Health Services for People with Haemoglobin Disorders

The Leeds Teaching Hospitals NHS Trust

Visit Date: 9th July 2019

Report Date: October 2019

8831

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Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in The Leeds Teaching Hospitals NHS Trust that took place on 9th July 2019. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V4, 2018 which were developed by the UK Forum on Haemoglobin Disorders working with the Quality Review Service (QRS). The peer review visit was organised by QRS 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 Teams (SHT)
- Local Haemoglobinopathy Teams (LHT) or linked providers

The Haemoglobin Disorder Network and Commissioning Quality Standards were not reviewed as part of the 2019-20 review programme, although reviewers did enquire about the local network and commissioning arrangements during the course of the review visit.

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. Any immediate risk identified includes the Trust's proposed actions to mitigate the risk and QRS's response to these proposals. Appendix 1 lists the visiting team that reviewed the services provided by The Leeds Teaching Hospitals NHS Trust. Appendix 2 contains the 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:

- The Leeds Teaching Hospitals NHS Trust
- NHS England and NHS Improvement Specialised Commissioning – Yorkshire and Humber Region
- NHS England and NHS Improvement Specialised Commissioning – Haemoglobinopathies

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, including commissioners of primary care. The lead commissioner in relation to this report is the NHS England & NHS Improvement Lead Commissioner for Yorkshire and Humber Region.

About the Quality Review Service

QRS is a collaborative venture between NHS organisations 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.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more

confidence and competence in reviewing the quality of clinical services. More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Acknowledgments

We would like to thank the staff of The 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. We are also grateful to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

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Review Visit Findings

Trust-wide

General Comments

This review looked at the health services provided for children, young people and adults with haemoglobin disorders. During the course of the visit, reviewers attended both Leeds Children's Hospital and St James's University Hospital, and visited the emergency departments, assessment units and wards on both sites; they met with patients and carers, and with staff providing services for the local health economy.

The combined adult and paediatric Leeds Specialist Haemoglobinopathy Team provided a service to the regions of North and West Yorkshire, which covered both low and high prevalence areas. The Trust's services included a specialist screening laboratory, an antenatal diagnosis and counselling service, and paediatric and adult haemoglobinopathy services delivered by the following clinical service units: pathology, women's services, Leeds Children's Hospital and oncology (incorporating haematology). The commissioning of the service for community care and counselling was being transitioned from the Leeds Community Trust to The Leeds Teaching Hospitals NHS Trust from 1st June 2019, with plans for the community service to be fully operational in the autumn of 2019. At the time of the visit both services were providing specialist support for patients cared for at Bradford Teaching Hospitals NHS Foundation Trust.

ADULTS

Data submitted by the Trust for 2018/19

Hospital	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	Usually seen by the linked hospitals/local teams (except for annual reviews)	No. of adults on long-term red cell transfusions (SHT /LHT)
St James's University Hospital	SHT	81	27 (inc 3 DBA[1])	39	26/8

CHILDREN AND YOUNG PEOPLE

Hospital	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	Usually seen by the linked hospitals/local teams (except for annual reviews)	No. of children on long-term red cell transfusions (SHT/LHT)
Leeds Children's Hospital	SHT	91	<5	39	7/9

[1] **Diamond Blackfan Anaemia Syndrome** (DBA) is a congenital erythroid aplasia that usually presents in infancy. DBA causes low red blood cell counts (anemia), without substantially affecting the other blood components (the platelets and the white blood cells), which are usually normal.

Support groups available for patients and carers	Y/N (number)
Sickle Cell Disease – Adults	N
Thalassemia – Adults	N
Sickle Cell Disease – Children, young people and families	N
Thalassemia – Children, young people and families	N

Concern

1. A number of issues in this report will require executive focus and support from the Trust in order for both the adult and the paediatric teams to function as comprehensive Specialist Haemoglobinopathy Teams (SHTs). Further support from the Trust executive will also be required if the services are successful in their bid to become a Haemoglobinopathy Coordinating Centre (HCC).

2. From discussions with staff during the visit, reviewers were not assured that the Trust had fully considered the clinical and financial impact on both the adult and the paediatric services that would result from any additional patient activity from Bradford Teaching Hospitals NHS Foundation Trust. Reviewers highlighted the importance of securing additional funding for this activity and expressed some concerns that the funding allocated to develop SHTs as part of the national reconfiguration of haemoglobinopathy services might be diverted to support the additional activity from Bradford.

Specialist Haemoglobinopathy Team (Adult Services): The Leeds Teaching Hospitals NHS Trust

General Comments and Achievements

This was an experienced team with strong leadership from the lead clinician and clinical nurse specialist (CNS). The service was well organised, though reliant on the key lead individuals. Communication between local referring teams and GPs was reported to be working well.

