WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

Yorkshire Network

Bradford Teaching Hospitals NHS Foundation Trust

Visit Date: 24th February 2015 Report Date: June 2015

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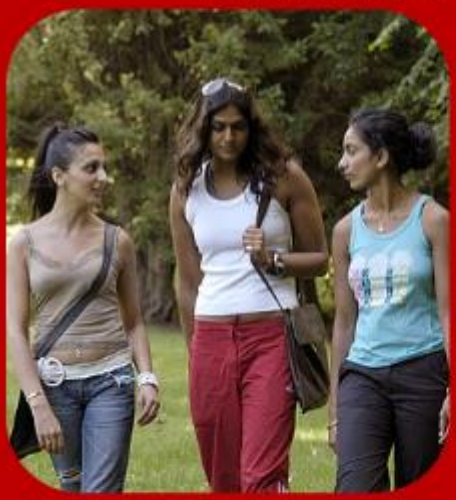

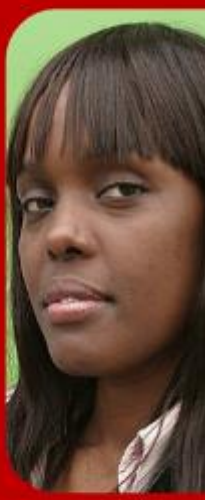

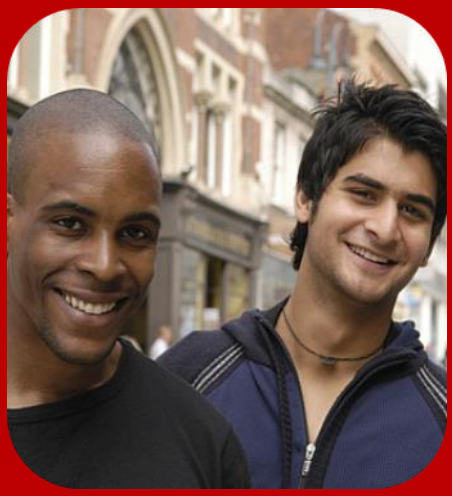

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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Bradford Teaching Hospitals NHS Foundation Trust (part the Yorkshire Network), which took place on 24th February 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014, which were developed by the UK Forum on Haemoglobin Disorders working with the West Midlands 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:

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

About West Midlands Quality Review Service

WMQRS was set up as a collaborative venture by 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

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HAEMOGLOBIN DISORDERS SERVICES IN THE YORKSHIRE NETWORK

At the time of the visit Bradford Teaching Hospitals NHS Foundation Trust was part of the Yorkshire Network which also included Leeds Teaching Hospitals NHS Trust and Sheffield Teaching Hospitals NHS Foundation Trust, both of which were specialist haemoglobinopathy centres (SHCs).

ADULT

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long-term red cell transfusions
Bradford Teaching Hospitals NHS Foundation Trust (Bradford Royal Infirmary)	SHC	21	19	22

CHILDREN AND YOUNG PEOPLE

Trust	Reviewed as:	No. children with sickle cell disease	No. children with thalassaemia	No. children on long-term red cell transfusions
Bradford Teaching Hospitals NHS Foundation Trust (Bradford Royal Infirmary, St Luke's Hospital)	SHC	15	32 (<5 patients managed in Leeds)	26

Since the last review of services (adult services were reviewed in September 2012; paediatric services were reviewed in January 2011 as a 'linked hospital' to Leeds Teaching Hospitals NHS Trust), 11 overseas students with sickle cell disease had left the care of the Trust.

EMERGENCY CARE

The majority of adult patients presented directly to ward 7 by phoning the ward, nursing or medical staff. During the day they were asked to attend the day unit for initial assessment if there was a haematology doctor available, or, if there was not, they were asked to go to the Emergency Department (ED). Outside normal working hours, patients went directly to ward 7 if a bed was available and were asked to go to the ED if there was not. Patients admitted to ward 7 out of hours were reviewed there by the on-call medical team. All patients with sickle cell disease known to the service had an emergency analgesia plan, available in a folder in both the ED and on ward 7. An emergency pain guidelines were available for patients who were not known to the service. There had been only 13 in-patient admissions in the year preceding the review.

Children with haemoglobin disorders were issued with an open access pass which allowed them direct access to care on the Paediatric Acute Assessment Unit (PAAU). In the PAAU children were assessed by the triage nursing team and then by the on-call paediatric junior doctor. Emergency care for severely unwell children was provided in a designated escalation bay within the PAU, which had facilities for intensive monitoring and stabilisation prior to transfer to a critical care unit. A regional retrieval service undertook specialist transfers of such patients when necessary.

