassaemia and received feedback from them. They received responses to 36 adult questionnaires.

Common themes raised by patients and carers were:

- Patients and carers were happy with the care they received from the medical and nursing teams
- Patients felt that community services had decreased and become less readily available in recent years
- Some patients said that they had to wait more than 30 minutes in the assessment unit for analgesia and that some staff there were not well informed about their condition

### **Services for Children and Young People**

The visiting team met a small number of patients and carers with sickle cell disease and thalassaemia and received feedback from them. They received responses to 31 questionnaires.

Common themes raised by patients and carers were:

- Carers and patients were happy with service from the paediatric Clinical Nurse Specialist (CNS) and paediatric consultants
- Some carers expressed their concern about a knowledge gap in providing care for haemoglobinopathy patients among staff in the Children's Assessment Unit and called for more staff training and information
- Some carers were unaware that emergency care plans were in place in the hospital for all children who attended the service
- Parents mentioned that they had experienced long waits for pain relief when their children presented with acute pain

Return to [Index](#)

## 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 Leicester team covered the south of the region including Northamptonshire and Kettering. 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 had regular business and educational meetings. The regional multi-disciplinary meeting was an excellent resource and ensured good patient care across the region.
- 2 Data collection was good and the data manager post, which had previously been funded on a short-term basis, had long-term funding agreed prior to the visit. 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.
- 3 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 lead 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 could 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 review visit 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.
- 6 Reviewers suggested that the Network should work with the local hospitals to improve access to emergency exchange transfusions and to routine T2\* scans and should clarify arrangements for transition of transfused patients from Northampton and Kettering.

## NETWORK CONFIGURATION

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)	<ul style="list-style-type: none"> <li>• Derby Teaching Hospitals NHS Foundation Trust, Royal Derby Hospital</li> <li>• Sherwood Forest Hospitals NHS Foundation Trust, Kings Mill Hospital</li> <li>• United Lincolnshire Hospital NHS Trust, Grantham &amp; District Hospital, Lincoln County Hospital, Pilgrim Hospital, Boston</li> </ul>
Nottingham University Hospitals NHS Trust (Nottingham Children’s Hospital - Queens Medical Centre)	<ul style="list-style-type: none"> <li>• Derby Teaching Hospitals NHS Foundation Trust, Royal Derby Hospital</li> <li>• Sherwood Forest Hospitals NHS Foundation Trust, Kings Mill Hospital</li> <li>• United Lincolnshire Hospital NHS Trust, Grantham &amp; District Hospital, Lincoln County Hospital, Pilgrim Hospital, Boston</li> </ul>
University Hospitals of Leicester NHS Trust (Leicester Royal Infirmary)	<ul style="list-style-type: none"> <li>• Kettering General Hospital NHS Foundation Trust, Kettering General Hospital</li> <li>• Northampton General Hospital NHS Trust, Northampton General Hospital</li> </ul>

Arrangements for specialist care for patients from Peterborough were under discussion at the time of the review visit.

Return to [Index](#)

## SPECIALIST TEAM: UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST – ADULT SERVICES

### General Comments and Achievements

This was a high quality service with lots of good features. The clinical staff, particularly the clinical nurse specialist, were highly valued by patients and were providing care in an innovative way. The service had been under pressure since the retirement of the previous haemoglobinopathy lead in 2015 and the Trust had been unable to appoint to this post. The Clinical Lead had stepped into the role of haemoglobinopathy lead and was supporting the service while longer-term solutions were sought.

Patient information was of generally high quality, with good information for students. The community service had performed well on its own recent peer review. The Teenage and Young Adults Unit was high quality and could be accessed by patients with haemoglobinopathies. A good training plan was in place for medical and nursing staff. The majority of patients were admitted directly to the Assessment Unit, avoiding admission to the Emergency Department.

The Trust had showed commitment to the development of a regional service evidenced by recent permanent funding of the data manager post. Reviewers commented that it is important for the survival of the network that this post continues.

### **Progress since the last visit**

Progress since the last peer review visit in June 2012 included the availability of Ferriscan and the T2\* Ferriscan in Leicester. In addition, out of hours provision of care had been improved.

### **Good Practice**

- 1 The out of hours service was extensive as the day unit was open for extended hours during the week and was open every Saturday and an out-patient clinic was available one Saturday per month.
- 2 Multi-disciplinary meetings (MDMs) were well established and embedded within the service. Local MDMs took place on a monthly basis and all serious adverse events, pregnant patients, newly transfused and transition patients were discussed. In addition, regional MDMs were held quarterly. Minutes for both MDMs were available.
- 3 Data collection was thorough and of a high standard, with all patients having an Annual Review entered on the NHR. These details were all copied to the patients.
- 4 The annual review proforma was thorough.
- 5 The 'Sickle Emergency Treatment Cards' which were designed to be worn on the ID badge were a simple and innovative aide memoire for staff.

