

Health Services for People with Haemoglobin Disorders

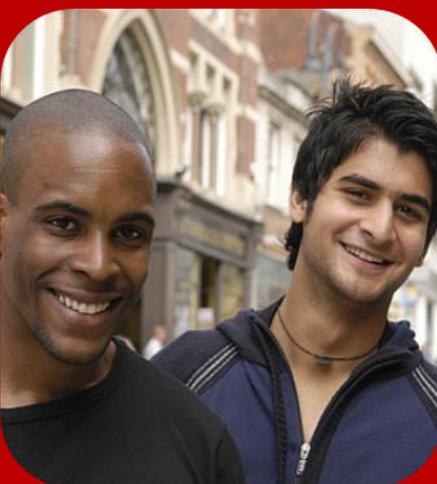
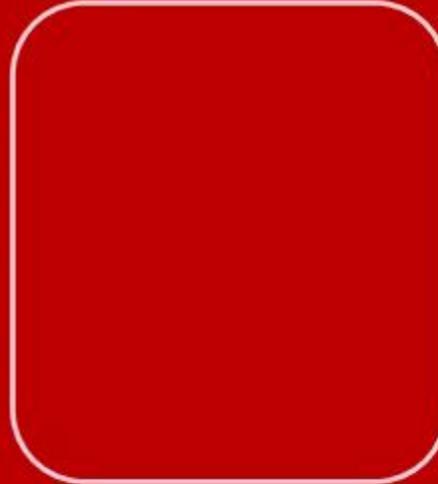
Yorkshire Network

Leeds Teaching Hospitals NHS Trust

Visit Date: 26th February 2015

Report Date: June 2015

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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Leeds Teaching Hospitals NHS Trust (part of the Yorkshire Network), which took place on 26th 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:

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

About West Midlands Quality Review Service

WMQRS 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 review visit Leeds Teaching Hospitals NHS Trust was part of the Yorkshire Network and both the adult and the paediatric services were commissioned as Specialist Haemoglobinopathy Centres (SHCs). Adult services were provided by St James's University Hospital and paediatric services by Leeds Children's Hospital, both part of Leeds Teaching Hospitals NHS Trust.

ADULTS

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long-term red cell transfusions
Leeds Teaching Hospitals NHS Trust (St James's University Hospital)	SHC	65	18	16 (incl. <5 SCD)
Calderdale and Huddersfield NHS Foundation Trust	LHT	22	<5	5
Harrogate and District NHS Foundation Trust	LHT	0	0	0
Northern Lincolnshire and Goole NHS Foundation Trust (Diana, Princess of Wales Hospital)	LHT	<5	0	0
The Mid Yorkshire Hospitals NHS Trust (Pinderfields Hospital)	LHT	<5	0	0
York Teaching Hospital NHS Foundation Trust	LHT	<5	0	0

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
Leeds Teaching Hospitals NHS Trust (Leeds Children's Hospital)	SHC	81	11	11 (incl. <5 SCD)
Calderdale and Huddersfield NHS Foundation Trust	LHT	13	<5	0
The Mid Yorkshire Hospitals NHS Trust (Pinderfields Hospital)	LHT	<5	0	0
The Mid Yorkshire Hospital NHS Trust (Dewsbury and District Hospital)	LHT	<5	<5	0
University Hospitals of Morecambe Bay NHS Foundation Trust (Royal Lancaster Infirmary)	LHT	<5	0	0
York Teaching Hospital NHS Foundation Trust	LHT	<5	0	0

EMERGENCY CARE

The majority of urgent adult acute admissions were via the Emergency Department (ED) at St James's University Hospital. During working hours patients were reviewed by the haematology team and out of hours by the on-call medical team. During working hours patients could also contact either the clinical nurse specialist or the haematology day care unit staff and, if staff were available, patients were assessed directly on the day unit or on the admission wards, J96 and J95. Out of hours patients could phone the haematology ward directly and, if staff were available, were assessed on the admission ward. Small numbers of adults attended the ED at Leeds General Infirmary. Emergency protocols were common across the Trust and patients were transferred to St James's University Hospital for admission to the haematology wards.

Existing paediatric patients had open access to clinics and in-patient wards for urgent review. If a patient presented to the ED they were directed to the on-call paediatric haematology service. An on-call paediatric haematology registrar (ST 4-8) or ward paediatric registrar (ST 4-8) provided junior cover on the ward and any patients presenting to the service for acute treatment were reviewed directly in the designated paediatric haematology ward. Paediatric haematologists or oncologists provided consultant cover and a 'benign haematology' rota provided specialist support for oncology consultants.

IN-PATIENT FACILITIES

Adult haematology in-patient care took place on the Bexley Wing at St James's University Hospital. The main wards were J89 and J99 which formed a 40 bedded unit specifically for the care of haematology patients. The admission wards (J96 and J95) were for the use of both haematology and oncology patients who were then moved to their specific team's base ward when appropriate beds became available. Young adults were able to access a young adult ward (J94) either by a direct admission or via J96 or J95. J94 was mainly funded to deliver care for patients with cancer but patients with haemoglobinopathies could be admitted to it.

