WM QRS West Midlands Quality Review Service

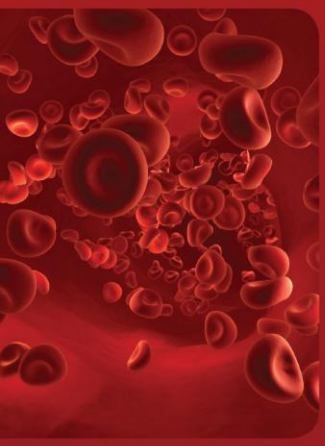
UK Forum on Haemoglobin Disorders

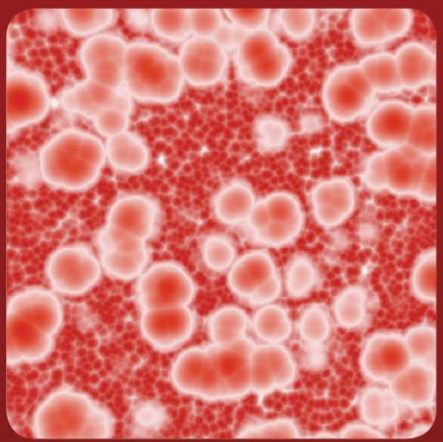
Health Services Caring for Adults with Haemoglobin Disorders

East Midlands

University Hospitals of Leicester NHS Trust
Nottingham University Hospitals NHS Trust

Visit date: June 12th 2012 Report Date: September 2013 Version 2




NHS

CONTENTS

INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia in the East Midlands, in particular at the University Hospitals of Leicester NHS Trust and Nottingham University Hospitals NHS Trust, which took place on June 12th 2012. The purpose of the visit was to review compliance with the 'Quality Standards for Health Services Caring for Adults with Haemoglobinopathies', 2011. The visit was organised by the West Midland Quality Review Service and supported by the UK Forum on Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Programme.

ACKNOWLEDGEMENTS

We would like to thank the staff of University Hospitals of Leicester NHS Trust and 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 visits. 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.

ADULT HAEMOGLOBIN DISORDERS SERVICES IN EAST MIDLANDS NETWORK

Trust	Hospital/s	Abbrev-iation	Reviewed as:	Abbrev-iation
University Hospitals of Leicester NHS Trust	Leicester Royal Infirmary	UHL	Specialist Haemoglobinopathy Team	SHT
Kettering General Hospital NHS Foundation Trust	Kettering General Hospital	KGH	Local Team / Linked Hospital	LHT
Northampton General Hospital NHS Trust	Northampton General Hospital	NGH	Local Team / Linked Hospital	LHT

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
University Hospitals of Leicester NHS Trust	SHT	74	26	17 (13 thal, <5 SCD) <5 on red cell exchange
Kettering General Hospital NHS Foundation Trust	LHT	12	0	
Northampton General Hospital NHS Trust	LHT	19	0	

Trust	Hospital/s	Abbrev-iation	Reviewed as:	Abbrev-iation
Nottingham University Hospitals NHS Trust	City Hospital Queens Medical Centre	NUH: CH QMC	Specialist Haemoglobinopathy Team	SHT
Derby Hospitals NHS Foundation Trust	Royal Derby Hospital	RDH	Local Team / Linked Hospital	LHT
United Lincolnshire Hospitals NHS Trust	-	ULH	Local Team / Linked Hospital	LHT
Sherwood Forest Hospitals NHS Foundation Trust	King's Mill Hospital	KH	Local Team / Linked Hospital	LHT

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia	No. patients on long term red cell transfusions
Nottingham University Hospitals NHS Trust	SHT	67	7	< 5 thal < 5 SCD
Derby Hospitals NHS Foundation Trust	LHT	35		
Sherwood Forest Hospitals NHS Foundation Trust	LHT	5		

NETWORK

The East Midlands Sickle cell and Thalassaemia Network had two specialist teams, one at University Hospitals of Leicester NHS Trust (UHL) and one at Nottingham University Hospitals NHS Trust (NUH). Both centres were visited on the same day by separate peer review teams. UHL linked with Kettering and Northampton General Hospitals. Some patients from Peterborough and Milton Keynes had also been seen at Leicester although these hospitals did not form part of the network and their referral patterns were not clearly defined. Patients from Kettering and Northampton were not seen at Leicester, although there were plans for outreach clinics from UHL for specialist review.

Nottingham (NUH) linked with King's Mill, Lincolnshire and Derby. Most of the King's Mill patients and all of the Lincolnshire patients attended Nottingham for specialist review.

SPECIALIST TEAM: UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

All acute services for haemoglobinopathy patients were at the Leicester Royal Infirmary site. Facilities for haematology patients were shared with the oncology services in the same building and included the Day Unit and the Acute Oncology Assessment Unit. There was a separate haematology ward and some haematology

patients were also admitted to the oncology/haematology ward. Occasionally, patients presented to the A&E department and would then be transferred to the haematology ward.