**Immediate Risks:** No immediate risks were identified.

### **Concerns**

- 1 The CNS had a large workload and arrangements for cover for absences was not robust. They covered the Saturday service by working bank shifts and answered their work phone even when not on duty. The role of the community team was under review. Whilst they provided a comprehensive service and received good patient feedback, some aspects of their care (for example, reviewing all new births with traits) should be reviewed and this may allow increased support of the hospital nursing team.
- 2 The lack of a robust succession plan for the lead consultant was of concern. The previous lead had retired the previous year and the Trust had not been able to fill this post. Although the Clinical Lead was supporting the service, reviewers did not consider they had adequate time in their job plan for this role. In addition, support was being provided by the Clinical Lead at the neighbouring SHT in Nottingham, who was also due to retire in the year following the visit. The Trust was looking at innovative ways of developing the post and finding a long-term solution and this issue was recorded in the Trust risk register.

### **Further Consideration**

- 1 Many of the guidelines needed to be updated as they did not reflect current practice. For example the pre-operative transfusion guideline and indications for hydroxycarbamide guideline were both out of date.

- 2 There was no patient information for the use of hydroxycarbamide. In combination with the out of date guideline, this may have explained the small numbers of patients on hydroxycarbamide treatment.
- 3 Mandatory audits had not all been completed at the time of the visit.
- 4 Whilst the system of direct access to the assessment unit worked well, the triage tool used was not specific and would not identify all the acute complications of sickle cell disease. A more specific triage tool may be useful.
- 5 The apheresis service was very busy and capacity for expansion was limited.
- 6 Although only small numbers of patients attended the Emergency Department there was no evidence of regular training in the care of people with haemoglobinopathies for Emergency Department staff.
- 7 A service operational policy was not in place although many of the aspects covered by the operational policy were seen as separate documents.

Return to [Index](#)

## LOCAL HAEMOGLOBINOPATHY TEAM: NORTHAMPTON GENERAL HOSPITAL NHS TRUST AND KETTERING GENERAL HOSPITAL NHS FOUNDATION TRUST

### General Comments and Achievements

Reviewers spoke to adult haematologists at Northampton General Hospital and Kettering General Hospital. At the time of the review visit the adult lead at Northampton had only 0.06 Programmed Activity in their job plan for the care of haemoglobinopathy patients. The number and complexity of patients had increased three-fold in the previous eight years with no additional resource. Patients were seen by all the haematology consultants in the out-patient clinics. An annual review clinic had been set up and was attended by the local lead clinician, the CNS, psychologist and data manager from Leicester. It was planned that the lead from Leicester would also attend this clinic although this had not yet happened. The local lead clinician participated in the regional meetings and multi-disciplinary meetings.

The adult lead at Kettering General Hospital or their deputy reviewed all the haemoglobinopathy patients and had been in post for many years. Patients were reviewed at least twice a year in the general haematology clinic. In addition two annual review clinics were held per annum and were attended by the CNS and psychologist from Leicester. The data manager entered their annual reviews onto the NHR. They felt well supported by the specialist team, particularly by the regional multi-disciplinary team meetings (MDT) and they would refer complex patients to the regional MDT or to the specialist centre. They felt the service would benefit from improved arrangements for transition, particularly of transfused patients, from direct access to T2\* scanning and from improved access to exchange transfusions in the emergency situation.

### Concerns

- 1 Staff at Northampton General Hospital did not feel well supported by the network and felt that patients attending there did not get the same service as was provided at the Specialist Centre. It was not clear to the reviewers that this was a network issue as the lead clinician only had 0.06PA in their job plan for haemoglobin disorders services and suggested that the job plan of the lead clinician is reviewed to ensure there is adequate time for service provision for this patient group.

### Further Consideration

- 1 At the time of visit there was no CNS support (acute or community) for either Northampton or Kettering. A CNS post covering both adult and paediatric services at both hospitals had been funded on a permanent basis and was being advertised.

- 2 Reviewers suggested that the Network should work with the local hospitals to improve access to emergency exchange transfusions and to routine T2\* scans and should clarify arrangements for transition of transfused patients.