In-patients were seen daily by the myeloid/red cell team which included a specialist registrar, a junior doctor and a consultant (on a 1 in 4 'attending' rota). In-patients were regularly reviewed by the lead nurse. The lead consultant, when not 'attending', contributed to the care of haemoglobinopathy patients (on a weekly basis or as required outside this). At the weekends in-patients were reviewed by the on-call haematology registrar or consultant.

A dedicated haematology and oncology in-patient facility for children at the Leeds General Infirmary was part of Leeds Children's Hospital. The unit comprised three wards. Children and young people up to the age of 13 years were cared for on ward 31 (13 beds at the time of the review but with capacity for 16 beds). Young people aged 13 to 19 years were admitted to ward 33 (eight beds) and those aged up to 18 years receiving autologous or allogeneic haemopoietic stem cell transplants (or other high dose chemotherapy procedures which required peripheral blood stem cell transplantation) were admitted to ward 32 (four beds). There were also a further 13 single rooms suitable for protective or source isolation. Patients with haemoglobin disorders were generally admitted to these three wards.

Manual exchange transfusions were infrequently required. A protocol was available within the Trust and was followed by attending medical staff both in and out of hours. Manual red cell exchanges were most frequently undertaken in the neonatal unit. An automated apheresis service was run by the National Blood Service and provided automated erythrocytapheresis to acutely ill children with satisfactory intravenous access. Access to this service out of hours was available as an exception. Intensive care was provided within the department for children, including those with haemoglobin disorders needing intensive care from across Yorkshire and the Humber region. Transfers to the Paediatric Intensive Care Unit in Leeds were undertaken by a dedicated paediatric retrieval service.

DAY UNIT FACILITIES

A large haematology day unit provided facilities for transfusion and acute pain management. The unit was open Monday to Friday 9am to 6pm. The apheresis suite was adjacent to the day unit and was run by the National Blood and Transplant. This suite had facilities to perform erythrocytapheresis. Since January 2015 the apheresis unit had provided a 24 hour service across Yorkshire and the Humber region.

The paediatric day unit comprised a dedicated ten bed facility with six consultation rooms specifically for the management of haematology and oncology patients. Teenagers had a specific waiting room. The day care ward was open from 8.30am to 6pm from Monday to Friday. No late evening or weekend service was available.

OUT-PATIENT CARE

A dedicated red cell clinic took place weekly on Wednesday afternoons at St James's University Hospital. This was attended by the lead consultant, lead nurse, community team and specialist registrar. There was also a monthly joint obstetric-haemoglobinopathy clinic. The apheresis unit and supportive day care unit were situated next to the out-patient area on the Bexley Wing.

Children with haemoglobin disorders were reviewed in the weekly benign haematology clinic. Trans-Cranial Doppler screening (TCD) was provided by paediatric radiologists, but not always on the same day as the child's medical appointment. Annual reviews were provided to patients from both Leeds and regional district hospitals except for Bradford who undertook their own annual reviews (although TCD was provided in Leeds for sickle cell patients from Bradford). Every effort was made to arrange TCD on the same day as medical appointments for children coming from outside Leeds. The lead clinician, lead nurse, a junior trainee and members of the community nursing team attended clinics.

Transition clinics took place in an ad hoc manner, depending on service needs. The lead adult clinician and nurse would attend clinics at Leeds Children's Hospital to meet young people who were being transferred to adult care. Only those aged over 18 were formally transferred to the adult haemoglobinopathy service at St James's University Hospital. Patients between the ages of 16 and 18 years were reviewed in the paediatric clinics. The Trust had plans to introduce a new transition process in April 2015.

COMMUNITY CARE

The community team comprised one nurse and two counsellors and was based at the Reginald Centre. The funding of this service was under review by primary care at the time of the visit and the lead counsellor was due to move to a new position within primary care.

The counsellors provided community support to patients with haemoglobin disorders and their families; this included an initial visit to a newly-diagnosed child, preparing nursery and school care plans, attending adult and paediatric hospital clinics and supervising drop-in sessions at the Reginald Centre. Support group meetings were also arranged at the Centre every six to twelve weeks and these meetings were a popular forum for parents and carers to meet and provide peer support.

LINKED PROVIDERS

Approximately 35 patients with haemoglobinopathies were seen at the Calderdale and Huddersfield NHS Foundation Trust and their care was provided by two of the four haematology consultants there. Clinical protocols were all provided by Leeds Teaching Hospitals NHS Trust (the SHC) but with local modifications.