The Sickle cell and Thalassaemia Advisory Group met every three months to review the whole service. This multidisciplinary group included laboratory, midwifery, nursing and lay members.

Accident and Emergency

The majority of patients with sickle cell crisis or requiring urgent assessment were seen in the oncology acute admissions unit (OAU) which operated 24 hours a day, seven days a week. Those requiring admission were then admitted to the haematology ward or shared oncology/haematology ward. The occasional patient, usually new to the department, presented to A&E but was transferred to the OAU or ward. Patients were assessed by a member of the oncology/haematology resident on-call team and reviewed by the haematology registrar as necessary.

Out-patient and Day Case Facilities

The department shared Day Case facilities with oncology services. Sickle cell and thalassaemia patients who were on transfusion programmes attended the day unit in booked slots and Saturday morning sessions were held once a month. There was a Cell Separator Unit where automated red cell exchanges could be carried out. These were usually performed via fistulae or peripheral access.

A weekly haemoglobinopathy out-patient clinic was held by the lead consultant and attended by the acute sickle nurse specialist and the clinical psychologist. All patients were offered a clinic consultation with the psychologist. Cardiac T2* imaging was available on UHL's Glenfield site.

In-Patient Facilities

Patients were admitted to the haematology ward or to the shared haematology/oncology ward depending on bed availability and clinical priority. The wards were co-located within the Osborne Building. The management of in-patients was overseen by the three haematology consultants in the "blue team" in an attending system.

Community Services

The Community Sickle Cell and Thalassaemia Service was located at the Merlyn Vaz Medical Centre, a custom-built health centre in the inner city, and was managed by University Hospitals of Leicester NHS Trust. Two specialist nurses delivered counselling and screening services for adults and children. Approximately 70% of their work was screening related. The nurses communicated regularly with the lead consultant and attended the psychosocial and medical multi-disciplinary team meetings, and the regional multi-disciplinary meeting. Specific patient issues were communicated via clinic letter/email from the consultant, or by a phone call from the hospital based nurse. Copies of community notes on the outcomes of visits were filed in the hospital notes.

User Feedback

Three users provided feedback about the service they received from the specialist team.

LOCAL TEAMS / HOSPITALS LINKED WITH LEICESTER

KETTERING GENERAL HOSPITAL

The review team had a telephone conversation with a consultant haematologist at Kettering General Hospital. This hospital had 12 patients with sickle cell disease. They were not all seen by the same consultant and formal annual reviews were not being undertaken. Patients with sickle cell disease who were pregnant were managed at Oxford. If the Kettering consultants had clinical concerns they said that they would telephone the lead clinician at Leicester who was readily available to give advice. Patients requiring specialist management or red cell exchange were transferred to Leicester.

NORTHAMPTON GENERAL HOSPITAL

Written information was provided as the lead consultant was on leave at the time of the review. The Northampton service cared for 19 patients, with 13 registered on the National Haemoglobinopathy Registry. There was no specialist clinic to review these patients and no formal annual reviews were undertaken. Northampton had six haematologists all of whom had experience in managing haemoglobinopathy patients. Patients had direct access to the haematology day unit during working hours and were admitted out of hours directly to the ward by the on-call haematology team.

SPECIALIST TEAM: NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST

Nottingham University Hospitals NHS Trust had two main hospital sites; City Hospital, where adult haematology services were based, and Queen's Medical Centre, where other acute services and the Accident and Emergency (A&E) Department were located.

Accident and Emergency

When patients attended the A&E department at Queen's Medical Centre they were assessed and given initial treatment before being transferred to City Hospital. For about a year before the review visit, in order to improve access, patients were being diverted from attending A&E and were asked to call the haematology bleep holder at City Hospital if they required admission. The bleep was held by the lead day unit nurse during working hours and by the lead in-patient haematology nurse out of hours. Patients were directed either to the day unit, the Specialist Receiving Room or the haematology ward, depending on bed availability.

Out-patient / Day Case Facilities

The department had a dedicated 22 station Day Case Unit. Sickle cell and thalassaemia patients who were on transfusion programmes attended the day unit in booked slots. There was a Cell Separator Unit which was equipped with two Optia cell separators where red cell exchanges could be carried out. These were usually performed via fistulae or peripheral access.

Day case access for sickle cell patients in crisis was available during working hours. Patients were asked to call the haematology bleep holder and attended before 2pm if possible. On arrival they were triaged by a nurse and pre-written analgesic prescriptions were available for all known patients so rapid analgesia could be given. One of the haematology doctors working on the day unit carried out the subsequent medical review. Patients were not encouraged to walk into the unit, but if this did happen the patients would be reviewed. Patients who were on hydroxycarbamide could attend the day case unit for blood tests and adjustment of medication, if required.