IN-PATIENT CARE

Adult patients were admitted to ward 7, a 14 bedded specialist haematology unit comprising mostly single rooms with two double bays. There had been a total of 17 adult in-patient admissions in the year preceding the review. The majority of in-patients were located on this ward although occasionally outlying wards were used. Four of the senior nurses on ward 7 had participated in secondments with the haematology clinical nurse

specialist (CNS) over the last two years and one had continued to work part-time on the ward and part-time as the haematology CNS. Haematology junior staff provided day-to-day care of in-patients with one haematology specialist registrar looking after all haematology in-patients. Haemoglobinopathy patients were reviewed by the lead consultant at least twice a week and more often if required. In the absence of the lead consultant, patients were reviewed by one of the other haematology consultants on a more ad hoc basis. Out of hours a haematology registrar was available for advice 24/7 and consultant advice was provided by other consultants from Bradford Teaching Hospitals NHS Foundation Trust and Airedale NHS Foundation Trust who worked a 1:6 on-call rota.

Children who required in-patient management were admitted to the general paediatric wards under the care of the admitting consultant, who worked a weekly on-call rota. Separate rotas were in place for paediatric and neonatal medicine. Specialist clinical advice was obtained from the lead clinician during working hours. During absences of the lead consultant, specialist advice was obtained from the consultant paediatric haematologist (haemoglobinopathy lead) at Leeds Teaching Hospitals NHS Trust (Leeds General Infirmary). Although no specific written escalation policy was available, all children who required high-dependency or intensive care were discussed with the specialist team at Leeds Teaching Hospitals NHS Trust and transferred there by specialist transport. All paediatric surgery was undertaken at Leeds General Infirmary.

DAY UNIT

The day unit on ward 7 was open from 9am to 5pm Monday to Friday for adults with haemoglobinopathies requiring transfusions. Patients could not receive transfusions out of hours or at weekends. The phlebotomy service had moved location shortly before the review and patients had to attend the busy general phlebotomy area for their pre-transfusion samples.

Paediatric patients attended a day case unit on ward 17 that contained three seated spaces for day case patients. Two to three patients received transfusions each day. The clinical nurse specialist (CNS) reviewed all children admitted for transfusions and completed a care plan booklet for the admission. The booklet included a comprehensive set of clinical assessment tools, including the number of cannulation attempts. Waiting times for transfusion were not audited. A designated nurse cannulated the children.

The day case unit was situated in the middle of the general paediatric ward, which also contained a schoolroom, accessed by in-patient and day case patients. The ward school staff liaised with the patient's school to ensure educational continuity. The PAAU was operational from 9am to 5pm Monday to Friday with no provision for out of hours care. Patients usually attended the day unit two days in advance for cross-match blood tests. All cannulation and phlebotomy was performed by the lead CNS who supervised all transfusions in the day unit. In her absence, a staff nurse with a special interest in haemoglobinopathy provided this care.

OUT-PATIENT CARE

Consultant-led out-patient clinics were held in Out-patients West every second and fourth Friday morning. The specialist nurse and haemoglobinopathy counsellor also attended the clinics. Six patients were normally seen in each clinic, with appointments lasting up to 45 minutes.

Paediatric out-patient care took place in St Luke's Hospital, approximately three miles from Bradford Royal Infirmary. Clinics were held every second and fourth Tuesday afternoon, and the specialist nurse and haemoglobinopathy counsellor attended the clinics. Within each clinic there were one new patient slot and six follow-up slots, each lasting up to 30 minutes. Transition clinics took place once every six to twelve months with the adult haemoglobinopathy consultant. All annual reviews took place locally. All MRI scans for assessment of iron overload were undertaken locally. Iron chelation was initiated and monitored locally by the lead clinician.

Local outreach clinics were provided by a visiting paediatric endocrinologist and cardiologists from Leeds General Infirmary for all children with thalassaemia. Children with complex chelation issues were seen or

discussed with the specialist team at Leeds Teaching Hospitals NHS Trust. Children were referred to Leeds for Trans-Cranial Doppler scans, with the results sent to the Bradford lead clinician for action. Repeat scans were arranged at Leeds if scans were found to be abnormal. Patients who missed their appointments for scans at Leeds had to be formally re-referred to Leeds. Fail-safe checks, such as ensuring that all eligible children did receive their scans, were undertaken in clinic by the Bradford lead clinician.

COMMUNITY BASED CARE

Community care was provided by 1.75 w.t.e. haemoglobinopathy counsellors, who provided support for both paediatric and adult patients and also for families with new-born babies affected by a haemoglobin disorder and couples identified as being at risk before their child was born. This service was based at the Manningham Clinic. Annual meetings with the regional screening laboratories took place, which were attended by the community nurse counsellors.