Return to [Index](#)

## SPECIALIST TEAM: UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST – SERVICES FOR CHILDREN AND YOUNG PEOPLE

### Progress since Last Visit

Since the last peer review visit, in May 2010, the paediatric service demonstrated significant progress in the establishment of the haemoglobinopathy service. Evidence of excellent medical and nursing leadership with innovative collaborations within the children's services was seen. A number of achievements were noteworthy, such as:

- Appointment of substantive lead and deputy consultants
- Appointment of 0.5 w.t.e. acute clinical nurse specialist
- Outreach clinics to local haemoglobinopathy teams established
- Close collaboration with the paediatric pain team
- Poster presentation at International Forum on Quality and Safety in Healthcare 2014
- Standardised clinic templates and transfusion record to ensure patient consistency
- Provision of Ferriscan technology
- Established transition programme
- Improved out-patient 'did not attend' rate with one-stop multi-disciplinary team clinics
- 100% entry onto the National Haemoglobinopathy Registry
- Good recent report from the screening programme peer review

### Good Practice

- 1 The service provided patient information sheets which were of a good standard. Among these, the psychology information sheet, information to GPs and parents about the chronic pain service, pain tool questionnaire, 'did not attend' follow up questionnaire by the community team and a 'new to area' questionnaire developed by the community team were of a particularly good standard.
- 2 A paediatric chronic pain service with the haemoglobinopathy lead clinician as a key member of the team was in place.
- 3 Teenagers and young adults (TYA) up to the age of 24 had access to the Teenage and Young Adult admission unit in Ward 27. All patients over 18 were managed by the adult team but nursing care was provided by the paediatric team on Ward 27. This ensured continuity of nursing care.
- 4 A well-established monthly multi-disciplinary meeting took place between the paediatric, adult and community services.
- 5 Quarterly video conferencing with SHCs and LHTs in the East Midlands, Sickle Cell and Thalassaemia Network was operational and provided an excellent network-wide sharing opportunity.

**Immediate Risks:** No immediate risks were identified.

## Concerns

- 1 Audit of waiting time to analgesia had not been completed. All patients who were met on the day of the review complained about waiting time for pain relief. The review team acknowledged that changes had been put in place to improve the service, but an audit is needed to demonstrate that the waiting time to analgesia has improved.

## Further Consideration

- 1 Guidelines were out of date and required updating.
- 2 As with other small services, building up expertise in the case of patients with haemoglobin disorders was difficult due to small numbers, hence collaborative working within the region is important. This was demonstrated by the good networking practice within the East Midlands Network but might be enhanced by, for example, more regional learning and education opportunities for CNS or junior medical staff.
- 3 A service operational policy was not in place although many of the aspects covered by the operational policy were seen as separate documents.
- 4 Mandatory audits had not all been completed at the time of the visit.
- 5 Policies for escalation of clinical care from Northampton and Kettering were not clearly documented at the time of the review visit.

Return to [Index](#)

## COMMISSIONING

### General Comments and Achievements

Commissioners had been involved 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. Clinical links were being developed between Peterborough and Leicester and a meeting between the teams was planned but at the time of the visit 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 at the time of the visit.
- 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 Commissioners could 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 Clinical nurse specialist 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.

Return to [Index](#)

## APPENDIX 1 MEMBERSHIP OF VISITING TEAM

### Clinical Leads

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

### Visiting Team

Baaba Davis	Service User	Not applicable
Linda Devereux	Commissioner	NHS England Specialised Commissioning Team - Cheshire Warrington and Wirral Area Team
Sajid Hussain	Service User	Not applicable
Louise Smith	Sickle Cell Clinical Nurse Specialist	Alder Hey Children's NHS Foundation Trust
Aldine Thomas	Clinical Nurse Specialist Haemoglobinopathies	Barts Health NHS Trust
Siobhan Westfield	Service User	Not applicable
Neil Westerdale	Advanced Nurse Practitioner Haemoglobinopathies	Guy's and St Thomas' NHS Foundation Trust

Return to [Index](#)

## APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

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

**Table 1 - Percentage of Quality Standards met**

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	44	35	80
Haemoglobin Disorders Clinical Network	9	5	56
Commissioning	3	3	100
<b>Total</b>	<b>56</b>	<b>43</b>	<b>77</b>

Paediatric Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	49	44	90
Haemoglobin Disorders Clinical Network	9	6	67
Commissioning	3	3	100
<b>Total</b>	<b>61</b>	<b>53</b>	<b>87</b>

### Pathway and Service Letters

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

### Topic Sections

Each section covers the following topics:

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

Return to [Index](#)

## SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-101 All	<p><b>Haemoglobin Disorder Service Information</b></p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> <li>a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services</li> <li>b. Clinic times and how to change an appointment</li> <li>c. Ward usually admitted to and its visiting times</li> <li>d. Staff of the service</li> <li>e. Community services and their contact numbers</li> <li>f. Relevant national organisations and local support groups</li> <li>g. Where to go in an emergency</li> <li>h. How to:               <ol style="list-style-type: none"> <li>i. Contact the service for help and advice, including out of hours</li> <li>ii. Access social services</li> <li>iii. Access benefits and immigration advice</li> <li>iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent)</li> <li>v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns</li> <li>vi. Get involved in improving services (QS HN-199)</li> </ol> </li> </ol>	Y	Specific guidelines were also provided for students attending de Montfort University.	Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-102 All	<p><b>Information about Haemoglobin Disorders</b></p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> <li>a. A description of the condition (SC or T), how it might affect the individual and treatment</li> <li>b. Problems, symptoms and signs for which emergency advice should be sought</li> <li>c. How to manage pain at home (SC only)</li> <li>d. Splenic palpation and Trans-Cranial Doppler scanning (children only)</li> <li>e. Transfusion and iron chelation</li> <li>f. Possible complications, including priapism and complications during pregnancy</li> <li>g. Health promotion, including: <ol style="list-style-type: none"> <li>i. Information on contraception and sexual health</li> <li>ii. Travel advice</li> <li>iii. Vaccination advice</li> <li>iv. Stopping smoking</li> </ol> </li> <li>h. National Haemoglobinopathy Registry, its purpose and benefits</li> <li>i. Self-administration of medications and infusions</li> </ol>	Y	Information was well-organised.	Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-103 All	<p><b>Information for Primary Health Care Team</b></p> <p>Written information should be sent to the patient's primary health care team covering available local services and</p> <ol style="list-style-type: none"> <li>a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC)</li> <li>b. Side effects of medication, including chelator agents [SC and T]</li> <li>c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs).</li> <li>d. Immunisations</li> <li>e. Indications and arrangements for seeking advice from the specialist service</li> </ol>	Y	However 'c' was not applicable.	Y	However 'c' was not applicable.
HN-104 All	<p><b>Care Plan</b></p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> <li>a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> <li>i. Information about their condition</li> <li>ii. Plan for management in the Emergency Department</li> <li>iii. Planned acute and long-term management of their condition, including medication</li> <li>iv. Named contact for queries and advice</li> </ol> </li> <li>b. A permanent record of consultations at which changes to their care are discussed</li> </ol> <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p>	Y		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-105 All	<p><b>School Care Plan (Paediatric Services Only)</b></p> <p>A School Care Plan should be agreed for each child or young person covering, at least:</p> <ol style="list-style-type: none"> <li>School attended</li> <li>Medication, including arrangements for giving / supervising medication by school staff</li> <li>What to do in an emergency whilst in school</li> <li>Arrangements for liaison with the school</li> </ol>	N/A		Y	However, patients reported that the care plans were not in use.
HN-106 SHC (A-LHT)	<p><b>Transition to Adult Services</b></p> <p>Young people transferring to the care of adult services should be offered written information covering at least:</p> <ol style="list-style-type: none"> <li>Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer</li> <li>A joint meeting between children's and adult services to plan the transfer</li> <li>A named coordinator for the transfer of care</li> <li>A preparation period prior to transfer</li> <li>Arrangements for monitoring during the time immediately after transfer</li> </ol>	Y		Y	Although an example of the application of these documents was not seen.

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-107 SHC	<p><b>Information about Trans-Cranial Doppler Ultrasound</b></p> <p>Written information should be offered to patients and their carers covering:</p> <ul style="list-style-type: none"> <li>a. Reason for the scan and information about the procedure</li> <li>b. Details of where and when the scan will take place and how to change an appointment</li> <li>c. Staff who will be present and will perform the scan</li> <li>d. Any side effects</li> <li>e. Informing staff if the child is unwell or has been unwell in the last week</li> <li>f. How, when and by whom results will be communicated</li> </ul>	N/A		Y	
HN-199 All	<p><b>Involving Patients and Carers</b></p> <p>The service's involvement of patients and carers should include:</p> <ul style="list-style-type: none"> <li>a. Mechanisms for receiving feedback from patients and carers</li> <li>b. An annual patient survey (or equivalent)</li> <li>c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service</li> <li>d. Examples of changes made as a result of feedback and involvement of patients and carers</li> </ul>	Y	Improved opening hours for transfusion, including on Saturday, was provided following involvement of patients and carers.	Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-201 All	<p><b>Lead Consultant</b></p> <p>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.</p>	Y	The lead consultant had retired in 2015 and the deputy consultant had taken on the lead role as it had not been possible to make an appointment for a replacement lead.	Y	
HN-202 All	<p><b>Cover for Lead Consultant</b></p> <p>Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.</p>	Y		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-203 All	<p><b>Lead Nurse</b></p> <p>A lead nurse should have appropriate time available for their leadership role and:</p> <ul style="list-style-type: none"> <li>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders</li> <li>b. Responsibility for liaison with other services within the network</li> <li>c. RCN competences in caring for people with haemoglobin disorders</li> <li>d. Competences in the care of children and young people (children's services only)</li> </ul>	Y	The workload of the acute clinical nurse specialist was extensive and should be reviewed.	Y	A competence-based job plan was seen.