The team reported that since the last visit in 2015 the service had seen an increase in patient activity of around 30%. Following the changes in the provision of the haemoglobin disorder service at Bradford Teaching Hospitals NHS Foundation Trust in early 2019, it was anticipated that there would be a further increase in the number of patients who would need support and an annual review from the team at Leeds.

The reviewers noted the significant progress that had been made following feedback on the self-assessment submitted to the UK forum validation panel in February 2019.

Reviewers were impressed with the range of case notes that were made available for review, which were reflective of the case mix cared for by the service and included examples for patients with particular complex needs.

Specialist Haemoglobinopathy Team	Local Haemoglobinopathy Teams
St James's University Hospital	• Airedale NHS Foundation Trust • Bradford Teaching Hospitals NHS Foundation Trust (partial), in process • Calderdale and Huddersfield NHS Foundation Trust (Huddersfield Royal Infirmary, Calderdale Royal Hospital) • Harrogate and District NHS Foundation Trust • Hull University Teaching Hospitals NHS Trust • Northern Lincolnshire and Goole NHS Foundation Trust (Princess of Wales Hospital, Grimsby) • The Mid Yorkshire Hospitals NHS Trust (Wakefield) • York Teaching Hospital NHS Foundation Trust (York and Scarborough Hospitals)

Staffing

Staffing for the SHT Adult Haemoglobinopathy Service [2]	Number of patients	Actual WTE (at time of the visit)
Consultant haematologist - >0.6 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	108	0.2
At least 0.25 WTE allocated to haemoglobinopathies CPD in the Adult Consultant Job plan	108	0
Trust employ a clinical psychologist for adult patients who has >0.5 WTE per 200 patients dedicated to work with patients with haemoglobinopathies?	108	0

[2] *Recommended Staffing: National NHS England compliance exercise for designation of SHTs 2019.*

Emergency Care

Urgent acute admissions were initially assessed via the emergency department (ED) at St James's University Hospital. Patients could contact the CNS, or the haematology ward staff (J88/89) during working hours, or the main haematology wards out of hours. If an admission was required, patients were then referred to the haematology admission wards (J96/95).

Inpatient Care

The main haematology wards were J88/J89. The wards had 40 specific beds for the care of haematology patients. The admission wards, J96/95, were for the use of haematology and oncology patients, who were then moved to the base ward for their specific team when a bed became available. Young adults were able to access a young adult ward (J94) and could be transferred to J94 either by direct admission or via wards J95 or J96. The young adult areas visited by the review team were very spacious and well designed for the needs of these patients.

Inpatients 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). Inpatients were regularly reviewed by the clinical nurse specialist. The lead consultant, when not 'attending', contributed to the care of haemoglobinopathy patients. At the weekends, inpatients were reviewed by the on-call haematology registrar or consultant.

Day Unit

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 service. This suite had facilities to perform erythrocytapheresis, and the apheresis unit provided a 24-hour service across the Yorkshire and Humber regions.

Community- Based Care

Community services were in the process of being re-commissioned, and reviewers were made aware of the progressive plans for supporting patients in the community and for reducing admissions.

Progress since last visit

- The 'red cell' CNS post had been secured as a permanent position, and the CNS had developed a haemoglobin disorders training programme for ED and ward staff.
- The adult haemoglobin disorder and perioperative guidelines had been updated since the submission to the UK forum in February 2019.
- A formal annual review process had been implemented.
- The service had actively recruited to the Efficacy and Safety Study of Luspatercept (ACE-536) versus placebo in Adults who require regular blood transfusions due to Beta Thalassaemia (BELIEVE).
- The haematology assessment unit was now operational daily from 8am to 8pm.
- An additional red cell clinic supported by the CNS had been implemented to improve access for patients.
- A transition lead for the Trust had commenced in post and was working with the CNS to improve the transition pathway for young people into the adult service.

Views of Service Users and Carers

The visiting team met with five patients and two family members during the course of the visit. The comments received from the users and carers covered the following matters:-

- The users and carers considered that staff and patient education and training about sickle cell disease was key to looking after patients with the disease.
- Patients were very appreciative of the support available from the CNS, particularly if they were struggling with taking long-term medication.