The haematology out-patient clinics were held in the dedicated Outpatient Suite on the ground floor of the Centre of Clinical Haematology. This had its own phlebotomy area and Sysmex blood count analyser. Eight consulting rooms and a quiet room were available. The main out-patient clinic for sickle cell and thalassaemia was held every Wednesday afternoon. A specialist nurse or community staff nurse was present at each session. Patients attended for annual review and routine visits. All patients were given a phone reminder one or two days before their appointment by the community team. Patients who did not attend their appointment were phoned by the acute nurse specialist. If a patient did not attend twice they were phoned by the community team.

The clinical lead also covered obstetric and paediatric haematology, so looked after the haemoglobinopathy patients during pregnancy as well as before and after transition.

In-patient Facilities

There were two haematology wards; Toghill and Fletcher. Fletcher housed the Bone Marrow Transplant Unit. Toghill Ward was the ward for general and malignant haematology conditions and sickle cell patients were admitted there if a bed was available. It had 22 beds including 10 single rooms. If beds were not available, patients were admitted to other clinical areas – usually the Specialist Receiving Unit (SRU) or Loxley Ward (a gynaecology ward, situated 20 minutes away), or one of the other medical wards. Toghill was a new ward with good facilities. The staff were aware of the sickle protocol and patients admitted to Toghill were reviewed daily by the haematology ward registrar. The Specialist Receiving Unit has been in place since 6th April 2011 and was formerly the Emergency Assessment Unit. The main users of this area were oncology, haematology, renal, diabetes/endocrinology and infectious diseases services. Patients could be admitted to other outlying wards but these were not reviewed. The lead clinician reviewed all in-patients at least twice a week. In her absence they were reviewed by one of the haematology registrars, overseen by the on-call haematology consultant. In-

patients were also reviewed daily by the acute specialist nurse, or in her absence by one of the community nurses.

Community Services

The Community Sickle Cell and Thalassaemia Service was located at the Mary Potter Centre, approximately two miles from the City Hospital. It was staffed by a lead specialist nurse and manager, a specialist nurse, community staff nurse and clerical assistant. It provided health reviews for new patients and six monthly health reviews for registered patients, as well as antenatal and neonatal screening and paediatric services. An annual user event was also organised.

OSCAR Nottingham provided an outreach worker who provided social and benefit advice. This post was new in September 2011 and took referrals from hospital or the community service.

User Feedback

Four users provided positive feedback about the service they received from the specialist team and, in particular, from the lead clinician.

LOCAL TEAMS / HOSPITALS LINKED WITH NOTTINGHAM

ROYAL DERBY HOSPITAL

The review team had a telephone conversation with the clinical lead/head of department at the Royal Derby Hospital. Thirty five sickle cell patients were known to the team there. A specialist haemoglobinopathy nurse had been in post for 10 years, but this post had recently been removed as part of Trust restructuring. Patients with sickle cell disease were seen in general haematology clinics and were not receiving local specialist review or review at the specialist centre (Nottingham). Patients admitted via A&E were seen by the emergency team and then admitted under the haematology team and looked after by the attending haematologist. Local protocols were in place. The haematologists at Derby had a good working relationship with the Nottingham lead clinician.

KING'S MILL HOSPITAL

The review team had a telephone conversation with the lead clinician at King's Mill Hospital. This hospital had five patients with sickle cell disease. Some of them attended Nottingham for annual review and were seen alternately in the local clinic. If the King's Mill Hospital staff had clinical concerns they would call the lead clinician at Nottingham who was reported as readily available and would always give advice. There were no specific protocols in place, but there had been no emergency admissions in the previous eight years. Staff from King's Mill Hospital attended the network educational meetings.

REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

The network had been established since 2009 with good support from specialist commissioners. There were regular network meetings and educational events and the services had worked together on network audits. Network posts had been set up in nursing, psychology and data management, which had significantly enhanced the service. The network had developed a successful business case to fund several posts including two acute sickle cell disease nurse specialists (part-time) at Leicester and Nottingham, a part-time psychologist at Leicester and Nottingham and a joint whole time equivalent data manager covering both Leicester and Nottingham. The latter was responsible for entering patients into the National Haemoglobinopathy Registry. These posts were based in the specialist centres but expansion of their role to cover the whole network was planned. Multi-disciplinary team meetings had recently commenced using video conferencing facilities. The clinical lead in Kettering had introduced specialist clinics and local guidelines which reflected the content of the regional guidelines. The Network could be used as a model for other areas trying to set up networks.

Immediate Risks

No immediate risks were identified.

Concerns

1 Patients at Derby, Northampton and Kettering and some patients at King's Mill were not receiving annual specialist reviews. These patients did not have access to nursing or medical support with specialist expertise in haemoglobin disorders. Whilst reviewers were told that emergency care was adequate, the lack of long-term specialist care was concerning. This could be achieved by either in-reach or out-reach models from the specialist centres (Nottingham and Leicester respectively) and should be addressed as a matter of urgency.