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-204 All	<p><b>Staffing Levels and Competences</b></p> <p>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> <li>Medical staffing for clinics and regular reviews</li> <li>Medical staffing for emergency care, in and out of hours</li> <li>Nurse staffing on the ward and day unit</li> <li>Clinical nurse specialist/s with responsibility for the acute service</li> <li>Clinical nurse specialist/s with responsibility for the community service</li> <li>Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion.</li> <li>Clinical or health psychologist with an interest in haemoglobin disorders</li> </ol> <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT).</p> <p>Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders.</p> <p>Cover for absences should be available.</p>	N	<p>However the lead had stepped into the role shortly before the review visit and was receiving development support.</p> <p>Cover for absence of the acute clinical nurse specialist was not in place.</p>	Y	
HN-205 All	<p><b>Competences and Training</b></p> <p>A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).</p>	Y		N	All nursing staff were not developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-206 SHC	<b>Specialist Advice</b> During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y	However the lead had stepped into the role shortly before the review visit and was supported by staff from the Nottingham SHC.	Y	
HN-207 All	<b>Training for Emergency Department Staff</b> 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	Few patients attended the Emergency Department as referral was straight to the Osbourne Assessment unit.	N	Few patients attended the Emergency Department as direct access to the Children's Admission Unit was available.
HN-208 All	<b>Safeguarding Training</b> 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	Although the staff safeguarding documents were not seen during the visit these were provided shortly after the visit and reviewed.
HN-209 SHC	<b>Doctors in Training</b> The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-210 SHC	<p><b>Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)</b></p> <p>Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.</p>	N/A		Y	
HN-299 All	<p><b>Administrative, Clerical and Data Collection Support</b></p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p>	Y		Y	
HN-301 All	<p><b>Support Services</b></p> <p>Timely access to the following services should be available:</p> <ul style="list-style-type: none"> <li>a. Psychologist with an interest in haemoglobinopathies</li> <li>b. Social worker</li> <li>c. Leg ulcer service</li> <li>d. Play specialist (children's services only)</li> <li>e. Chronic pain team</li> <li>f. Dietetics</li> <li>g. Physiotherapy</li> <li>h. Occupational therapy</li> <li>i. Mental health services (adult and CAMHS)</li> </ul> <p>In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.</p>	Y		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-302 SHC	<p><b>Specialist On-site Support</b></p> <p>Access to the following specialist staff and services should be available on the same hospital site as the specialist team:</p> <ul style="list-style-type: none"> <li>a. Manual exchange transfusion (24/7)</li> <li>b. Acute pain team including specialist monitoring of patients with complex analgesia needs</li> <li>c. Consultant obstetrician with an interest in care of people with haemoglobin disorders</li> <li>d. Respiratory physician with interest in chronic sickle lung disease</li> <li>e. High dependency care, including non-invasive ventilation</li> <li>f. Intensive care (note 2)</li> </ul>	Y		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-303 SHC A-LHT	<p><b>Specialist Services - Network</b></p> <p>Access to the following specialist staff and services should be available:</p> <ul style="list-style-type: none"> <li>a. Erythrocytapheresis</li> <li>b. Pulmonary hypertension team</li> <li>c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis</li> <li>d. Consultant cardiologist</li> <li>e. Consultant endocrinologist</li> <li>f. Consultant hepatologist</li> <li>g. Consultant neurologist</li> <li>h. Consultant ophthalmologist</li> <li>i. Consultant nephrologist</li> <li>j. Consultant urologist with expertise in managing priapism and erectile dysfunction</li> <li>k. Orthopaedic service</li> <li>l. Specialist imaging, including <ul style="list-style-type: none"> <li>i. MRI tissue iron quantification of the heart and liver</li> <li>ii. Trans-Cranial Doppler ultrasonography (children)</li> </ul> </li> <li>m. Neuropsychologist</li> <li>n. DNA studies</li> <li>o. Polysomnography and ENT surgery</li> <li>p. Bone marrow transplantation services</li> </ul> <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p>	Y		Y	Red blood cell exchange was provided by Birmingham Children's Hospital.