VIEWS OF SERVICE USERS AND CARERS

The visiting team met a number of patients with both sickle cell and thalassaemia and their carers, and received feedback from them. Some service users had been asked to attend the review visit by the haematology clinical nurse specialist. Thalassaemia patients receiving transfusions on the day of the visit were also asked to meet the reviewers. Fourteen responses to a patient and carer questionnaire had been received, the majority from patients with thalassaemia.

Common themes raised by patients and carers were:

- A desire for the service to become a centre of excellence for patients with haemoglobinopathy disorders.
- A lack of information being given to patients and carers about the care that they received. Some lack of confidence in nursing and medical staff was also reported with patients unsure that they were always receiving up to date advice and active management of their care.
- A perceived high level of staff turnover and poor retention of experienced staff and some concern expressed by patients about whether staff on the day unit had had appropriate training.
- Concerns about the day unit expressed by children who were about to transition to the adult service and who had visited the unit. Reviewers considered that these concerns were above and beyond the normal trepidation experienced by many children about to transition to adult care. Adult patients also expressed concern that the facilities, which they considered to be overcrowded, would not be sufficient for the number of paediatric patients who would transition in the immediate future.
- A lack of response to patient and carer feedback. Some patients expressed the opinion that they did not feel it was worth giving feedback as there was no evidence that the service acted upon it.
- The lack of a focus group available to patients and carers.

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REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

The Network consisted of three specialist centres (Leeds, Sheffield and Bradford), with services commissioned by specialist commissioners. Leeds and Sheffield were meeting the majority of requirements for specialist centres, and offered numerous specialist services. All three hospitals acted as hubs for a number of local hospitals, providing clinical support and guidelines and offering annual review clinics. The adult services were aware of the majority of haemoglobinopathy patients in the region and offered annual review appointments. Local haemoglobinopathy services had access to the guidelines from Leeds or Sheffield (depending on location), were able to call these centres for clinical advice and referred patients for annual review to one of them. Formal network arrangements were not yet in place for the paediatric services but most patients attended the nearest specialist centre for review.

Progress since Last Visit

Whilst the Yorkshire Network did not meet many of the network standards, for example network education and training or network data collection, there was evidence of good informal working networks with the local haemoglobinopathy centres which had developed since the previous peer review visits. This had been achieved largely through the endeavour of the Clinical Leads at Sheffield and Leeds. A small number of meetings between the three centres had taken place over the 12 months before the review. These meetings had been co-ordinated by the commissioners. Business meetings were taking place between the major centres in Yorkshire to plan the way forward.

Good Practice

1 Since January 2015 NHS Blood and Transplant had provided a 24 hour apheresis service for the whole of Yorkshire. This was a mobile service which travelled to anywhere in the region if required.

Immediate Risks: No immediate risks were identified.

Concerns

1 The service at Bradford was not providing several elements of a specialist service.

2 The majority of network standards were not met at the time of the review visit.

Further Consideration

1 The services at Sheffield and Leeds both provided strong leadership for their own service and for their local hospitals. With relatively little support from commissioners or Trust managers the network standards could be met which should lead to improvements in the quality of care across the whole region. This could include provision of:

   a. Network involvement of patients and carers

   b. Network programme of education and training

   c. Development of network guidelines (the majority of guidelines had already been developed by Sheffield/Leeds and would need only minor modifications to be suitable for use across the network)

   d. Data collection on network outcomes

   e. Collation of network audits

f. Network review and learning events.

2 Both The Leeds Teaching Hospitals NHS Trust and Sheffield Teaching Hospitals NHS Foundation Trust had set up informal arrangements for supporting their local haemoglobinopathy units, including providing them with guidelines and clinical advice. Reviewers suggested that commissioners should consider reviewing the specialist centre status of their hospitals, utilising the outcomes of the peer review reports. In particular, reviewers suggested that the service at Bradford should consider working with one of the other specialist centres to ensure that all patients have access to specialist care.

3 Northern Lincolnshire and Goole NHS Foundation Trust were reported as linking with specialist centres at both Leeds (for adults) and Sheffield (for children and young people). The network may wish to consider the benefits of patients from this Trust linking with a single centre, especially to improve the process of transition to adult care.

NETWORK CONFIGURATION

The network configuration at the time of the review was as follows. The network had no Accredited Local Haemoglobinopathy Teams.