- Patients reported that the pathway worked well during normal working hours when they could contact the CNS, who would alert the ED of the patient's arrival or arrange an admission, but outside these hours the patient experience was variable.
- Some family members commented that they needed to be the patient's advocate when attending the ED, as staff did not understand the need for prompt and appropriate analgesia. They reported that there was also reluctance by ED staff to listen to patients and access their care plans, which were available on the Trust IT system.
- Not all the patients who met with the visiting team were keen on being admitted to the oncology ward for acute care, partly because of the specialty of the ward, but also because they did not feel that all staff were knowledgeable about haemoglobin disorders.
- All those who met with the reviewers considered that the lack of access to psychology and social care support was an issue, and that they would benefit from better access to these services.
- Help with re-launching a support group would be appreciated, as would information about the use of complementary therapies for the management of symptoms.
- Reviewers heard mixed views about the phlebotomy service. Some patients had experienced long waiting times and their feedback had not been acted on, whereas others commented that their views had been listened to and waiting times were better. Comments were also received about the venepuncture competences of some phlebotomists, especially for patients with poor venous access.
- Some patients commented on the time spent having pre-transfusion blood tests and asked whether the pathway could be improved. Patients were required to attend the hospital, often waiting for hours, for tests, and to attend for another whole day for the blood transfusion. Patients also commented that, although out of hours blood transfusions were available, in practice there was little flexibility to arrange suitable times outside the normal working day.
- Some patients were concerned that they did not have sufficient time allocated for them when they attended for clinical reviews.

Good Practice

1. The acutely unwell sickle cell guidance was very comprehensive, detailing investigations, diagnosis, analgesia guidance, treatment and management. The guideline also included a very good summary flow chart, which included generic pain management guidance as well as information about other key medications. Reviewers were particularly impressed with the guideline's written advice to other health professionals about the patient being the 'expert' about their condition.

2. The guidelines covering the 'acutely unwell thalassaemia patient' were also very well written and clear. Reviewers were particularly impressed with the table checklist, with key questions for staff to cover when seeing a patient who was acutely unwell. The checklist also included additional prompts about 'what to consider' and what to 'remember to do'.

3. Thalassaemia information for patients was well written, especially the information covering what to expect if long-term blood transfusions were required.

4. Electronic patient care plans seen at the time of the visit were very comprehensive, well-structured and easy to understand. This would be especially important if the plans needed to be accessed in an emergency.

5. The annual review documentation completed for patients by the CNS in the nurse-led clinic was very good. Reviewers were impressed that all patients had a holistic needs assessment undertaken as part of their annual review, and that the patient's agreement for the sharing of information between services was also documented in the patient's care plan.

6. A survey was in progress for patients to give feedback on the role of the CNS in terms of what was working well and any areas the patients thought should be considered in developing the CNS service.

Immediate Risks: None

Concerns

1. **Consultant staffing**

   Reviewers were concerned that the service had insufficient consultant medical staff with appropriate competences in the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care and clinics. At the time of the visit the consultant had only two programmed activity (PA) sessions for work with the service, which included work with the network as well as providing advice for the Bradford Teaching Hospitals NHS Foundation Trust. Cover for the lead consultant was supplied by other consultant haematologists who may not have competences in haemoglobin disorders. The Trust was aware of the situation, and recruitment of an additional haematologist with allocated PAs for the haemoglobin disorder service was in progress.

2. **Clinical Nurse Specialist cover**

   The CNS had a wide-ranging role and no cover for absences. Patients who met with the visiting team were concerned about the vulnerability of the service, as they considered the CNS to be pivotal to the smooth running of the service. They commented that when the CNS was away, the only way to contact the haematology department was by leaving a message on the answering machine. The issue was further exacerbated by the lack of a functioning community haemoglobinopathy team; in the future this team could be able to provide some support to patients.

3. **Access to psychology**

   Access to psychology was limited. In practice, referrals could be made to the general psychology service. However, the general psychology service would not have the relevant experience in caring for patients and families with haemoglobin disorders (national workforce recommendations of 1wte for 300 patients. Reviewers were also concerned that some patients reported that they had been told that they did not require access to psychological support.

4. **Access to analgesia**

   The most recent service audit of compliance with the NICE clinical guideline on the management of acute pain showed that only 14% of patients had received analgesia within 30 minutes of arrival in the Emergency Department. A training programme for staff had been delivered, and meetings with key ED staff had been held to try and improve the care for patients; however, patients who met with the visiting team still reported that they did not receive timely analgesia.

5. **Ward nurse competences**

   A competence framework was not yet in place for staff on those wards to which people with haemoglobin disorders were usually admitted, to identify whether staff had appropriate competences to care for patients with haemoglobin disorders.

6. **Patient annual reviews**

   The team reported that only 50% of patients had received an annual review in the last year because of the lack of consultant and nurse time available. Reviewers were concerned that, with the existing resources, this situation was unlikely to improve and would potentially worsen with the anticipated increase in patient referrals from Bradford.