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-304 All	<b>Laboratory Services</b> 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	<b>Facilities Available</b> 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	Facilities for teenagers and young adults were good.	Y	
HN-402 All	<b>Facilities for Out of Hours Care</b> Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	Good access to Saturday transfusions and clinic was available.	Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-501 SHC A-LHT	<p><b>Transition Guidelines</b></p> <p>Network-agreed guidelines on transition to adult care should be in use covering at least:</p> <ul style="list-style-type: none"> <li>a. Age guidelines for timing of the transfer</li> <li>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</li> <li>c. Allocation of a named coordinator for the transfer of care</li> <li>d. A preparation period and education programme relating to transfer to adult care</li> <li>e. Communication of clinical information from paediatric to adult services</li> <li>f. Arrangements for monitoring during the time immediately after transfer to adult care</li> <li>g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams</li> </ul>	Y		Y	The Trust was planning to change the document to 'Ready, steady, go' as the document in use at the time of the review was out of date.
HN-502 All	<p><b>Monitoring Checklists</b></p> <p>Checklists should be in use for:</p> <ul style="list-style-type: none"> <li>a. First out-patient appointment (SHC &amp; A-LHT only)</li> <li>b. Routine monitoring</li> <li>c. Annual review (SHC &amp; A-LHT only)</li> </ul> <p>Use of the checklists should cover both clinical practice and information for patients and families.</p>	N	A good annual review checklist was in use but a checklist for 'a' was not yet in use.	Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-503 LHT	<p><b>Clinical Guidelines: LHT Management and Referral</b></p> <p>Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.</p>	N/A	Network agreed guidelines for indications for advice or transfer were not yet available.	N/A	
HN-504 All	<p><b>Transfusion Guidelines</b></p> <p>Transfusion guidelines should be in use covering:</p> <ol style="list-style-type: none"> <li>Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion</li> <li>Offering access to exchange transfusion to patients on long-term transfusions</li> <li>Protocol for carrying out an exchange transfusion</li> <li>Hospital transfusion policy</li> <li>Investigations and vaccinations prior to first transfusion</li> <li>Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate.</li> <li>Areas where transfusions will usually be given</li> <li>Recommended number of cannulation attempts</li> </ol>	Y	The guideline on indications for transfusion needed to be reviewed. Guidelines were not clear enough to be user-friendly for junior staff. The standard operating policy for apheresis was not clear.	Y	The pre-operative transfusion guideline needed to be revised in line with the TAPS (Transfusion Alternatives Preoperatively in Sickle Cell Disease) trial findings.

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-505 All	<p><b>Chelation Therapy</b></p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ul style="list-style-type: none"> <li>a. Indications for chelation therapy</li> <li>b. Choice of chelation drug/s, dosage and dosage adjustment</li> <li>c. Monitoring of haemoglobin levels prior to transfusion</li> <li>d. Management and monitoring of iron overload, including management of chelator side effects</li> <li>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2</li> <li>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.</li> <li>g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.</li> </ul>	Y	However the guideline needed to be updated.	Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-506 All	<p><b>Clinical Guidelines: Acute Complications</b></p> <p>Network-agreed clinical guidelines on the management of acute complications should be in use covering at least:</p> <p><b>For patients with sickle cell disease:</b></p> <ul style="list-style-type: none"> <li>a. Acute pain</li> <li>b. Fever, infection and overwhelming sepsis</li> <li>c. Acute chest syndrome</li> <li>d. Abdominal pain and jaundice</li> <li>e. Acute anaemia</li> <li>f. Stroke and other acute neurological events</li> <li>g. Priapism</li> <li>h. Acute renal failure</li> <li>i. Haematuria</li> <li>j. Acute changes in vision</li> <li>k. Acute splenic sequestration (children only)</li> </ul> <p><b>For patients with thalassaemia:</b></p> <ul style="list-style-type: none"> <li>l. Fever, infection and overwhelming sepsis</li> <li>m. Cardiac, hepatic or endocrine decompensation</li> </ul>	Y	These guidelines would benefit from revision and updating to improve clarity, including the pain protocol, and to ensure consistency with NICE (National Institute for Health and Care Excellence) recommendations.	Y	
HN-507 All	<p><b>Specialist Management Guidelines</b></p> <p>Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ul style="list-style-type: none"> <li>a. During anaesthesia and surgery</li> <li>b. Who are pregnant</li> <li>c. Receiving hydroxycarbamide therapy</li> </ul>	Y		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-508 All	<b>Clinical Guidelines: Chronic complications</b> Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: <ol style="list-style-type: none"> <li>Renal disease</li> <li>Orthopaedic problems</li> <li>Retinopathy</li> <li>Cardiological complications / pulmonary hypertension</li> <li>Chronic respiratory disease</li> <li>Endocrinopathies</li> <li>Neurological complications</li> <li>Chronic pain</li> <li>Liver disease</li> <li>Growth delay / delayed puberty (children only)</li> <li>Enuresis (children only)</li> </ol>	Y	However the guidelines needed to be updated and would benefit from further clarification.	Y	
HN-509 SHC	<b>Referral for Consideration of Bone Marrow Transplantation</b> 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 use.	Y	
HN-510 All	<b>Thalassaemia Intermedia</b> Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: <ol style="list-style-type: none"> <li>Indications for transfusion</li> <li>Monitoring iron loading</li> <li>Indications for splenectomy</li> </ol>	Y		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-511 All	<p><b>Clinical Guideline Availability</b></p> <p>Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.</p>	N	All clinical guidelines were not yet available on the intranet.	Y	The guideline on intranet was out of date.