2 The lead at Northampton had limited engagement with network meetings due to time constraints.

3 Peterborough and Milton Keynes were mentioned as being part of the network but there did not appear to be a formal relationship with either Trust, although the nurse from Milton Keynes did attend some network meetings. It was not clear whether either of these Trusts had support from other specialist centres.

Further Considerations

1 Further development and sharing of network protocols would help to ensure consistency of clinical practice across the network.

2 The Network website may benefit from further development. At the time of the visit it was only accessible from the East Midlands Commissioning site. Network protocols and patient information sheets could be displayed on this website.

3 Reviewers encouraged the further development of the network governance function, including in relation to audit and service development.

4 Some of the very specialist services (for example, renal services, orthopaedic services) were managing very small numbers of adult haemoglobin disorder patients and consideration could be given to providing these on a network basis.

SPECIALIST TEAM: UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

General Comments and Achievements

This was a committed and enthusiastic team with strong clinical leadership. The service had been enhanced by the appointment of the clinical nurse specialist and psychologist who had raised the profile of the service within the haematology department and the hospital as a whole. There was strong support from senior management. A general haematology management protocol was in place, which was available on the intranet and in files on the haematology ward and Oncology Assessment Unit (OAU). The A&E and OAU were visited and facilities were appropriate. There were excellent links with the community team. There was a good programme of training and teaching at all levels. The patients benefited from direct access to the haematology team for urgent assessment and care and all patients were managed in haematology wards by experienced teams. The users provided positive feedback about the service they received from the specialist team. The thalassaemia users found the availability of Saturday transfusions very helpful. Their only concern was that blood was sometimes late in arriving. Another user was not aware of any patient support group. There was a facility for weekend and out of hours transfusions and T2* scanning was available at the UHL Glenfield site two miles away.

Immediate Risks

No immediate risks were identified.

Concerns

1 A transition service had not been established due to vacancies in the paediatric haemoglobinopathy service at medical and nursing level, although protocols and guidelines had been developed by the adult team.

2 Specialist nursing was only available part of the time. At other times the service relied on community and day unit nurses to provide specialist support which was in addition to their normal roles.

Further Consideration

1 Some of the protocols were quite brief and whilst adequate for specialist use, may benefit from the inclusion of more detail to make them more suitable for use by non-specialists.

2 For clarity, it may be helpful to separate the sickle cell and thalassaemia guidelines.

3 As part of a review of the acute pain management protocol , it may be helpful to consider alternatives to intravenous morphine and emphasising monitoring for adverse events.

4 Annual reviews were being done but copies were not being sent to patients and data were not being entered on the National Haemoglobinopathy Registry.

Good Practice

1 Laminated quick reference hand-held guidelines for acute sickle crisis were given to haematology nurses.

2 The presence of the psychologist in the routine out-patient clinic had led to increased acceptance of this service by the patients and improved patient care.

3 All patients were seen routinely during admission by a physiotherapist and offered incentive spirometry.

LOCAL TEAMS / LINKED HOSPITALS

KETTERING GENERAL HOSPITAL

General Comments and Achievements

Care for in-patients and out-patients was provided by general haematologists. Quarterly review clinics were planned with the acute nurse and psychologist from Leicester. There were good working relationships with the Leicester team who the Kettering staff consulted for advice or specialist acute management, but there were no formal arrangements about who to call if the lead clinician was away. Clinicians from Kettering were attending network educational meetings.

Immediate Risks

No immediate risks were identified

Concerns

1 The patients at Kettering did not have access to comprehensive local care or to appropriate specialist care. They were not having annual specialist reviews by staff with specialist expertise in haemoglobin disorders.

2 No medical lead for haemoglobinopathies had been identified.

3 Pathways for management of ongoing care and of long-term disease complications were not robust. Reviewers were told that Kettering haematologists had developed their own guidelines and were not using network guidelines.

4 Community support was not available for patients in Kettering.

NORTHAMPTON GENERAL HOSPITAL

General Comments and Achievements

The patients at Northampton had direct access to the haematology unit for urgent care but arrangements for annual review or specialist chronic disease management were not robust, although plans were in place to set up an annual review clinic with the East Midlands Sickle Cell and Thalassaemia Network. Staff from Northampton reported using network and national guidelines. Due to work commitments consultants were only able to attend network meetings occasionally.

Immediate Risks

No immediate risks were identified.

Concerns

1 Patients at Northampton were not having annual specialist reviews by staff with specialist expertise in haemoglobin disorders. Haematologists expressed a willingness to participate in network meetings and audits but were not able to fully engage with the network due to time constraints. There was no locally-based specialist nursing expertise.