Specialist Haemoglobinopathy Centres	Local Haemoglobinopathy Teams
• Sheffield Teaching Hospitals NHS Foundation Trust (Royal Hallamshire Hospital) • Sheffield Children's NHS Foundation Trust	• Doncaster and Bassetlaw Hospitals NHS Foundation Trust • Barnsley Hospital NHS Foundation Trust • Chesterfield Royal Hospital NHS Foundation Trust • The Rotherham NHS Foundation Trust • Hull and East Yorkshire Hospitals NHS Trust • Northern Lincolnshire and Goole NHS Foundation Trust • United Lincolnshire Hospitals NHS Trust (Lincoln County Hospital and Pilgrim Hospital Boston)
• Leeds Teaching Hospitals NHS Trust (St James's University Hospital)	• York Teaching Hospital NHS Foundation Trust • Harrogate and District NHS Foundation Trust • Calderdale and Huddersfield NHS Foundation Trust • The Mid Yorkshire Hospitals NHS Trust (Pinderfields Hospital and Dewsbury and District Hospital) • Northern Lincolnshire and Goole NHS Foundation Trust •
• Bradford Teaching Hospitals NHS Foundation Trust (Bradford Royal Infirmary, St Luke's Hospital)	• Airedale NHS Foundation Trust[1]

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[1] No information on links for Airedale NHS Foundation Trust was available. This Trust has been linked with Bradford Teaching Hospitals NHS Foundation Trust because of the shared consultant haematologist rota.

SPECIALIST TEAM: BRADFORD TEACHING HOSPITALS NHS FOUNDATION TRUST

SERVICE FOR ADULTS

General Comments and Achievements

A committed multi-disciplinary team provided personalised care for their patients. In 2014 both the adult and paediatric teams had attended a motivational interviewing training session run by a clinical psychologist. A transition process was in place and appeared to be working well. Emergency and out of hours erythrocytapheresis was available 24/7, provided by NHS Blood and Transplant (NHSBT) as an outreach service.

Progress since Last Visit

The previous peer review visit had taken place in September 2012 and some progress had been made to mitigate the concerns identified at that visit. Training had been put in place for both ward staff and senior nurses, who were seconded to the clinical nurse specialist for clinical training. Annual reviews, using an annual review proforma were taking place. Increased amounts of data were entered onto the National Haemoglobinopathy Registry (NHR) although this was not being done in a systematic way and the information was often incomplete. Seventy-three out of 87 patients (adults and children) had been registered, and 62 patients had annual reviews entered on the NHR. Three adverse events had been reported.

The service planned to review incidents in the departmental mortality and morbidity meeting although there had been no mortality since the last peer review. MRI scans for assessment for liver and cardiac iron overload were available locally.

Good Practice

1 Individual care plans for both sickle cell disease and thalassaemia patients had been completed. They were comprehensive and available both on the ward and in the Emergency Department.

Immediate Risks: No immediate risks were identified

Concerns

1 The lead consultant's job plan did not have sessions identified for haemoglobinopathy work, although two clinics per month (equivalent to 0.5 PA) were run in addition to in-patient work. There was no formal cover for absences available from a doctor with haemoglobinopathy expertise.

2 The review team were concerned about the lack of specialist services available:

   a. A small number of patients, as a result of individual patient choice, were receiving annual reviews outside the Trust. There did not appear to be clear criteria and responsibilities in place.

   b. Chronic disease complications:

      Out-patient screening for chronic complications of sickle cell disease and thalassaemia was not being performed in a systematic way. There was a lack of clear management guidance in some areas and some evidence that available guidelines were not being followed. For example, patients with sickle cell disease were not being monitored routinely for renal complications (proteinuria) or cardiac complications. MRI scans for iron overload were not always being performed at regular intervals, despite being available locally.

      Clear referral guidelines for patients with chronic disease complications were not available and referral was on an ad hoc basis.

   c. Patients with chronic organ impairment were being referred to local clinicians who did not have sufficient experience of patients with haemoglobinopathy disorder to provide specialist advice.

3 At the time of the visit psychology support was difficult to access and no psychologists with expertise in the care of people with haemoglobin disorders were available.

4 Nursing support was provided by a generic haematology clinical nurse specialist who had no specific job plan time allocated to the care of people with haemoglobin disorders. Nursing support appeared insufficient for the workload, an issue that was also highlighted by feedback from patients. In addition, cover for absences of the clinical nurse specialist was not available.

5 Ward and Emergency Department staff had not undertaken training in the care of people with haemoglobin disorders. A training programme and teaching materials had been prepared but nursing staff had been unable to deliver the programme because staff had not been released from the ward or Emergency Department.

6 Guidelines for care were not comprehensive and many had not been updated since the previous peer review visit in September 2012. The lead clinician reported that the service was waiting for the development of the network guidelines but local guidelines had not been completed in the interim.