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-512 SHC	<p><b>Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)</b></p> <p>Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least:</p> <ol style="list-style-type: none"> <li>Identification of ultrasound equipment and maintenance arrangements</li> <li>Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210)</li> <li>Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound</li> <li>Ensuring all patients are given relevant information (QS HN-107)</li> <li>Use of an imaging consent procedure</li> <li>Guidelines on cleaning ultrasound probes</li> <li>Arrangements for recording and storing images and ensuring availability of images for subsequent review</li> <li>Reporting format, including whether mode performed was imaging or non-imaging</li> <li>Arrangements for documentation and communication of results</li> <li>Internal systems to assure quality, accuracy and verification of results</li> <li>Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)</li> </ol>	N/A		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-601 All	<p><b>Service Organisation</b></p> <p>A service organisation policy should be in use covering arrangements for:</p> <ul style="list-style-type: none"> <li>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)</li> <li>b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission</li> <li>c. Patient discussion at multi-disciplinary team meetings (QS HN-602)</li> <li>d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population</li> <li>e. Arrangements for liaison with community paediatricians and with schools (children's services only)</li> <li>f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated</li> <li>g. Follow up of patients who do not attend</li> <li>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.</li> <li>i. Accessing specialist advice (QS HN-206)</li> <li>j. Two-way communication of patient information between SHC and LHTs</li> <li>k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together</li> </ul>	N	An operational policy was not yet available but documents covering some of the aspects were seen.	N	No formal policy document was seen, but individual documents covered certain aspects of QS HN-601. However, these documents had not all been ratified by Trust Governance team.

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-602 All	<p><b>Multi-Disciplinary Meetings</b></p> <p>Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).</p>	Y	Multi-disciplinary team meetings were good.	Y	Well established multi-disciplinary team meetings were in place.
HN-603 All	<p><b>Service Level Agreement with Community Services</b></p> <p>A service level agreement for support from community services should be in place covering, at least:</p> <ol style="list-style-type: none"> <li>Role of community service in the care of patients with haemoglobin disorders</li> <li>Two-way exchange of information between hospital and community services.</li> </ol>	N/A		N/A	
HN-604 All	<p><b>Network Review and Learning Meetings</b></p> <p>At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798)</p>	Y		Y	
HN-605 SHC	<p><b>Neonatal screening programme review meetings</b></p> <p>The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.</p>	Y		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-701 SHC	<p><b>Data Collection</b></p> <p>Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.</p>	Y	Data for adult and paediatric patients were merged.	Y	
HN-702 All	<p><b>Annual Data Collection - Activity</b></p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> <li>Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances</li> <li>Length of in-patient stays</li> <li>Re-admission rate</li> <li>'Did not attend' rate for out-patient appointments</li> </ol>	Y	It was acknowledged that data may be incomplete or have inaccuracies.	Y	It was acknowledged that data may be incomplete or have inaccuracies.

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

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-704 All	<p><b>Audit</b> Clinical audits covering the following areas should have been undertaken within the last two years:</p> <p><b>Achievement of screening follow-up standards:</b></p> <p>a. At least 90% of infants with a positive screening result attend a local clinic by three months of age</p> <p>b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age</p> <p>c. Less than 10% of cases on registers lost to follow up within the past year</p> <p><b>For patients with sickle cell disease:</b></p> <p>d. Proportion of patients with recommended immunisations up to date</p> <p>e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required</p> <p>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</p> <p>g. Availability of extended red cell phenotype in all patients</p> <p>h. Proportion of children:</p> <p>i. at risk of stroke who have been offered and/or are on long-term transfusion programmes</p> <p>ii. who have had a stroke</p> <p><b>For patients with thalassaemia:</b></p> <p>i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505)</p> <p>j. Proportion of patients who have developed new iron-related complications in the preceding 12 months</p> <p><b>All patients:</b></p> <p>k. Waiting times for transfusion</p>	N	Audits covering 'd', 'e', 'i', 'j' and 'k' were not seen.	N	Audits for 'a', 'b' and 'c' were seen but other audits had not yet been completed.