2 Community support was not available for patients in Northampton.

SPECIALIST TEAM: NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST

General Comments and Achievements

This was a very good service led by a committed clinical lead and nursing staff, offering specialist care. The service had been developed by the clinical lead since their appointment and had benefitted more recently from increased resources from the network. The number of patients was growing rapidly, with an increase in patient numbers of around two-thirds in the last eight years. There was a very good working relationship between the community and secondary care team, including cross-cover of the acute nurse specialist and regular multi-disciplinary team meetings. The nursing team had implemented the RCN competencies for the specialist team, which was impressive as these had only recently been produced. The Day Unit, which was spacious and of high quality, worked well. The development of an acute pain day service worked well and benefited the patients. Nurses in the Specialist Receiving Unit were aware of the sickle cell protocol.

Immediate Risks

No immediate risks were identified.

Concerns

1 It was clear from admissions data that patients were admitted to many different in-patient wards. Patients on the Specialist Receiving Unit, Loxley Ward or outlying wards were reviewed daily by the laboratory haematology registrar, but this often occurred late in the day. Some staff on Loxley Ward and on some of the outlying wards were not aware of the sickle protocol and expressed concerns about looking after patients with sickle cell disease. Expansion of the use of the haematology ward or further training for staff on the outlying wards would be helpful.

2 At the time of the review there was no access to out of hours transfusion, although this had been requested by patients. A business plan was being developed to support opening the day unit on Saturdays.

3 This service was run by a clinical lead without effective cover arrangements and users expressed concerns about the robustness of the service if the lead clinician was absent. Whilst cover was provided by haematology colleagues, the system for specialist cover was not robust. Consideration should be given to providing this on a network basis.

Further Considerations

1 Access to liver iron scanning (Ferriscan/R2 scans) was not available at the time of the visit, although T2* cardiac scans could be accessed in Leicester (Glenfield Hospital) or in London. Consideration should be given to routinely accessing T2* in Leicester.

2 Annual reviews were being done but copies were not being sent to patients and were not being entered on the National Haemoglobinopathy Registry.

3 Some of the protocols (particularly those relating to acute complications) were quite brief and whilst adequate for specialist use, may benefit from the inclusion of more detail to make them more suitable for use by non-specialists.

4 There was no active support group, although there was a new OSCAR worker locally who worked closely with the sickle cell and counselling services. Information about this post had been given out to patients but some did not seem aware of the service and further publicity may be helpful.

5 Whilst having an A&E and in-patient wards on different sites was challenging, the A&E admissions and transfer policy seemed to work well. Patients had direct access to City Hospital, but reported that there were often delays in this process. Waiting times in the SRU were raised as a concern by the users but this was not reflected in the patient survey and a specific audit of this would show if this was a widespread issue, or a one-off problem. Further investigation of this issue may be helpful.

Good Practice

1 There was an excellent annual review proforma which was clearly in use. This could be used as a model for other centres.

2 There was a very good 'did not attend' (DNA) policy which seemed robust. A telephone clinic was offered, with GP liaison, for patients who recurrently did not attend.

3 The relationship with the community team was strong and close, and had produced initiatives such as the 'I believe I can fly' book, based on patient experiences. This was a useful resource and could benefit other services.

4 Very good patient information was available, some of which (for example, the travel guide) could be shared nationally.

5 There were some very good care protocols and pathways including a good flow chart for acute care, and proformas for pre-operative care and transfer of care between providers.

LOCAL TEAMS / LINKED HOSPITALS

ROYAL DERBY HOSPITAL

General Comments and Achievements

The patients at Derby did not have access to local comprehensive care or specialist care. Care for inpatients and outpatients was provided by general haematologists. There was no specialist nurse support and since the loss of this post the lead clinician no longer saw sickle patients in a specialist clinic. The antenatal role of the post had been taken on by a generic antenatal screening co-ordinator. There were no concerns about the provision of emergency care but there was no robust pathway for chronic care and management of long term disease complications. There were good working relationships with Nottingham and the lead clinician at Nottingham would provide telephone advice if required.

Immediate Risks

No immediate risks were identified.

Concerns

1 Patients at Derby did not have access to appropriate specialist care. They were not having annual specialist reviews by staff with specialist expertise in haemoglobin disorders. Specialist nurse support was not available for Derby patients. This was of particular concern because of the number of patients with haemoglobin disorders in Derby and because a specialist nurse had been in post but the post had been withdrawn.

2 Community support was not available for patients in Derby.

KING'S MILL HOSPITAL

General Comments and Achievements

There were very small numbers of patients at King's Mill. Some, but not all, of these patients had specialist review at Nottingham. Those who did not have a formal specialist review, because they were not willing or able to travel to Nottingham, were informally discussed with the specialist team. The King's Mill team was able to obtain advice from Nottingham as required. They reported good communication from the specialist team.

Immediate Risks

No immediate risks were identified.