Patients requiring urgent care presented to the Emergency Department and were admitted under the haematology team for acute in-patient care. There were around 12 admissions per year and any concerns about acute or chronic care were referred to Leeds Teaching Hospitals NHS Trust. Patients were also referred to Leeds for their annual review. An audit of time to pain relief (according to the NICE guidelines) was taking place at the time of the visit but had not been completed and it was planned to present this at a network

meeting. There was no specialist nurse support and community support was provided by generic community nurses. Training had been offered to the Emergency Department but had not yet been taken up.

Fewer than five patients were seen regularly by the adult haematology service at York Teaching Hospital NHS Foundation Trust and patients were occasionally admitted acutely at York. Protocols which were based on the NICE guidelines and the Leeds Teaching Hospitals NHS Trust protocols, were in place for the treatment of acute complications. Annual reviews and specialist care (such as orthopaedic surgery) were provided by Leeds Teaching Hospitals NHS Trust. A general haematology specialist nurse was in post but did not have specialist haemoglobinopathy experience.

VIEWS OF SERVICE USERS AND CARERS

The visiting team met a small number of patients with both sickle cell and thalassaemia and their carers, and received feedback from them. Service users had been invited by letter to attend the review, several weeks in advance of the visit. Reviewers did not see any responses to the patient and carer questionnaire.

Common themes raised by patients and carers were:

Adult service

- Appreciation of the lead consultant and clinical nurse specialist and their efforts to improve the quality of the service available, including the reduction of waiting times for transfusions (which had been raised as a concern at the previous visit).
- Appreciation of the excellent facilities available.
- Long waits in the Emergency Department for analgesia.
- Access to specialist advice was difficult when either the adult lead nurse or consultant were not available, which could be up to two days per week. A small number of patients reported contacting Whittington Health NHS for advice in these circumstances. Other patients reported that telephone messages were often not acted upon when the clinical nurse specialist was not available.
- Poor access to the chronic pain team.
- The service was responsive to patients' needs, and any patient feedback was considered.

Paediatric service:

- Appreciation of the professional and compassionate clinical team and the individualised and responsive service they gave.
- Sufficient opportunities for carers to raise any concerns and confidence that they would be taken seriously and concerns would be acted upon.

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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
<ul style="list-style-type: none"> • Sheffield Teaching Hospitals NHS Foundation Trust (Royal Hallamshire Hospital) • Sheffield Children’s NHS Foundation Trust 	<ul style="list-style-type: none"> • 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)
<ul style="list-style-type: none"> • Leeds Teaching Hospitals NHS Trust (St James’s University Hospital) 	<ul style="list-style-type: none"> • 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 •
<ul style="list-style-type: none"> • Bradford Teaching Hospitals NHS Foundation Trust (Bradford Royal Infirmary, St Luke’s Hospital) 	<ul style="list-style-type: none"> • Airedale NHS Foundation Trust¹

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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: LEEDS TEACHING HOSPITALS NHS TRUST

ADULT SERVICE

General Comments and Achievements

The lead consultant and lead nurse had worked very well together in developing the service over the past three years and had addressed many of the issues identified in the previous peer review visit report. The team offered an appropriate specialist service and had developed excellent links with other teams.

The facilities, especially the teenager and young person's unit, were of high quality, and access for haemoglobinopathy patients was the same as for haematology–oncology patients.

Patients recognised that services, particularly access to and waits on the day unit had improved and feedback about the haemoglobinopathy team was very positive. A pathway for direct admission to the wards was in use, 24 hour apheresis was available and liaison with the ambulance service was good.

Patients with thalassaemia had a personalised transfusion plan in their notes which was updated on an annual basis.

Progress since Last Visit

The previous peer review visit took place in May 2012 and good progress had been made in addressing some of the concerns raised.

The clinical nurse specialist role had been secured as a permanent position (it had previously been charitably funded for two years) and the lead consultant's job plan had designated time for care of patients with haemoglobin disorders.

The relationship between the hospital and the community team had developed, and regular meetings between them had been introduced. Informal meetings took place on a weekly basis prior to clinic and formal multi-disciplinary meetings took place quarterly.

Other progress achieved included the introduction of comprehensive guidelines and protocols, the routine use of a proforma for annual reviews in clinic and the availability of out of hours transfusions at weekends.

Good Practice

- 1 Good patient information was available covering both sickle cell and thalassaemia. The review team was particularly impressed with the clear sickle cell discharge information.
- 2 The information available to GPs was clear and of good quality.

Immediate Risks No immediate risks were identified

Concerns

- 1 The level of nursing support available was of concern for a number of reasons:
 - a. The lead nurse had only 22.5 hours in her job plan which was insufficient for the workload. The lack of nursing support had contributed to the lack of training for staff in the Emergency Department and on the haematology wards.
 - b. There was no cover for absences of the lead nurse.
- 2 The lead consultant's job plan had only two PAs allocated for the care of patients with haemoglobin disorders, which reviewers considered insufficient to provide an adequate service. There was no named deputy for the lead consultant and no arrangement for access to specialist haemoglobinopathy advice in the absence of the lead consultant.