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-705 All	<b>Guidelines Audit</b> The service should have a rolling programme of audit, including: <ol style="list-style-type: none"> <li>Audit of implementation of clinical guidelines (QS HN-500s).</li> <li>Participation in agreed network-wide audits.</li> </ol>	Y		Y	
HN-706 SHC	<b>Research</b> The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N	The SHC did not yet participate in research relating to the care of patients with haemoglobin disorders.	Y	
HN-707 HC	<b>Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)</b> The service should monitor and review at least annually: <ol style="list-style-type: none"> <li>Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512)</li> <li>Results of internal quality assurance systems (QS HN-512)</li> <li>Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)</li> <li>Results of 'fail-safe' arrangements and any action required</li> </ol>	N/A		Y	

Ref	Quality Standard	Adults Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-798 All	<p><b>Review and Learning</b></p> <p>The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include:</p> <p>a. Review of any patient with a serious adverse event or who died</p> <p>b. Review of any patients requiring admission to a critical care facility</p>	Y	Discussions were good at local and regional multi-disciplinary meetings.	Y	Discussions were good at local and regional multi-disciplinary meetings.
HN-799 All	<p><b>Document Control</b></p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p>	N	Guidelines were out of date.	N	Guidelines were out of date.

Return to [Index](#)

## HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-199	<p><b>Involving Patients and Carers</b></p> <p>The network should have mechanisms for involving patients and their carers from all services in the work of the network.</p>	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.
HY-201	<p><b>Network Leads</b></p> <p>The network should have a nominated:</p> <ol style="list-style-type: none"> <li>Lead consultant and deputy</li> <li>Lead specialist nurse for acute care</li> <li>Lead specialist nurse for community services</li> <li>Lead manager</li> <li>Lead for service improvement</li> <li>Lead for audit</li> <li>Lead commissioner</li> </ol>	Y	A good flow chart of 'who did what' in the network was seen.	Y	Insufficient time was allocated in the job plan of network leads.
HY-202	<p><b>Education and Training</b></p> <p>The network should have agreed a programme of education and training to help services achieve compliance with Qs HN-204 and HN-205.</p>	Y	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.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-501	<p><b>Transition Guidelines</b></p> <p>Network guidelines on transition to adult care should have been agreed covering:</p> <ol style="list-style-type: none"> <li>Age guidelines for timing of the transfer</li> <li>Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer</li> <li>Allocation of a named coordinator for the transfer of care</li> <li>Communication of clinical information from paediatric to adult services</li> <li>Arrangements for monitoring during the time immediately after transfer to adult care</li> <li>Arrangements for communication with Local Haemoglobinopathy Team (if applicable)</li> </ol> <p>Guidelines should be explicit about transition directly to any accredited LHTs.</p>	N	Network-wide guidelines were not yet in place and both SHCs in the network used their own local guidelines.	N	Network-wide guidelines were not yet in place and both SHCs in the network used their own local guidelines.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-502	<p><b>Clinical Guidelines</b></p> <p>Network guidelines should have been agreed covering:</p> <ul style="list-style-type: none"> <li>a. Annual review (QS HN-502)</li> <li>b. Routine monitoring (QS HN-503)</li> <li>c. Transfusion (QS HN-504)</li> <li>d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505)</li> <li>e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303)</li> <li>f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303)</li> <li>g. Specialist management (QS HN-507)</li> <li>h. Thalassaemia intermedia (QS HN-510)</li> </ul> <p>Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.</p>	N	Network-wide guidelines were not yet in place and both SHCs in the network used their own local guidelines.	N	Network-wide guidelines were not yet in place and both SHCs in the network used their own local guidelines.
HY-701	<p><b>Ongoing Monitoring</b></p> <p>The network should monitor on a regular basis:</p> <ul style="list-style-type: none"> <li>a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701)</li> <li>b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.</li> </ul>	Y	Monitoring was done systematically by the data manager.	Y	Monitoring was done systematically by the data manager.

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

Return to [Index](#)

## COMMISSIONING

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HZ-601	<p><b>Commissioning of Services</b></p> <p>Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular:</p> <ol style="list-style-type: none"> <li>Designated SHC/s for the care of people with with sickle cell disease</li> <li>Designated SHC/s for the care of adults with thalassaemia</li> <li>Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia</li> <li>Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia</li> <li>Community care providers</li> </ol>	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	<p><b>Clinical Quality Review Meetings</b></p> <p>Commissioners should regularly review the quality of care provided by:</p> <ol style="list-style-type: none"> <li>Each service, in particular QS HN-703</li> <li>Each network, in particular, achievement of QS HY-702 and QS HY-798</li> <li>Service and network achievement of relevant Qs</li> </ol>	Y		Y	

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

Return to [Index](#)