Concerns

If the clinical team at King's Mill had urgent clinical concerns, there was an informal arrangement that they would call the specialist clinician in Nottingham. However this was not formalised and there were no alternative arrangements if the clinician in Nottingham was away.

COMMISSIONING

General Comments and Achievements

The East Midlands Sickle and Thalassaemia Network was established in 2009 and had been recognised as a 'Beacon Site'. The original service development plan for 2009/10 detailed the work needing to be done to develop the network. The achievements for the first twelve months of the network together with a prioritised work-plan for the following year were provided. Whilst some of the items remained to be achieved or were only partially achieved there was a clear indication of progress that had been made and what action was required to develop a fully functioning network.

Immediate Risks

No immediate risks were identified.

Concerns

1 Patients in Derby, Northampton and Kettering did not have access to appropriate local and specialist team care. Peterborough and Milton Keynes were mentioned as being part of the network arrangements but this was not a formal arrangement and it was not clear whether they were supported by another specialist centre. Clarity in commissioning provision of specialist services across the whole geographic area is required and appropriate referral pathways and protocols need to be established which ensure patients can access specialist care.

2 Commissioning arrangements did not ensure that all patients received high quality and equitable care, including provision of appropriate cover absences within the specialist teams, formalisation of access from local hospitals, and ensuring support by the specialist teams for the whole pathway of care.

Good Practice

1 The appointment to network posts, in particular the data manager post, was identified as good practice by the review team.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAMS

UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

Dr Kate Ryan	Consultant Haematologist – Clinical Lead for Peer Review Programme	Central Manchester University Hospital NHS Foundation Trust
Dr Tullie Yeghen	Consultant Haematologist	Lewisham Healthcare NHS Trust
Dr Paul Telfer	Senior Lecturer (Honorary Consultant) in Haematology	Barts Health NHS Trust
Lindsay Randall	Specialist Nurse	Coventry & Warwickshire Partnership NHS Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Pip Maskell	Quality Manager	*On behalf of*: West Midlands Quality Review Service

NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST

Dr Jo Howard	Consultant Haematologist – Clinical Lead for Peer Review Programme	Guy's & St Thomas' NHS Foundation Trust
Dr Jenny Welsh	Consultant Paediatric Haematologist	Sheffield Children's Hospital NHS Trust
Sekayi Tangayi	Service Manager/Nurse Lead & Specialist Nurse	East London NHS Foundation Trust
Nicola Howe	Senior Commissioning Manager	London Specialised Commissioning Group
Ajay Dattani	Service User	Birmingham
Sharon Ensor	Quality Manager	*On behalf of*: West Midlands Quality Review Service

APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

The Quality Standards are in the following sections:

HN - Services for Adults with Haemoglobin Disorders

HY - Haemoglobin Disorders Network (Adults):

Quality Standards for Haemoglobin Disorders Clinical Networks are given separately from those for Specialist Haemoglobinopathy Teams. These Standards are the responsibility of Specialist Haemoglobinopathy Teams but, by agreement, the functions may be delegated to other organisations or coordinating groups.

HZ - Haemoglobin Disorders – Commissioning

These Quality Standards are the responsibility of commissioners.

Each section covers the following topics:

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

NOTE. Different Quality Standards (QSs) are not comparable in terms of their importance or likely impact on the quality or outcomes of the service, and a figure summarising the number of QS's met cannot be used to assess the overall standard of the services provided or to compare this Trust's services with others.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y		Y	Service user and carer Information was excellent but users suggested that it was not always easily available. A patient folder with all the patient information was available in clinic. Information leaflets were displayed in clinics and new patients were given a complete range of information. A patient website was also planned.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-102 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 and transfusion services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. How to contact the service for help and advice, including out of hours e. Staff of the service f. Community services and their contact numbers g. Relevant support groups h. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns i. How to get involved in improving services (QS HN-199)	N	Information available covered most of the requirements of the QS. There was no information about times for phlebotomy services. A self-help group for sickle cell patients was not established.	Y	Written information for patients was very good (in particular the patient handbook) but there was no support group. Attempts had been made to set up support group there had been little interest in this. An annual update meeting for patients provided support.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-103 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, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	N	The written information provided did not cover what patients should do in an emergency.	Y	Information was excellent and the review team identified the travel advice as good practice that could be shared with other networks.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-104 All	**Information for Primary Health Care Team** Written information for the patient's primary health care team should be available covering their roles and responsibilities, including: a The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b Information covering side effects of medication, including chelator agents [SC and T] c Guidance for GPs on shared care for hydroxycarbamide and iron chelation therapy (if being prescribed by GPs).	Y		Y	
HN-105 All	**Care Plan** All patients should be offered: a An individual care plan or a written summary of their annual review b A permanent record of consultations at which changes to their care are discussed	Y	The care plans were offered to patients providing a record of consultations and doubling up as annual reviews.	N	Consultation letters including comprehensive annual reviews were evident but they were not routinely offered to patients. Summary information was sent to patients after initial or ongoing reviews.
HN-106 SHT A-LHT	**Transition Information** Information should be available for young people covering arrangements for transition to adult care. This information should cover all aspects of QS HN-501.	Y		Y	Information was available but was not the most recent Department of Health (2011) version.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	Y		Y	There was evidence of involving patients and carers but the audit of patients' experience was not targeted at some of the areas where patients reported concerns.
HN-201 All	**Lead Consultant** A nominated lead consultant haematologist 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	