7 Patients reported long waits for analgesia in the Emergency Department (ED) and no recent audit of waits for analgesia against the NICE standards had been undertaken. Patients reported that pain relief was not always administered within the recommended timescale of less than 30 minutes and patients had to continue upon arrival with the medication they had used at home, before being escalated to the appropriate analgesia. Some patients were reluctant to attend the ED because of the delays in treatment. Shortly before the review, the ED had improved its triage procedure, but analgesia waits had not been audited following these changes to assess their impact.

8 Expected clinical audits, as stipulated in the Quality Standards, had not been completed at the time of the review, other than a patient audit on transfusion and chelation. Waiting times for analgesia and for transfusion had not been audited. There was no evidence that audit had been used to promote service changes or improvement in the clinical management of patients.

9 No formal multi-disciplinary team meetings were in place, although the team met and discussed patients informally after each clinic. Recommended audits had also not been completed.

10 Day unit facilities were small and insufficient for the number of patients. Plans for a new day unit were in the Trust's business plan but staff expressed concerns that the plans were insufficient for the expected expansion in patient numbers. Patients were also concerned about this, especially because of the expected number of young people transferring to adult services.

11 Clinic appointments were not easily accessible, with patients reporting delays of several months in booking appointments.

12 There was no provision for out of hours transfusions. The Trust was aware of this and was looking at new models of working.

13 Patients were concerned that the service was not listening to their complaints and feedback. Reviewers saw no evidence of actions taken in response to patient feedback. Some patients said that there was therefore no point in making complaints or giving feedback. Reviewers were particularly concerned about patient feedback on breaches of patient confidentiality.

Further Consideration

1 Reviewers suggested that the Trust consider the development of clear links with a Specialist Haemoglobinopathy Centre with specialist expertise in the care of patients with chronic disease complications of their haemoglobin disorders. Reviewers suggested that written referral guidelines to these services should be developed. Patients with thalassaemia should be able to access teams with expertise in fertility, cardiology and endocrinology and patients with sickle cell disease should be able to

access teams with expertise in the renal, orthopaedic, neurological and urological complications of sickle cell disease and specialist obstetricians.

2 Clinic letters and care plans were not routinely copied to patients.

3 Routine data on service outcomes such as length of stay or 'did not attend' rates were not available. Reviewers considered that managers would find service planning and improvement challenging without these data. This was compounded by the lack of administrative support for the service.

4 Available guidelines did not indicate appropriate document control procedures.

5 Routine red cell erythrocytapheresis was provided by NHSBT in Leeds. As there were no in-patient facilities available for these patients in Leeds, patients were therefore admitted to Bradford for line insertion, stayed in hospital overnight, were transferred to Leeds the next day for the procedure and then returned to Bradford the day after that. This took place every six to eight weeks. Reviewers suggested that this process was not 'patient-friendly' and may benefit from review.

6 Patient information was incomplete and would benefit from review. Some of the information about haemoglobin disorders presented to reviewers consisted of abstracts of journals and peer reviewed articles which reviewers considered inappropriate for many patients.

7 A service organisation policy was not available.

8 Patients had expressed concern about the turnover of experienced nursing staff within the team. Four of the senior nurses on ward 7 had participated in secondments with the haematology CNS over the previous two years, and one had continued to work part-time on the ward and part-time as the haematology CNS. Patients were concerned that this had resulted in a lack of long-term knowledge about patients.

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Specialist Team: Bradford Teaching Hospitals NHS Foundation Trust

Services for Children and Young People

General Comments and Achievements

The lead clinician and nurse were hardworking and committed to improving services for patients with haemoglobinopathies. Clinic letters were comprehensive and served as an excellent care plan for the patient. A transition process was in place and seemed to be working well.

Progress since Last Visit

The service for children and young people was reviewed as part of the visit to Leeds Teaching Hospitals NHS Trust in January 2011 when Bradford Teaching Hospitals NHS Foundation Trust was a linked hospital. Since that review an annual review proforma had been produced and was in use and twice yearly network meetings were held with Leeds General Infirmary for discussion of more complex cases.

Good Practice

1 The review team was impressed by the quality of the care plan in place for pre-transfusion checks for children on regular transfusions. The lead nurse was present in the day unit for supervision of transfusions, which enabled personalised care for these children and reduced waiting times for transfusions.

Immediate Risks: No immediate risks were identified

Concerns

1 The clinical team considered that the service provided care as a Local Haemoglobinopathy Team but information from commissioners was that the service was commissioned as a Specialist Haemoglobinopathy Centre (SHC). Reviewers concluded that although the team provided a dedicated and committed service, it lacked some essential components of an SHC, in particular:

   a. Availability of 24/7 specialist cover

   b. Access to other services with a specialist expertise in the care of people with haemoglobin disorders

   c. Dedicated psychology support

   d. Training and research opportunities for nursing and medical staff.