Further Consideration

1. Multi-disciplinary meetings to discuss and review patient care, with community representation, had been suspended due to the changes in the community service provision. Reviewers considered that it would be important to re-establish these meetings as soon as possible.
2. In the light of the comments received by patients and families at the time of the visit, further work should be undertaken to ensure that the good practice identified in this report is fully implemented.
3. Access to the chronic pain team was only via the GP, who would refer to the team, creating delays in the receipt of support by patients to help manage their pain. It was not clear to reviewers why the haemoglobin disorders team could not refer directly to the chronic pain team.
4. Information for patients covering haemoglobin disorders was not displayed in any of the clinical areas visited. Staff told reviewers that information would be given to patients when they attended the clinics.
5. As part of the work to develop the service, identifying 'link' nurses may help with building a wider network of expertise across the Trust.
6. The draft service operational policy seen by the reviewers would benefit from review to clarify the 'fail safe' arrangements for patients who 'do not attend' appointments on multiple occasions. Reviewers considered that clarifying the options for accessing the service at a later date and the mechanisms for communicating the advice to the patient's GP would be a useful addition to the policy.

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Specialist Haemoglobinopathy Team (Children and Young People Services): The Leeds Teaching Hospitals NHS Trust

General Comments and Achievements

This was a responsive service, which was well-led by the lead clinician, clinical nurse specialist (CNS) and lead nurse. Patients and carers were highly appreciative of the care that they received. The lead nurse for benign haematology, who had recently been appointed, provided additional leadership to the existing team. Staff were optimistic and enthusiastic about plans for the future development of the service.

At the time of the visit the number of paediatric patients with sickle cell disease had increased by 23% since the last peer review in 2015. The number of paediatric patients with thalassaemia had remained unchanged since the last visit.

Specialist Haemoglobinopathy Team	Local Haemoglobinopathy Teams
Leeds Children's Hospital	• Airedale NHS Foundation Trust • Bradford Teaching Hospitals NHS Foundation Trust – joint MDT • Calderdale and Huddersfield NHS Foundation Trust (Huddersfield Royal Infirmary, Calderdale Royal Hospital) • Hull University Teaching Hospitals NHS Trust • The Mid Yorkshire Hospitals NHS Trust • York Teaching Hospital NHS Foundation Trust (York and Scarborough Hospitals)

Staffing

Staffing for the SHC Paediatric Haemoglobinopathy Service [3]	Number of patients	Actual WTE (at time of visit)
Consultant haematologist/paediatrician - >0.6 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	94	0.2
Is at least 0.25 WTE allocated to haemoglobinopathies CPD in the Paediatric Consultant Job	94	0.1
Trust employ a clinical psychologist for paediatric patients who has >0.5 WTE per 150 patients dedicated to work with patients with haemoglobinopathies?	94	0

Emergency Care

All existing patients had open access to the clinic or inpatient wards for urgent review. Patients presenting to the Emergency Department were directed to the on-call paediatric haematology service. The Leeds Health Pathways guideline, available on the intranet, advised immediate telephone communication with the haematology ward, and provided advice regarding emergency assessment and management if required.

Inpatient Care

The dedicated haematology and oncology inpatient facility on A Floor of the Clarendon Wing at the Leeds General Infirmary was part of the Leeds Children's Hospital. The unit comprised three co-located wards that worked closely together. 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); teenagers (from 13 years until their 19th

[3] *Recommended Staffing: National NHS England compliance exercise for designation of SHTs 2019.*

birthday) were cared for on Ward 33 (eight beds), and children and young people up to the age of 18 having Allogeneic Haematopoietic Stem Cell Transplants were cared for on Ward 32, the Bone Marrow Transplant Unit (four beds). Patients with sickle cell disease and thalassaemia were generally admitted to one of these three wards. If patients were admitted to other areas, they were reviewed by the paediatric haematology oncology medical team and the CNS.

Day Care and Outpatient Care

The paediatric day unit comprised a dedicated ten-bedded facility with six consultation rooms specifically for the management of haematology and oncology patients. Teenagers had a specific waiting room and dedicated bay for their use. The unit provided facilities for transfusion, including red cell exchange, as well as facilities for patients receiving treatment and invasive investigations and recovering afterwards.

The day care ward was open from 8.30am to 6pm from Monday to Friday. No late evening or weekend service was available.

Community Based Care

As with the adult service, the paediatric service was in a transition period with the re-commissioning of the community service, and reviewers were made aware of the progressive plans for supporting patients in the community and for reducing admissions.