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHTs this should be a named deputy within the SHT with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHT. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHT advice and support.	Y		N	There was a system of cover but it was not necessarily by a deputy with regular experience of caring for people with haemoglobin disorders.
HN-203 All	**Lead Nurse** A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders.	Y	The Lead Nurse had well organised systems in place, including 'portable, laminated guidelines'.	Y	There was clear documentation of the competences required but it was not dated.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	Y		Y	

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-205 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 b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available.	Y		N	"a" and "c" were met but "b" was not. Patients were admitted to a wide variety of wards and staff in the outlying wards did not have appropriate competences in the care of people with haemoglobin disorders. Reviewers were concerned about the extent of reliance on Registrars' experience and that less experienced staff may not have the appropriate competences.
HN-206 All	**Training Plan** 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-205).	Y		Y	There was a good training plan for the specialist nursing staff (community and acute). There was an excellent teaching programme for in-patient nursing staff, but this had not yet been implemented.
HN-207 All	**Training Plan – Other Staff** A programme of induction and training covering the care of patients with haemoglobin disorders should be run for: a. Clinical staff in the Emergency Department b. Non-consultant medical staff c. Allied health professionals working with the SHT / LHT (QS HN-301).	N	Not all relevant staff had training plans but they were evident for non-clinical and for allied health professional staff.	N	A training plan had been designed and the coordinator of medical staff had been contacted to discuss implementation.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-298 All	**Administrative and Clerical Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	A network post was available.	Y	A network post was available.
HN-301 All	**Support Services** Timely access to the following services should be available: a. Dietetics b. Physiotherapy c. Occupational therapy d. Leg ulcer service	N	There was no evidence of access to dietetics or occupational therapy.	Y	

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-302 All	**Specialist Services** Access to the following specialist staff and services should be available: a. Erythrocytopheresis or manual exchange transfusion (24/7) b. Acute and chronic pain team c. Pulmonary hypertension team d. Consultant obstetrician e. Fertility services f. Consultant cardiologist g. Consultant endocrinologist h. Consultant hepatologist i. Consultant ophthalmologist j. Consultant nephrologist k. Consultant urologist with expertise in managing priapism and erectile dysfunction l. Orthopaedic service m. Psychologist with an interest in haemoglobinopathies n. Specialist imaging o. DNA studies	Y	Although Ferriscan was not available it was under consideration.	Y	A psychologist had recently been appointed. Some specialist services were being organised across the network (see also main report). Access to Ferriscan was being negotiated.
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	Y		Y	

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
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.	Y		N	Out-patient facilities were good but patients were admitted to different wards at some distance from the Clinical Haematology wards where staff did not have relevant experience in looking after patients with haemoglobin disorders. Information was available on the wards but some staff did not know about it.
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y		N	There was no routine service for out of hours care although users reported that in their feedback they had requested this facility. In addition the lead clinician would informally see patients in clinic after 5pm if they could not miss work.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-501 SHT A-LHT	**Transition Guidelines** 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. 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)	Y	Staff were concerned about vacancies in the paediatric services.	Y	
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First out-patient appointment b. Annual review for both sickle cell disease and thalassaemia	N	Annual reviews were not yet entered in the National Haemoglobinopathy Registry, however this was reported as a 'work in progress'. Annual reviews were not evident in patient notes seen by reviewers.	Y	The Annual Review Proforma was particularly good.
HN-503 All	**Clinical Guidelines: Routine Monitoring** Clinical guidelines on routine out-patient monitoring and management between annual reviews should be in use. Local Haemoglobinopathy Team guidelines should specify the indications for early referral to the Specialist Haemoglobinopathy Team.	N	Guidelines were not available in the Emergency Department. Some of the guidelines were still to be approved. Some guidelines were kept in a folder in the clinic.	Y	