- 3 The service did not have access to a psychologist with a specialist interest in haemoglobinopathies.
- 4 An annual review proforma had been developed and was used for the annual review process, but not all patients received an annual review.
- 5 At the time of the review, annual reviews and adverse events were not yet being entered onto the National Haemoglobinopathy Registry (NHR). The service had no data management and administrative support. Clinical time was therefore being spent on administrative work.
- 6 Reviewers were told of plans to re-organise community services and reduce the amount of counsellor time. Reviewers were seriously concerned that this would destabilise the service as the community team provided counselling for the screening programme and also ran adult support groups.
- 7 Data expected by the Quality Standards were not yet being collected. It was difficult to see how the service could be effectively managed and improved in the absence of these data.
- 8 Patients experienced long waits in the Emergency Department (ED). An audit showed that only 33% of patients received analgesia within 30 minutes. At the time of the visit these data had not yet been presented to the ED staff. The pathway had, however, changed since the audit with improved staffing levels and reviewers were not sure that it was representative of current practice.

Further Consideration

- 1 Access to the chronic pain service was poor with long delays in patients being seen. Reviewers were also told of delays in feedback to the haemoglobinopathy team.
- 2 Care plans were not being shared with all patients. Reviewers considered the service should ensure that copies of both clinic letters and formal care plans are sent to patients.
- 3 The banding of the lead nurse role may benefit from review as it appeared low for the role undertaken.
- 4 Reviewers considered the service to be responsive to their needs and feedback, but the Trust may wish to consider a patient survey and ensure that patients are aware of mechanisms for providing formal feedback to the Trust. For example, reviewers were told by some patients that they had experienced long waits in the out-patient clinics and that they were not aware that out of hours transfusions were available.
- 5 The haemoglobinopathy service should ensure that patients have access to pre-implantation genetic diagnosis if requested.
- 6 Guidelines were not available throughout the Trust although there are plans to make them available on the Trust intranet. At the time of the visit a password was required to access them.

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SPECIALIST TEAM: LEEDS TEACHING HOSPITALS NHS TRUST

PAEDIATRIC SERVICE

General Comments and Achievements

The paediatric team provided a responsive service that was highly valued by patients and their carers. The lead nurse appeared to work beyond the allocated ten hours per week and effectively planned ahead for any periods of leave by ensuring patient prescriptions and other arrangements were in place.

Facilities were child and teenage-friendly. The review team was impressed by the in-patient facilities in the department, particularly the dedicated teenage ward and the new play and relaxation area.

The Trust planned to use the 'Ready, Steady, Go' transition process from April 2015 and an adolescent transition nurse for chronic diseases post had been funded, but no-one was yet in post at the time of the visit.

Guidelines for management of acute complications for haemoglobin disorders were easily accessible on the Trust intranet and were also available through the intranet to local GPs. Nurses and junior doctors were well versed with the location of these guidelines and found them useful. All children and young people under the care of the service had open access to the day unit and ward. Young people over the age of 16 years who presented for the first time to the Trust were reviewed by the adult team in the Emergency Department and were then referred to the paediatric team.

Progress since Last Visit

The previous review visit had taken place in January 2011 and good progress had been made in some areas since then. The service was carrying out annual reviews on site and regular internal multi-disciplinary meetings were in place between radiology, medical, nursing and community staff. Joint multi-disciplinary meetings were also being initiated with the service at Bradford Teaching Hospitals NHS Foundation Trust. A 'benign haematology' on call rota was provided by the haematology consultants, enabling the provision of 24/7 specialist input at consultant level.

Good Practice

- 1 The review team was impressed by the 'Leeds Pathway' guidelines development, which was accessible directly by both hospital clinicians and by GPs. The guidelines provided clear links and referral pathways to hospital services for GPs.
- 2 Regular support group meetings took place at the community centre, with excellent patient and family feedback.
- 3 Patient information for sickle cell and thalassaemia was comprehensive.
- 4 Specialist advice and support was easily available to local teams within the region.

Immediate Risks No immediate risks were identified.

Concerns

- 1 Nursing support was a concern for a number of reasons:
 - a. There was only ten hours of nursing time available to the service which was insufficient for the workload.
 - b. There was no cover for absence of the lead nurse.
 - c. The lead nurse was funded on a temporary basis and plans for permanent funding were not clear.
- 2 The service did not have access to a psychologist with a specialist interest in haemoglobinopathies.
- 3 The service had no data management and administrative support. Clinical time was therefore being spent on administrative work.
- 4 Annual reviews and adverse events were not yet entered onto the National Haemoglobinopathy Registry.
- 5 Some audits, including an audit of waiting time for analgesia, had not yet been carried out.
- 6 Reviewers were told of plans to re-organise community services and reduce the amount of counsellor time. Reviewers were seriously concerned that this would destabilise the service as the community team provided counselling for the screening programme and also ran adult support groups.