2 Nurses in both the day unit and the acute assessment unit had not undertaken appropriate training in the care of people with haemoglobin disorders. The majority of the care was provided by the lead clinical nurse specialist who also covered care of children and young people with haemophilia. A ward nurse had developed significant relevant clinical expertise but was not recognised as a specialist nurse.

3 The day unit was small, was only able to accommodate three transfusions a day and was not open at weekends. Patients reported occasional postponement of transfusions. The Trust planned to include a new paediatric facility in a new wing of the hospital.

4 No formal multi-disciplinary team (MDT) meetings were in place, although the team met and discussed clinic patients informally at every clinic. The team intended to start formal MDT meetings in the future.

5 Expected clinical audits, as stipulated in the Quality Standards, had not been completed at the time of the review.

6 Data on children were entered onto the National Haemoglobinopathy Registry (NHR) following consent, but annual reviews and adverse events were not systematically entered onto the NHR.

Further Consideration

1 The lead clinician and lead nurse were providing a service that did not reflect the scope of their job plans. The Trust may wish to consider updating the job plans to adequately reflect their role.

2 Reviewers suggested that the service establish a formal outreach annual review service from a specialist consultant from within the Yorkshire network region. Local clinical expertise could be enhanced through engagement with regional specialist teams.

3 Annual review checklists were not yet in place, although the clinicians provided comprehensive clinic letters, which were copied to the parents and which served as patient-specific clinical care plans.

4 Routine data on service outcomes such as length of stay or ‘did not attend’ rates were not available. Reviewers considered that managers would find service planning and improvement challenging without these data. This was compounded by the lack of administrative support for the service.

5 Some patient information was available but the development of additional information for patients with thalassaemia may be helpful as the available information was not comprehensive.

6 Clinical guidelines for acute complications were available within an overall management booklet and reviewers suggested that this format may not be easy to use when working with an acutely ill child. The Trust may wish to consider a different format for these guidelines.

7 A service organisation policy was not available.

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COMMISSIONING

General Comments and Achievements

There was good specialist commissioner engagement during the review process. Commissioning arrangements in the hospitals were not clear (see 'Concerns' below).

Progress since Last Visit

Commissioners had organised two meetings with representatives from Bradford, Leeds and Sheffield and a further meeting was planned.

Concerns

1 Commissioning arrangements for the services at Bradford Teaching Hospitals NHS Foundation Trust were unclear. Clinicians and local management staff were unsure of the scope of their service and self-assessed as a Local Haemoglobinopathy Team whereas specialist commissioners from NHS England considered they were commissioning a specialist service.

2 At the previous review of services for adults (September 2012), reviewers had been concerned as to whether the number of patients being seen by the Trust enabled it to function appropriately as a specialist centre. It was suggested that as part of new network arrangements, commissioning specialist care from a specialist team with a larger number of patients and ensuring local access through an Accredited Local Haemoglobinopathy Team in Bradford may be a better alternative. This issue not been adequately addressed, as shown by the findings of this review visit.

3 At the previous visit reviewers had been unable to clarify the arrangements for patients from Airedale. This was still not clear.

4 Commissioners did not meet any of the expected Quality Standards. The configuration of clinical networks had not been formally agreed. There was no regular review of the quality of care provided by the services.

5 Additional issues requiring commissioners' attention are included in the network section of this report. Issues identified in the Bradford Teaching Hospitals NHS Foundation Trust section of this report will also require commissioner monitoring and support to ensure they are addressed.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead/s:

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

Visiting Team:

Lindy Defoe	Haemoglobinopathy Specialist Nurse	South Tees Hospitals NHS Foundation Trust
Dr Moira Dick	Consultant Paediatrician	King's College Hospital NHS Foundation Trust
Karen Madgwick	Transfusion Practitioner	North Middlesex University Hospital NHS Trust
Elaine Miller	National Coordinator	UK Thalassaemia Society
Dr Kate Ryan	Consultant Haematologist	Central Manchester University Hospitals NHS Foundation Trust
Dr Chris Sotirelis	Service User	
Sarah Tadd	Clinical Nurse Specialist	University Hospitals of Leicester NHS Trust
Vanessa Wills	Service User	

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

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

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist services for People with Haemoglobin Disorders	44	8	18
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	56	8	14
Service for Children and Young People	**Number of Applicable QS**	**Number of QS Met**	**% met**
Specialist services for People with Haemoglobin Disorders	46	15	33
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	58	15	26

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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

SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-101 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199)	N	There was no information on how to provide feedback to the service ('hv') or how to become involved in improving the service ('hvi'). A recent patient survey was available with responses.	Y	