Progress since last visit

- A lead nurse had been appointed for benign haematology.
- All patients with sickle cell disease were able to have red cell exchange transfusions.
- Access to translation software had been arranged so that patient information could be translated to many languages on the website.
- There had been an increase in the number of patients on hydroxycarbamide.
- The proportion of patients attending for their annual review had increased.
- The assessment of the transition process had been completed, and a formal transition pathway introduced.
- Nineteen children and young people had received a stem cell transplant in the last five years.

Views of Service Users and Carers

The visiting team met with three parents during the course of the visit. The comments received from the users and carers covered the following matters:-

- The users and carers considered that the service was ‘amazing’ and that all members of the team provided care for the whole family.
- All those who met with the visiting team were extremely complimentary about the lead clinician and CNS and held them in very high regard.
- The facilities were lovely and very child- and teenage-friendly, with one child expressing a wish to visit and play more often.
- Parents commented that support was always available from members of the team for the development of Education, Health and Care Plans, and if required the team would provide letters of support for any other issues.
- Overall, the users and carers who met with the visiting team were extremely happy with the service.

Good Practice

1. Reviewers were impressed with the annual review letters seen at the time of the visit. The letters were clearly written and very user focused. Important information was highlighted at the beginning of the letter, with information about how patients could manage their pain as well as the reiteration of general health advice.

2. Health care plans were very detailed for patients with both sickle cell disease and thalassaemia. The care plans included a wealth of information about what teaching staff should be aware of, including: the emotional and psychological impact of treatment on the child; daily management such as ensuring children were hydrated and were able to take regular toilet breaks; and possible emergency situations, with the actions that teachers should take.

Immediate Risks: None

Concerns

1. **Consultant staffing**

   Reviewers were concerned that the lead consultant had insufficient time for available for the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care and clinics. At the time of the visit the consultant was also the clinical director for children's services and the clinical lead for the haemophilia service.

2. **Ward nurse competences**

   A competence framework was not yet in place for staff on those wards to which people with haemoglobin disorders were usually admitted, to identify whether staff had appropriate competences to care for patients with haemoglobin disorders. Registered nurses did have competencies in administering blood transfusions.

3. **Access to psychology**

   Access to psychology was limited. In practice, referrals could be made to the general psychology service, but the general psychology service would not have the relevant experience in caring for patients with haemoglobin disorders and their families.

Further Consideration

1. As a specialist haemoglobinopathy service, the team had limited involvement in research. Reviewers considered that the Trust should be supporting the team to develop their involvement in clinical trials and research.

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Commissioning

General Comments

The service had good links with both local and specialised commissioners.

The report contains a number of issues which would need to be addressed in order for both the adult and the paediatric teams to function as comprehensive Specialist Haemoglobinopathy Teams (SHTs). Further support from commissioners will also be required if the services are successful in their bid to become a Haemoglobinopathy Co-ordinating Centre.

Good Practice

1. Reviewers were impressed with the approach to collaborative commissioning and the development of an Aligned Incentives Contract between NHSE, the CCG and the Trust. This approach to commissioning and subsequent partnership structure, which included joint planning boards established in each clinical area (including haemoglobinopathy), enabled governance and oversight of issues. All contracts with providers were based on the quality of care delivered, with a clear focus on encouraging collaborative problem-solving approaches to ensure high quality services were commissioned. The commissioners were also meeting with members of NHS England's National Case Mix and Information, NHS Digital to share their experiences and draft contractual documentation.

Further Consideration

1. Commissioners who met with the visiting team confirmed that the new community team would be in place by September 2019. However, from discussions with staff, it was not clear that the team would be fully operational by this deadline. Nonetheless, reviewers were reassured that the proposed community service specification, once implemented, would provide a better quality community service for patients and their families.
2. From discussions with staff during the visit, commissioners at both regional and national level were continuing to work with both Bradford Teaching Hospitals NHS Foundation Trust and The Leeds Teaching Hospitals NHS Trust to enable ongoing specialist support for patients from Bradford; however, a sustainable plan covering the clinical and financial impact on both the adult and the paediatric services resulting from any additional patient activity had not yet been agreed. Reviewers highlighted the importance of securing additional funding for this activity and expressed some concerns that the funding allocated to develop SHTs as part of the national reconfiguration of haemoglobinopathy services might be diverted to support the additional activity from Bradford.