Further Consideration

- 1 The lead consultant job plan may benefit from review to ensure it reflects the post's senior regional advisory and strategic role, including the roles of clinical director for Leeds Children Hospital and responsibilities for tertiary haemoglobinopathy, all paediatric haemophilia and shared responsibility for children with other benign haematology disorders.
- 2 Formal haemoglobinopathy multi-disciplinary meetings were not yet in place.
- 3 The banding of the lead nurse role may benefit from review as it appeared low for the role undertaken.

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COMMISSIONING

General Comments and Achievements

Specialist commissioners attended the review visit and met the review team. The commissioners were relatively new in post and were still in the process of understanding the needs of people with haemoglobin disorders across the Yorkshire region.

Progress since Last Visit

At the time of the previous visits the service was commissioned by the local clinical commissioning group and not as a Specialist Haemoglobinopathy Centre.

Immediate Risks No immediate risks were identified.

Concerns

- 1 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.
- 2 Additional issues requiring commissioners' attention are included in the network section of this report. Issues identified in the Leeds Teaching Hospitals NHS Trust section of this report will also require commissioner monitoring and support to ensure that they are addressed. In particular, Leeds Teaching Hospitals NHS Trust was providing a specialist service but did not yet have all the infrastructure required to deliver a specialist service to the Yorkshire region; in particular, it did not have sufficient specialist nursing support, data and administration support or a dedicated psychologist.

Further Consideration

- 1 Reviewers also suggested that commissioners work with their specialist centres to formalise the relationships between specialist and local centres and to support the specialist centres to collect network activity data.

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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:

Dr Michele Afif	Consultant Paediatrician	London North West Healthcare NHS Trust
Joanne Bloomfield	Specialist Nurse & Manager	Nottingham Sickle Cell and Thalassaemia Service
Lindy Defoe	Haemoglobinopathy Specialist Nurse	South Tees Hospitals NHS Foundation Trust
Dr Helen De Marco	Senior Clinical Psychologist	University College London Hospitals NHS Foundation Trust
Elaine Miller	National Coordinator	UK Thalassaemia Society
Dr Kate Ryan	Consultant Haematologist	Central Manchester University Hospitals NHS Foundation Trust

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

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

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist services for People with Haemoglobin Disorders	44	18	41
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	56	18	32
Services for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist services for People with Haemoglobin Disorders	50	33	66
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	62	33	53

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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

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-101 All	<p>Haemoglobin Disorder Service Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> 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-200) 	N	No information was available on how to report a safeguarding concern.	Y	Good information was available.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-102 All	<p>Information about Haemoglobin Disorders</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions 	Y	Very good leaflets for both conditions were available.	Y	

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-103 All	<p>Information for Primary Health Care Team</p> <p>Written information should be sent to the patient's primary health care team covering available local services and</p> <ol style="list-style-type: none"> a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service 	Y	Good, comprehensive information was available in one document.	Y	GPs had access to hospital guidelines and information about referral.
HN-104 All	<p>Care Plan</p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> 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 <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p>	N	Not all patients received individual care plans. Some patients with complex care needs received a pain crisis plan.	Y	All patients were copied into letters and flagged on the computer system.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-105 All	<p>School Care Plan (Paediatric Services Only)</p> <p>A School Care Plan should be agreed for each child or young person covering, at least:</p> <ol style="list-style-type: none"> School attended Medication, including arrangements for giving / supervising medication by school staff What to do in an emergency whilst in school Arrangements for liaison with the school 	N/A		Y	A very good school care plan was available.
HN-106 SHC (A-LHT)	<p>Transition to Adult Services</p> <p>Young people transferring to the care of adult services should be offered written information covering at least:</p> <ol style="list-style-type: none"> Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer A joint meeting between children's and adult services to plan the transfer A named coordinator for the transfer of care A preparation period prior to transfer Arrangements for monitoring during the time immediately after transfer 	N	A formal transition process was not yet in place. A new process was due to be implemented in April 2015.	N	A formal transition process was not yet in place. A new process was due to be implemented in April 2015.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-107 SHC	<p>Information about Trans-Cranial Doppler Ultrasound</p> <p>Written information should be offered to patients and their carers covering:</p> <ol style="list-style-type: none"> Reason for the scan and information about the procedure Details of where and when the scan will take place and how to change an appointment Staff who will be present and will perform the scan Any side effects Informing staff if the child is unwell or has been unwell in the last week How, when and by whom results will be communicated 	N/A		N	Good draft information was available but required a governance review before it could be used.
HN-199 All	<p>Involving Patients and Carers</p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> Mechanisms for receiving feedback from patients and carers An annual patient survey (or equivalent) Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service Examples of changes made as a result of feedback and involvement of patients and carers 	N	A formal process for patient feedback was not in place although patients indicated that concerns could be raised informally. An annual patient survey had been carried out in 2012.	N	The oncology patient survey was being used by the Trust. There was no evidence of patients and carers being routinely involved in decisions about the organisation of the service but families did consider that the Trust was responsive to their needs.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-201 All	<p>Lead Consultant</p> <p>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.</p>	Y	<p>The lead consultant only had two PAs allocated for work with patients with haemoglobin disorders.</p> <p>See main report.</p>	Y	<p>The lead consultant only had 1.75 PAs allocated for work with patients with haemoglobin disorders.</p> <p>See main report.</p>
HN-202 All	<p>Cover for Lead Consultant</p> <p>Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.</p>	N	<p>There was no cover for absences. Some out of hours cover was available from the haematology team.</p>	Y	<p>Cover was available from the paediatric haematology team.</p>