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-102 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	There was no information for transfusion and iron chelation ('e') or health promotion ('g'). It was not clear which information was primarily for adults and which was for children and young people. Some of the evidence presented to reviewers consisted of abstracts of journals and peer-reviewed articles which were not appropriate for many patients. See main report.	N	There was no information for splenic palpation and Trans-Cranial Doppler scanning. More information was available for patients with sickle cell disease, although there were larger numbers of patients with thalassaemia. It was not clear which information was primarily for adults and which was for children and young people. See main report.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-103 All	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service	N	No information was available.	Y	
HN-104 All	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	N	Care plans for acute care of sickle cell disease and long-term transfusion management were contained in patient notes and were available in the Emergency Department, ward and day unit areas. Not all patients were aware of these and they did not all have copies of the care plans. Some patients felt that they were not informed of any updates to their care plans and that some care plans had not been updated since they had been created. See main report.	Y	Copies of letters were sent to parents and patient notes were available on the shared drive in both the Emergency Department and the paediatric unit.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-105 All	**School Care Plan (Paediatric Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school	N/A		N	A thalassaemia school care plan was available. There was also a sickle cell and thalassaemia policy for schools but it was not clear if this was in use.
HN-106 SHC (A-LHT)	**Transition to Adult Services** Young people transferring to the care of adult services should be offered written information covering at least: a. Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer b. A joint meeting between children's and adult services to plan the transfer c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Arrangements for monitoring during the time immediately after transfer	N	Some information was in place but there was little available on nursing, or clinical psychological and counsellor support within the service. The information did not describe how transition was managed within the Trust.	N	A generic transition booklet for all teenagers was available but this was not specific to haemoglobin disorders. Written information was in place for young people with thalassaemia but not for those with sickle cell disease.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-107 SHC	**Information about Trans-Cranial Doppler Ultrasound** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated	N/A		Y	Written information was available.
HN-199 All	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	N	A patient survey had been performed prior to the peer review visit but there was no evidence of previous surveys or patient feedback. Patients did not feel they had adequate opportunity to give feedback about the service or that their feedback was listened to. See main report.	N	A patient survey had been performed prior to the peer review visit but there was no evidence of previous surveys or patient feedback. Patients did not feel they had adequate opportunity to give feedback about the service or that their feedback was listened to. A transition project involving young people with thalassaemia had been carried out. See main report.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-201 All	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	N	The lead consultant provided two clinics a month, but further commitment was not clear in their job plan. See main report.	Y	The lead consultant had one PA within her job plan. This was not adequate for this population and did not reflect the workload. See main report.
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	N	There was no formal cover for absence. See main report.	N	There was informal cover from the general paediatricians in Bradford and the clinical lead in Leeds General Infirmary.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	N	Two general haematology nurses were in post: a band six nurse for 19 hours per week and a band seven nurse for 24 hours per week. There were no dedicated haemoglobinopathy sessions.	N	One w.t.e band seven general haematology nurse was in post. There was no specific time in their job plan for haemoglobinopathy services.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-204 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	There was no clinical nurse specialist with responsibility for the acute service in post ('d'), no access to a psychologist ('g') and insufficient staffing on the day unit.	N	There was no clinical nurse specialist with responsibility for the acute service in post ('d') and no access to a psychologist ('g').
HN-205 All	**Competences and Training** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).	N	A training plan had been developed but had not been acted on due to insufficient staff numbers. See main report.	N	A training plan had been developed but had not been acted on due to insufficient staff numbers. See main report.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		**Y**	
HN-207 All	**Training for Emergency Department Staff** The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	N	Training for ED staff had not taken place.	N	Training for ED staff had not taken place.
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	N	It was not clear if all staff had undertaken appropriate training.	N	It was not clear if all staff had undertaken appropriate training.
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	Specialist Registrars received adequate training over the whole of their training rotation.	Y	Specialist Registrars received adequate training over the whole of their training rotation.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-210 SHC	**Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A		N/A	Trans-Cranial Doppler ultrasounds were carried out at Leeds Teaching Hospitals NHS Trust.
HN-299 All	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	Insufficient support was available.	N	Insufficient support was available.
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.	N	There was no access to a psychologist with an interest in haemoglobinopathies. See main report.	N	There was no access to a psychologist with an interest in haemoglobinopathies although a newly appointed psychologist with an interest in chronic diseases was due to start at the Trust. See main report.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	N	There was no access to manual exchange transfusion (‘a’), a consultant obstetrician (‘c’) or a respiratory physician (‘d’).	N	There was no access to an acute pain team (‘b’) or a respiratory physician (‘d’).