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Joanne Bloomfield	Lead Specialist Nurse and Manager	Nottingham Sickle Cell and Thalassaemia Service
Dr Subarna Chakravorty	Consultant Paediatric Haematologist	King's College Hospital NHS Foundation Trust
Dr Emma Drasar	Consultant Haematologist	University College London Hospitals NHS Foundation Trust and Whittington Health NHS Trust
Roanna Maharaj	Patient representative	UK Thalassaemia Society
Rachel McFee	Manager of OSCAR	OSCAR Patients Group, Sandwell
Patrick Ojeer	Patient representative	
Barry O'Neill	Specialised Commissioning East Midlands	NHS England
Giselle Padmore-Payne	Senior Clinical Nurse Specialist for Haemoglobinopathies	King's College Hospital NHS Foundation Trust
Julie Plant	Senior Matron, Children's Services Directorate	The Royal Wolverhampton NHS Trust
Louise Smith	Sickle Cell CNS	Alder Hey Children's NHS Foundation Trust

QRS Team		
Sarah Broomhead	Assistant Director	Quality Review Service

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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 varies 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

Details of compliance with individual Quality Standards can be found below.

Service	Number of applicable QS	Number of QS met	% met
Adults	42	29	69
Children	51	47	92
Total	93	76	82

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Specialist Services for People with Haemoglobin Disorders

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-101	**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 vi. Get involved in improving services (QS HN-199)	Y		Y	Patient information about the psychological support available would be better if it were more explicit. The Trust website had a programme that enabled information to be translated into a range of different languages.

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-102	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition (SC or T), how it might affect them and treatment available 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. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	Information for 'e', covering 'top up' transfusions, and 'f', priapism, was not available. The patients with thalassaemia who met with the visiting team had not received any information about their condition other than information that they had sourced from national websites.	Y	Information was in place covering sickle cell disease. Specific information for patients was in place covering 'a', 'b', and 'e', with other information included in the annual report letter given to patients.

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	Y		Y	
HN-104	**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: i. Hydroxycarbamide and iron chelation therapy (if being prescribed by GPs) ii. Immunisations iii. Contraception and sexual health d. Indications and arrangements for seeking advice from the specialist service	Y	'c(i)' was not applicable as GPs did not prescribe hydroxycarbamide. Annual review letters were clear about other actions required by the GP to prescribe other medications.	Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-105	**Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)** 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. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	N/A		Y	Information about TCD was very clear, and was displayed for patients in the radiology department.
HN-106	**School Care Plan (Children's 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 e. Specific health or education need (if any)	N/A		Y	The Education, Health and Care (EHC) Plans were very detailed. See good practice section of the report.
HN-194	**Environment** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services b. A named coordinator for the transfer of care c. A preparation period prior to transfer d. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards	Y	The 'Ready Steady Go'® programme had been implemented and workshops with young people were held on a regular basis. There would be a benefit in reviewing the information to ensure that it covered all the stages of the transition pathway. Personalised plans, 'd', were included in the patient notes and annual reviews.	Y	The 'Ready Steady Go'® programme had been implemented, with young people commencing on the transition pathway at the age of 11 years. Staff were careful to avoid any meetings around key exam times. A joint clinic with both the adult and the paediatric CNS was in place.
HN-199	**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	Reviewers did not see any examples of changes made as a result of the feedback and involvement of patients and carers. Some patients who met with the reviewing team did not consider that their feedback had been acted on by the team.	Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-201	**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 an appropriate number of session/s identified for this role within their job plan and cover for absences should be available.	Y		N	At the time of the visit the lead consultant had limited time available for the role. The lead clinician was also the clinical director for children's services and the clinical lead for the haemophilia service. See main report.
HN-202	**Lead Nurse** A lead nurse should be available with: 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. Competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	N	The lead nurse did not have cover for absences. All other aspects of the QS were met.	Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-203	**Medical Staffing and Competences** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including: **All services:** a. Haematology or paediatric medical staffing for clinics and regular reviews b. 24/7 consultant and junior staffing for emergency care **SHCs only:** c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours d. If doctors in training are part of achieving 'a' or 'b' then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	Evidence was not available to show that the covering consultants had undertaken relevant CPD in caring for people with haemoglobin disorders. Patients who met with the visiting team also commented that, in their experience, other medical staff were often not clear about how to care for patients with haemoglobinopathies.	Y	Reviewers were told that all covering paediatric haematology consultants had up to date annual appraisals, and that part of these ensured adequate CPD as per the requirements of the RCPath. A paediatric haematology consultant was always available to guide management by phone if a paediatric oncology consultant was the attending consultant**.**

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-204	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion 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	A competence framework for ward nurses, 'c', was not yet in place. An education programme was provided by the CNS. The community service was in the process of being re-commissioned.	N	A competence framework for ward nurses, 'c', was not yet in place. Ward staff did have competencies in administering blood transfusions. The CNS had no cover for absences. The community service was in the process of being re-commissioned.