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-203 All	<p>Lead Nurse</p> <p>A lead nurse should have appropriate time available for their leadership role and:</p> <ol style="list-style-type: none"> Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders Responsibility for liaison with other services within the network RCN competences in caring for people with haemoglobin disorders Competences in the care of children and young people (children's services only) 	N	<p>A lead nurse was in place but there was insufficient time for her to fulfil all the responsibilities stated in this Quality Standard.</p> <p>There was no evidence that the lead nurse had achieved RCN competences (point 'c').</p> <p>See main report.</p>	N	<p>A lead nurse was in place but had insufficient time to fulfil all the responsibilities stated in this Quality Standard.</p> <p>See main report.</p>

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-204 All	<p>Staffing Levels and Competences</p> <p>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ul style="list-style-type: none"> 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 <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT).</p> <p>Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders.</p> <p>Cover for absences should be available.</p>	N	The service did not have access to a psychologist with an interest in haemoglobin disorders and there was no specialist cover for medical and nursing absences.	N	The service did not have access to a psychologist with an interest in haemoglobin disorders and there was no specialist cover for nursing absences.
HN-205 All	<p>Competences and Training</p> <p>A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).</p>	N	No training plan was in place.	N	No training plan was in place.

Ref	Quality Standard	Adult		Children and Young People	
		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.	N	Specialist advice was not available at all times.	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 had taken place in the past but not in the year before the review visit due to a shortage of staff and staff turnover.	N	All children and young people known to the service had open access to the day unit and wards and therefore did not have to go through the Emergency Department (ED). Young people who presented for the first time to the Trust were reviewed in the adult ED and then referred to the paediatric team. Training had not taken place in the ED in the year before the review visit.
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	Evidence for specialist nurse compliance was provided but reviewers did not see evidence for other staff. Safeguarding training was part of Trust mandatory training.	Y	
HN-209 SHC	Doctors in Training The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y		Y	

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-210 SHC	<p>Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)</p> <p>Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.</p>	N/A		Y	Two radiologists carried out TCD scanning. All abnormal scans were discussed and reviewed.
HN-299 All	<p>Administrative, Clerical and Data Collection Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p>	N	No support was available.	N	No support was available.
HN-301 All	<p>Support Services</p> <p>Timely access to the following services should be available:</p> <ol style="list-style-type: none"> Psychologist with an interest in haemoglobinopathies Social worker Leg ulcer service Play specialist (children's services only) Chronic pain team Dietetics Physiotherapy Occupational therapy Mental health services (adult and CAMHS) <p>In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-204) if required.</p>	N	There was no access to a psychologist with an interest in haemoglobinopathies and there were long delays in accessing the chronic pain team (see main report).	N	There was no access to a psychologist with an interest in haemoglobinopathies (see main report) or to a leg ulcer service.

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

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-303 SHC A-LHT	<p>Specialist Services - Network</p> <p>Access to the following specialist staff and services should be available:</p> <ul style="list-style-type: none"> a. Erythrocytapheresis 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 <ul style="list-style-type: none"> 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 <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p>	N	There was no access to a neuropsychologist ('m') or to pre-implantation genetic diagnosis. All other services were easily accessible.	Y	Signposting for fertility, contraception and sexual health services ('c') could be improved.
HN-304 All	<p>Laboratory Services</p> <p>UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.</p>	Y		Y	

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-401 All	<p>Facilities Available</p> <p>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.</p>	Y	<p>Facilities were good. Patients stated that it was sometimes difficult to book into the day unit.</p> <p>See main report.</p>	Y	See main report.
HN-402 All	<p>Facilities for Out of Hours Care</p> <p>Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.</p>	N	Out of hours care was available only in exceptional circumstances.	N	Out of hours care was available only in exceptional circumstances.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-501 SHC A-LHT	<p>Transition Guidelines</p> <p>Network-agreed guidelines on transition to adult care should be in use covering at least:</p> <ol style="list-style-type: none"> Age guidelines for timing of the transfer Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer Allocation of a named coordinator for the transfer of care A preparation period and education programme relating to transfer to adult care Communication of clinical information from paediatric to adult services Arrangements for monitoring during the time immediately after transfer to adult care Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams 	N	Transition guidelines were held by the paediatric department. The adult department had a brief guideline which did not include guidance for 'b', 'c' or 'g'.	Y	Guidelines were in place but the service did not have any patients ready to transition. Since 2013 patients aged 11 years and above had received education and discussion regarding transition and working towards independence and self-care. These sessions were due to be formalised in 2015 through the national 'Ready Steady Go' programme.
HN-502 All	<p>Monitoring Checklists</p> <p>Checklists should be in use for:</p> <ol style="list-style-type: none"> First out-patient appointment (SHC & A-LHT only) Routine monitoring Annual review (SHC & A-LHT only) <p>Use of the checklists should cover both clinical practice and information for patients and families.</p>	N	Monitoring checklists were not in place for the first out-patient appointment ('a'). It was not clear that checklists were routinely used for annual reviews.	Y	