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	N	There was no access to specialist staff and services for points ‘d’ to ‘k’, ‘m’, ‘o’ or ‘p’. Some specialists were available at other Trusts (‘b’ in Sheffield, ‘c’ in Nottingham and ‘n’ in Oxford)	N	There was no access to specialist staff and services for points ‘c’, ‘f’ to ‘j’, or ‘m’ to ‘p’. A consultant from Leeds provided an outreach service for ‘d’ and ‘e’. There was a lack of clarity about how much specific specialist knowledge was available within the network. See main report.
HN-304 All	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		Y	

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-401 All	**Facilities Available** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	N	The day unit was very small. See main report.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	There were no facilities for out of hours care.	N	There were no facilities for out of hours care.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-501 SHC A-LHT	**Transition Guidelines** Network-agreed guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y	Transition guidelines were in place.	N	A care pathway and guideline for thalassaemia only was available.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	N	There were no monitoring checklists for points ‘a’ and ‘b’. The annual review proforma was good.	N	Annual review checklists were not in place although clinicians provided comprehensive clinic letters.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-503 LHT	**Clinical Guidelines: LHT Management and Referral** Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A	The service was reviewed as an SHC.	N/A	The service was reviewed as an SHC.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Offering access to exchange transfusion to patients on long-term transfusions c. Protocol for carrying out an exchange transfusion d. Hospital transfusion policy e. Investigations and vaccinations prior to first transfusion f. Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. g. Areas where transfusions will usually be given h. Recommended number of cannulation attempts	Y	Transfusion guidelines were in place but information for points 'c' and 'h' could be made clearer. The guidelines were primarily aimed at the transfusions of patients with sickle cell disease.	N	The transfusion guidelines had not yet been ratified.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-505 All	**Chelation Therapy** Network-agreed clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	N	It was not clear how up to date the chelation therapy guidelines were, and there were no guidelines for 'e', only a company marketing brochure.	Y	

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	N	There were no guidelines for points 'b', 'd', 'h', or 'j' to 'm'. The acute pain guidelines could be clearer.	Y	Clinical guidelines were available in an overall management booklet. See main report.
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	N	There were no guidelines for points 'a' or 'c'.	N	There were no guidelines for point 'a'. Point 'b' was N/A.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	N	There were no guidelines for points 'b' to 'i'.	N	Guidelines were available for thalassaemia only.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N	No guidelines were in place.	Y	
HN-510 All	**Thalassaemia Intermedia** Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	N	No guidelines were in place.	Y	
HN-511 All	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	N	Not all guidelines were available.	N	Not all guidelines were available or up to date.

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

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-601 All	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	N	There was no service organisation policy in place. See main report.	N	There was no service organisation policy in place. See main report.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	N	There were no formal multi-disciplinary meetings in place. Ad hoc meetings took place after clinic but these were not minuted and there was no formal agenda. See main report.	N	Informal meetings only took place after clinic.
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A		N/A	
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	N	Network meetings did not take place.	N	Network meetings did not take place.
HN-605 SHC	**Neonatal screening programme review meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	Y		Y	
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	Y		N	Patient data were entered onto the NHR but not adverse events or annual updates.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-702 All	**Annual Data Collection - Activity** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	N	Data were not available. See main report.	N	Data were not available. See main report.

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

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	N	An audit of thalassaemia patients looking at ferritin and Hb pre-transfusion was available. No recommendations from this audit were available. See main report.	N	No audits were available. See main report.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-705 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	No rolling programme of audit was in place.	N	No rolling programme of audit was in place.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N	The Trust did not participate in haemoglobinopathy research projects.	N	The Trust did not participate in haemoglobinopathy research projects.
HN-707 SHC	**Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required	N/A		N/A	

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HN-798 All	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility	Y		Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	The majority of guidelines had not been through document control.	N	The majority of guidelines had not been through document control.

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**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.	N	No network was in place.	N	There were no mechanisms in place.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	N	No network was in place.	N	No network leads were in place.
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-204 and HN-205.	N	No network was in place.	N	There was no programme of education in place.

		Adults		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	No network was in place.	N	No network transition guidelines were in place.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**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 (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303) g. Specialist management (QS HN-507) h. Thalassaemia intermedia (QS HN-510) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.	N	No network was in place.	N	Network clinical guidelines were not in place.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	N	No network was in place.	N	No ongoing monitoring was in place.

		Adults		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QSs HN-703, HN-704, HN-705 and HN-707.	N	No network was in place.	N	No programme of audit was in place.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	No network was in place.	N	No network policy on research was in place.
HY-798	**Network Review and Learning** The SHC should meet at least twice a year with its referring LHT teams to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from any positive feedback or complaints involving liaison between teams d. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams e. Consider the content of future training and awareness programmes (QS HY-202)	N	No network was in place.	N	There was no network review and learning programme in place.

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COMMISSIONING

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

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	No network was in place.	N	Network review and learning meetings were not in place.

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