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-205	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multi-disciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuro-psychology 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	The service had insufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders. *The British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggested workforce recommendation is 1 wte: 300 pts.*	N	The service had insufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders. Reviewers were told that a joint business case with the bleeding disorder service to increase the level of psychology support was planned. Patients could access the general psychology service. *The British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggested workforce recommendation is 1 wte: 300 pts.*
HN-206	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.	N	A training plan showing that staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders was not yet in place. Some staff did attend educational meetings.	N	A training plan showing that staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders was not yet in place. In practice, education sessions were held for all groups of staff.

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-207	**Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A		Y	
HN-299	**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	The administrative post was vacant at the time of the review. Some cover was available from other administrative staff but not to enable data collection.	Y	
HN-301	**Support Services** Timely access to the following services should be available. In Specialist Centres 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) as required. a. Social worker/ benefits adviser b. Leg ulcer service c. Play specialist (children's services only) d. Chronic pain team (adult services only) e. Dietetics f. Physiotherapy (in-patient and community-based) g. Occupational therapy h. Mental health services (adult and CAMHS) i. DNA studies j. Polysomnography	Y	Access to the chronic pain team service was via the GP. A community physiotherapy service was not available; patients could be referred to the Trust service.	Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department/s should have competences in urgent care of people with haemoglobin disorders.	N	Patient views and the results of the latest pain audit showed that patients did not receive timely analgesia when attending the ED.	Y	Admissions were generally to the paediatric unit rather than via the ED.
HN-303	**Specialist On-site Support** Access to the following specialist staff and services should be easily available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Erythrocytapheresis c. Acute pain team including specialist monitoring of patients with complex analgesia needs d. High dependency care, including non-invasive ventilation e. Level 2 and 3 critical care	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-304	**Specialist Services - Network** Access to the following specialist staff and services with an appropriate level of specialist expertise in the care of people with haemoglobin disorders should be available: a. Pulmonary hypertension team (adults) b. Consultant obstetrician with an interest in care of people with haemoglobin disorders and specialist high risk anaesthetics (adults) c. Respiratory physician with interest in acute/chronic sickle lung disease and obstructive sleep apnoea (adults & children) d. Fertility, including pre-implantation genetic diagnosis and sperm storage (adults) e. Consultant cardiologist with interest in sickle cardiomyopathy, iron overload related heart disease (adults) f. Consultant endocrinologist with interest in thalassaemia related endocrinopathy and osteoporosis (adults) g. Consultant paediatric endocrinologist with interest in growth problems related to haemoglobinopathies and thalassaemia related endocrinopathy (children) h. Hepatobiliary team with an interest in sickle hepatopathy, viral liver disease, iron overload-related liver disease (adults & children) i. Consultant neurologist and neurosurgeon with an interest in sickle vasculopathy (adults & children) j. Hyperacute stroke service (adults) k. Consultant ophthalmologist with an expertise in sickle retinopathy and chelation related eye disease (adults & children) l. Consultant nephrologist with expertise in sickle nephropathy (adults & children) m. Consultant urologist with expertise in managing priapism and erectile dysfunction (adults & children) n. Orthopaedic service with expertise in managing sickle and thalassaemia related bone disease (adults & children) o. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) p. Bone marrow transplantation services (children only) q. Physiotherapy services (in patient and community based) r. Interventional and neuroradiology for neurovascular complications	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-305	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y		Y	
HN-401	**Facilities and Equipment** Facilities and equipment should be appropriate for the usual number and case mix of patients. Equipment should be appropriately maintained.	Y		Y	
HN-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-502	**Monitoring Protocols** Protocols should be in use covering the monitoring expected at: a. First out-patient appointment (SHC only) b. Routine monitoring c. Annual review (SHC & any LHTs to which annual reviews are delegated) Protocols should cover both clinical practice and information for patients and families.	Y		Y	
HN-503	**Clinical Guidelines: LHT Management and Referral** 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.	Y		Y	
HN-504	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. emergency and regular transfusion ii. use of simple or exchange transfusion iii. offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for carrying out a manual and automated exchange transfusion c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts	Y		Y	The number of cannulation attempts was not clear in the guidance, but reviewers were assured that a policy was in place.