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-503 LHT	<p>Clinical Guidelines: LHT Management and Referral</p> <p>Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.</p>	N/A	The service was reviewed as an SHC.	N/A	The service was reviewed as an SHC.
HN-504 All	<p>Transfusion Guidelines</p> <p>Transfusion guidelines should be in use covering:</p> <ol style="list-style-type: none"> Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion Offering access to exchange transfusion to patients on long-term transfusions Protocol for carrying out an exchange transfusion Hospital transfusion policy Investigations and vaccinations prior to first transfusion Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. Areas where transfusions will usually be given Recommended number of cannulation attempts 	Y		Y	

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-505 All	<p>Chelation Therapy</p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ul style="list-style-type: none"> 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	Point 'g' was not met.	Y	Point 'f' was not applicable.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-506 All	<p>Clinical Guidelines: Acute Complications</p> <p>Network-agreed clinical guidelines on the management of acute complications should be in use covering at least:</p> <p>For patients with sickle cell disease:</p> <ul style="list-style-type: none"> 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) <p>For patients with thalassaemia:</p> <ul style="list-style-type: none"> l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation 	Y	Good guidelines were available. The pre-operative transfusion guidelines could be clearer and etilefrine was not included in the priapism guidance.	Y	Guidelines were available but many were brief and the advice on the monitoring of oxygen saturation required updating.
HN-507 All	<p>Specialist Management Guidelines</p> <p>Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ul style="list-style-type: none"> a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy 	Y		N	There was no pre-operative guidance. Guidance for 'c' was good.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-508 All	<p>Clinical Guidelines: Chronic complications</p> <p>Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least:</p> <ul style="list-style-type: none"> a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only) 	Y		Y	
HN-509 SHC	<p>Referral for Consideration of Bone Marrow Transplantation</p> <p>Guidelines for referral for consideration of bone marrow transplantation should be in use.</p>	Y		Y	
HN-510 All	<p>Thalassaemia Intermedia</p> <p>Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering:</p> <ul style="list-style-type: none"> a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy 	Y	Guidelines for 'c' could be updated.	Y	
HN-511 All	<p>Clinical Guideline Availability</p> <p>Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.</p>	N	The pain protocol was available on the intranet but a password was required to search and access other guidelines.	Y	Good guidelines were available.

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

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-601 All	<p>Service Organisation</p> <p>A service organisation policy should be in use covering arrangements for:</p> <ul style="list-style-type: none"> 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 but in practice most of the elements of the QS were in place.	N	There was no service organisation policy but in practice most of the elements of the QS were in place.

Ref	Quality Standard	Adult		Children and Young People	
		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).	Y	Quarterly formal multi-disciplinary meetings took place as well as more informal meetings before clinics.	Y	Internal, multi-disciplinary meetings were in place with radiology, medical, nursing and community staff.
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.	Y	Funding arrangements were unclear after March 2015.	Y	Funding arrangements were unclear after March 2015.
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 review and learning meetings were not yet in place.	N	Network review and learning meetings were not yet in 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 (QS HN-704), identify issues of mutual concern and agree action.	N/A		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.	N	Annual review data were not being consistently entered onto the National Haemoglobinopathy Registry.	N	Patient data were entered onto the National Haemoglobinopathy Registry but not annual reviews or adverse events.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-702 All	Annual Data Collection - Activity The service should monitor on an annual basis: <ol style="list-style-type: none"> Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances Length of in-patient stays Re-admission rate 'Did not attend' rate for out-patient appointments 	N	Some data were collected (part of 'a' and 'd') but were not monitored on an annual basis.	Y	

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-703 SHC	<p>Annual Data Collection – Network Patient Data</p> <p>The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia:</p> <ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: <ul style="list-style-type: none"> 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	Network patient data were not collected.	Y	