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
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. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	Y	Transfusion guidelines were available but they did not contain sufficient detail for the 'non' expert.	Y	
HN-505 All	**Chelation Therapy** Clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. 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 / SHT.	N	Monitoring of haemoglobin levels prior to transfusion was not mentioned and the use of non-invasive estimation was not clear. 'f' – was not relevant as GPs did not prescribe.	Y	There was no access to liver iron scanning (Ferriscan/R2 scans) at the time of the visit although T2 cardiac could be accessed in Leicester (Glenfield Hospital) or London.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-506 All	**Clinical Guidelines: Acute Complications** 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 **For patients with thalassaemia:** k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	Y	Flowcharts were not yet in place. There was no evidence of guidelines around surgical management. The guidance regarding emergencies lacked detail for general staff if an 'expert' was not available.	N	Guidelines were available but they contained insufficient detail especially relating to acute episodes. Guidelines were not readily available on the wards.
HN-507 All	**Emergency Department Guidelines** Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department.	N	Guidelines were not available in A&E, however specific guidelines were in preparation in line with A&E documents.	N	A flow chart had been designed for SRU but was not available in the Emergency Department.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-508 All	**Clinical Guidelines: Chronic complications** 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 Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team.	Y	It may be helpful to separate the sickle cell and thalassaemia guidelines for clarity.	Y	
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	N/A		N/A	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	Y		Y	The pre-operative guidelines and plan were particularly good.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-511 All	**Thalassaemia Intermedia** Clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy.	Y		Y	Network guidelines were available.
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QSHN-602) b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509: A-LHTs and LHTs only). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care.	N	Elements to produce an operational policy were available but there was no consolidated policy document.	N	There was no separate operational policy, but the individual aspects were in place in several different documents. There was a very good 'did not attend' policy.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
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 (QS HN-205) 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 service level agreement documenting roles and communication was not in place.	N	A service level agreement documenting roles and communication was not in place.
HN-701 SHT A-LHT	**Data Collection** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	N	Annual reviews were being done but were not yet entered on the National Haemoglobinopathy Registry.	N	Patients were registered on the National Haemoglobinopathy Registry but annual reviews were not updated.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-702 All	**Ongoing Monitoring** The service should monitor on an ongoing basis: a. Number of patients having acute admission, day unit admission or A&E attendances b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year c. Length of in-patient stays d. Re-admission rate e. DNA rate f. Waiting times for transfusion	N	Data were available for 2010/2011 only.	Y	

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-703 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **For patients with sickle cell disease:** a. Proportion of patients with recommended immunisations up to date b. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required c. 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. This audit should cover all hospitals where patients with sickle cell disease may attend. **For patients with thalassaemia:** d. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) e. Proportion of patients who have developed new iron-related complications in the preceding 12 months	N	There were plans to carry out a clinical audit.	Y	No patients were eligible for 'e' therefore this was not applicable.
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	Some auditing was evident, however, there was no evidence of a rolling programme	N	There was no rolling programme of audit but there were plans for inclusion in the Clinical Haematology programme.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N	No evidence of research was seen by the Review Team.	N	The SHT was not participating in any research at the time of the visit, but some research was planned.

Ref	Quality Standard	Met Y/N	Leicester	Met Y/N	Nottingham
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months	Y		Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		N	There was no document control procedure in place.

EAST MIDLANDS HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	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.	Y	There was a mechanism for patient involvement in the network but attendance of patients and carers was low.
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	
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSsHN-205 and HN-206.	Y	
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	Local guidelines were in place.

Ref	Quality Standard	Met Y/N	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 (QSHN-505) e. Management of acute complications (QS HN-302), including indications for referral to specialist services (QS HN-302) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-302) g. Transfer for critical care (QS HN-509) h. Specialist management (QSHN-510) i. Thalassaemia intermedia (QSHN-511) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHTs.	N	Local guidelines were in place.
HY-701	**Annual Meeting** The network should hold a meeting at least annually involving network leads (QS HY-201) and lead consultants and lead nurses for each LHT / SHT in the network (QSs HN-201 and HN-203) to review the network's progress towards achievement of Quality Standards and its implementation of agreed service development plans.	Y	
HY-702	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Register (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	N	The network was monitoring 'a' but not 'b'. Some data were collected but there was no evidence of a proportion of patients having had an annual review.
HY-703	**Audit** The network should have an agreed programme of audit and review covering, over the whole programme, network-wide achievement of QSs HN-702, HN-703 and HN-704	N	An audit programme was ready to be implemented.
HY-704	**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	There was no evidence of a policy on research but it was referred to in the network Terms of Reference.

Ref	Quality Standard	Met Y/N	Comments
HY-798	**Review and Learning** The network should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses', especially those involving more than one service within the network.	Y	

COMMISSIONING

Ref	Quality Standard	Met Y/N	Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks and, within each network, the configuration of services for people with haemoglobin disorders across each network, in particular: a. Designated SHT/s for the care of adults with sickle cell disease b. Designated SHT/s for the care of adults with thalassaemia c. Accredited LHTs for care of adults with sickle cell disease or thalassaemia d. Other LHTs/ Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	N	See main report (commissioning concerns section).
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by each network, in particular, achievement of QSHY-702 andHY-798.	Y	Minutes of clinical quality review meetings were provided.