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-505	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-506	**Clinical Guidelines: Acute Complications** 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	Y		Y	
HN-507	**Specialist Management Guidelines** Guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y	Guidance covering pregnancy had recently been agreed, but was not yet available on the intranet.	Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-508	**Clinical Guidelines: Chronic complications** Guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y		Y	
HN-509	**Referral for Consideration of Bone Marrow Transplantation (Children's Services Only)** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N/A		Y	
HN-510	**Non-Transfusion Dependent Thalassaemia (nTDT)** Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-601	**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 SHC (Children's SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Arrangements for liaison with community paediatricians and with schools (children's services only) e. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated (children's services only) f. Follow up of patients who do not attend g. 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. h. Accessing specialist advice (QS HN-304) i. Two-way communication of patient information between SHC and LHTs j. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	N	A service operational policy was in the process of being developed. The draft guidance would benefit from review to clarify the 'fail-safe' arrangements for patients who did not attend multiple times, for example, by including an option to access the service at a later date, and communication to GPs.	Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-602	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and representatives of support services (QS HN-301).	N	MDT meetings were not being held because of the changes in the commissioning of the community services, but reviewers were assured that there were plans to recommence MDT meetings.	Y	
HN-603	**Delegation of Annual Reviews** If annual reviews are undertaken by LHT/s on behalf of the SHC, a written agreement should be in place covering: a. Monitoring protocols (QS HN-502) b. LHT management and referral guidelines (QS HN-503) c. National Haemoglobinopathy Registry data collection (QS HN-701)	N/A	Annual reviews were not delegated to local referring teams.	Y	Arrangements were in place for patients from Bradford. Annual reviews were not undertaken by any other locally referring teams.
HN-604	**Out of Hours Elective Care** Arrangements should be in place for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	However, some patients commented that although out of hours blood transfusions were available, in practice there was little flexibility to arrange suitable times outside the normal working day.	Y	Access to blood transfusions out of hours was not routinely offered as no patient requests for out of hours blood transfusions had been received.
HN-605	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A	Community services were in the process of being re-commissioned and would be provided by the Trust.	N/A	Community services were in the process of being re-commissioned and would be provided by the Trust.

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-606	**Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)** A Standard Operating Procedure for Trans-Cranial Doppler ultrasound should be in use covering at least: a. Trans-Cranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-207) d. Arrangements for ensuring staff performing Trans-Cranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	N/A		Y	
HN-607	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-608	**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-703), identify issues of mutual concern and agree action.	N/A		Y	
HN-701	**National Haemoglobinopathy Registry** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies and patients lost to follow up.	Y		Y	
HN-702	**Activity Data** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-703	**Quality Dashboard** The service should monitor Quality Dashboard data including the number and percentage of: a. Adverse events reported on the NHR for which a mortality or serious case review has taken place b. Children who have had Trans-Cranial Doppler screening undertaken within national guidelines c. Patients given pain relief within half an hour of presentation with sickle crisis d. Patients with possible sickle disorders identified by neonatal screening who have been entered on a care pathway e. Eligible children beginning penicillin at or before three months of age f. Patients registered on the National Haemoglobinopathy Registry who had an annual review undertaken within the last year g. Patients on long-term transfusion who received cardiac MRI, and the proportion of those receiving a cardiac MRI who achieved a figure of less than 20ms h. Eligible patients with sickle cell disease who received an MRI for liver iron, and the proportion of those who received an MRI for liver iron who achieved more than 7 mg/gm/DW (sickle cell and thalassaemia separately)	Y		Y	
HN-704	**Other Quality Data** The service should monitor on an annual basis: a. Proportion of children who have been offered treatment following Trans-Cranial Doppler Screening	N/A		Y	

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. Availability of extended red cell phenotype in all patients and the proportion of patients who have developed antibodies b. Whether all eligible patients on long term transfusion have been offered automated exchange transfusion c. Waiting times for elective: i. Phlebotomy ii. Cannulation iii. Setting up of the blood transfusion (for pre-ordered blood)	N	Audits covering pain, length of inpatient stay and patient feedback (friends and family) had been undertaken, but other audits as defined in the QS had not been performed.	Y	
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	Y	The team had participated in the network 'time to analgesia' audit.	Y	The team had participated in the network 'time to analgesia' audit.
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		Y	While patients had been enrolled into one study (BELIEVE), there were no paediatric trials available or trials for sickle cell disease patients; however, the team were keen to engage with more research.

Ref	Standard	Adults		Children	
		Met?	Comments	Met?	Comments
HN-708	**Trans-Cranial Doppler Quality Assurance (Children's 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-207) b. Results of internal quality assurance systems (QS HN-606) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)	N/A		Y	
HN-798	**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 c. Annual review of trends in National Haemoglobinopathy Registry data, activity data, Quality Dashboard, other quality data and other audits (QSs HN-701 to HN-705)	N	Evidence to show compliance with this QS was not seen at the time of the visit.	Y	
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

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