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-704 All	<p>Audit</p> <p>Clinical audits covering the following areas should have been undertaken within the last two years:</p> <p>Achievement of screening follow-up standards:</p> <ol style="list-style-type: none"> At least 90% of infants with a positive screening result attend a local clinic by three months of age At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age Less than 10% of cases on registers lost to follow up within the past year <p>For patients with sickle cell disease:</p> <ol style="list-style-type: none"> Proportion of patients with recommended immunisations up to date Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required 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 Availability of extended red cell phenotype in all patients <p>h. Proportion of children:</p> <ol style="list-style-type: none"> at risk of stroke who have been offered and/or are on long-term transfusion programmes who have had a stroke <p>For patients with thalassaemia:</p> <ol style="list-style-type: none"> Evidence of effective monitoring of iron overload, including imaging (QS HN-505) Proportion of patients who have developed new iron-related complications in the preceding 12 months <p>All patients:</p> <ol style="list-style-type: none"> Waiting times for transfusion 	N	<p>This Standard was not met as there was no audit for 'e', 'g' or 'j' and the audit for 'd' was from 2010.</p> <p>The audit for 'k' showed that all patients waiting for transfusion had been seen in less than one hour.</p>	N	No audits had been carried out for 'f', 'g' or 'k'.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-705 All	Guidelines Audit The service should have a rolling programme of audit, including: <ol style="list-style-type: none"> Audit of implementation of clinical guidelines (QS HN-500s). Participation in agreed network-wide audits. 	N	A rolling programme of audit was not yet in place.	N	A rolling programme of audit was not yet in place.
HN-706 SHC	Research The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		N	The service did not participate in research.
HN-707 SHC	Trans-Cranial Doppler Quality Assurance (Paediatric Services Only) The service should monitor and review at least annually: <ol style="list-style-type: none"> Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-502) Results of internal quality assurance systems (QS HN-512) Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) Results of 'fail-safe' arrangements and any action required 	N/A		Y	
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: <ol style="list-style-type: none"> Review of any patient with a serious adverse event or who died Review of any patients requiring admission to a critical care facility 	Y		Y	

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HN-799 All	Document Control All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Adult		Children and Young People	
		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	A network as expected by the QSs was not yet in place.	N	A network as expected by the QSs was not yet in place.
HY-201	Network Leads The network should have a nominated: <ol style="list-style-type: none"> Lead consultant and deputy Lead specialist nurse for acute care Lead specialist nurse for community services Lead manager Lead for service improvement Lead for audit Lead commissioner 	N	A network as expected by the QSs was not yet in place.	N	A network as expected by the QSs was not yet 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	A network as expected by the QSs was not yet in place.	N	A network as expected by the QSs was not yet in place.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HY-501	<p>Transition Guidelines</p> <p>Network guidelines on transition to adult care should have been agreed covering:</p> <ul style="list-style-type: none"> 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) <p>Guidelines should be explicit about transition directly to any accredited LHTs.</p>	N	A network as expected by the QSs was not yet in place.	N	A network as expected by the QSs was not yet in place.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HY-502	<p>Clinical Guidelines</p> <p>Network guidelines should have been agreed covering:</p> <ul style="list-style-type: none"> 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) <p>Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.</p>	N	A network as expected by the QSs was not yet in place.	N	A network as expected by the QSs was not yet in place.
HY-701	<p>Ongoing Monitoring</p> <p>The network should monitor on a regular basis:</p> <ul style="list-style-type: none"> 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	A network as expected by the QSs was not yet in place.	N	A network as expected by the QSs was not yet in place.

Ref	Quality Standard	Adult		Children and Young People	
		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 Qs HN-703, HN-704, HN-705, HN-707.	N	A network as expected by the Qs was not yet in place.	N	A network as expected by the Qs was not yet in place.
HY-703	Research The network should have agreed: <ol style="list-style-type: none"> A policy on access to research relating to the care of patients with haemoglobin disorders A list of research trials available to all patients within the network. 	N	A network as expected by the Qs was not yet in place.	N	A network as expected by the Qs was not yet in place.
HY-798	Network Review and Learning The SHC should meet at least twice a year with its referring LHT teams to: <ol style="list-style-type: none"> Identify any changes needed to network-wide policies, procedures and guidelines Review results of audits undertaken and agree action plans Review and agree learning from any positive feedback or complaints involving liaison between teams Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams Consider the content of future training and awareness programmes (QS HY-202) 	N	A network as expected by the Qs was not yet in place.	N	A network as expected by the Qs was not yet in place.

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COMMISSIONING

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HZ-601	<p>Commissioning of Services</p> <p>Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular:</p> <ul style="list-style-type: none"> a. Designated SHC/s for the care of people 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	This work had not yet been carried out.	N	This work had not yet been carried out.
HZ-701	<p>Clinical Quality Review Meetings</p> <p>Commissioners should regularly review the quality of care provided by:</p> <ul style="list-style-type: none"> 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 yet in place.	N	Clinical quality review meetings were not yet in place.

Ref	Quality Standard	Adult		Children and Young People	
		Met? Y/N	Comments	Met? Y/N	Comments
HZ-798	<p>Network Review and Learning</p> <p>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.</p>	N	Network review and learning meetings were not yet in place.	N	Network review and learning meetings were not yet in place.

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