Health services for people with haemoglobin disorders

Bradford Teaching Hospitals NHS Foundation Trust

Visit Date: 5th March 2020

Report Date: June 2020

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Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Bradford Teaching Hospitals NHS Foundation Trust that took place on 5th March 2020. 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 Team (SHT)
- Local Haemoglobinopathy Teams (LHT) or linked providers

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

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 those proposals. Appendix 1 lists the visiting team that reviewed the services at Bradford Teaching Hospitals NHS Foundation 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:

- Bradford Teaching Hospitals NHS Foundation Trust
- NHS England & NHS Improvement Specialised Commissioning – Haemoglobinopathies
- NHS Airedale, Wharfedale and Craven Clinical Commissioning Group
- NHS Bradford City Clinical Commissioning Group
- NHS Bradford Districts 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, including commissioners of primary care. The lead commissioner in relation to this report is the NHS England & NHS Improvement Lead Commissioner for Haemoglobinopathies.

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 Bradford Teaching Hospitals NHS Foundation Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are also grateful to the users and carers who took the 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 care of children, young people and adults with haemoglobin disorders. During the course of the visit, reviewers met with patients, parents and carers, and with staff providing the services; they visited the emergency department (ED), day units and wards. Reviewers did not visit the paediatric out-patients department based at St Luke's Hospital (SLH) as part of this review visit.

Over the last year there had been a significant change to the delivery of care for patients with haemoglobin disorders, with the decommissioning of the specialist service function at the Trust and its replacement by a local haemoglobin service. At the time of the visit, arrangements for providing specialist haemoglobinopathy care were still being discussed with other SHTs across the network.

The Clinical Haemoglobinopathy Service (CHS) provided a clinical service for the population of Bradford (approximately 530,000). The Trust provided services for children, young people and adults with haemoglobin disorders and other red cell disorders, and coordinated the management of any haemoglobinopathy screening results. The CHS was based on the Bradford Royal Infirmary (BRI) site for the care of adults. Acute services for children and young people were provided at the BRI, and out-patient services at SLH.

Across the local health economy, the prevalence of people with thalassaemia was slightly higher than the prevalence of those with sickle cell disease, and the service also cared for a few patients with other transfusion-dependent red cell disorders.

Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) was part of the Yorkshire and Humber Haemoglobinopathy Network, which also included Leeds Teaching Hospitals NHS Trust and Sheffield Teaching Hospitals NHS Foundation Trust, both of which were specialist haemoglobinopathy teams (SHTs).

At the time of the visit the BTHFT adults' and children and young people's services were reviewed as local haemoglobinopathy teams (LHT).

Trust-wide Serious Concerns

1. **Organisational Pathway**

   Reviewers were seriously concerned that the pathway for accessing specialist advice, support and care for patients with haemoglobin disorders from an SHT within the network had not yet been agreed, given that the services at BTHFT had not been designated to continue as an SHT following the formal NHS England (NHSE) designation exercise for commissioning SHTs for Sickle Cell Disease and Thalassaemia. Reviewers were seriously concerned that the ongoing delays in formalising the accountability and responsibilities for specialist access had the potential for patients to receive suboptimal treatment.

2. **User and Carer Views**

   Reviewers were seriously concerned at the level of disquiet and concern expressed by the services users and carers about their experiences at the Trust (see views of services users and carers on pages 11 and 16); this disquiet was in contrast to what reviewers heard in their discussions with staff during the visit. For example, staff confirmed following the review visit that patients were always informed about their results in their clinic letters, that patients were offered specialist centre referral to London or Leeds, and that monitoring of iron chelation side effects was always performed. Reviewers considered that, in the light of the differing views of patients and staff and the seriousness of some of the comments, that BTHFT,

commissioners, SHT and HCCs work collaboratively with the users and carers to discuss any concerns regarding their experience of clinical care and address those concerns in a timely manner.

ADULTS

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long-term red cell transfusions
Bradford Teaching Hospitals NHS Foundation Trust	LHT	18	24	25

CHILDREN AND YOUNG PEOPLE

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long-term red cell transfusions
Bradford Teaching Hospitals NHS Foundation Trust	LHT	22	32	26

Support Groups	Adults	Children and Families
Sickle Cell Disease	Y	Y
Thalassaemia	Y	Y

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Local Team (Adult Services): Bradford Teaching Hospitals NHS Foundation Trust

General Comments and Achievements

This was an enthusiastic team, clearly keen to improve the services they provided to their patients and to develop the LHT. A locum consultant haematologist had been in post for 12 months and was the designated lead for the haemoglobin disorder service. The Trust had plans to recruit to the vacant consultant haematologist post.

Two clinical nurse specialist (CNSs) (1 WTE) to cover haemoglobin disorders and inherited and acquired bleeding disorders, who provided cover for each other, had been in post for 12 months. The CNSs had been appointed following some months without a substantive postholder, and had made considerable progress in developing the service and rebuilding trust with their patients.

Plans were being implemented to co-locate all the specialist nursing, community genetic counselling and administrative teams in one area to enhance collaborative working further.

A network-wide business case to fund some psychology time for both the adult and the paediatric LHTs was in the process of being agreed.

The team had plans to develop competences and training plans for specialist nurses and other staff caring for patients with haemoglobin disorders, to implement an audit programme, to benchmark with other services across the network, and to build on the patient involvement work that had already commenced.

The team recognised that the next 12 months would be a time of great change as they developed the service.

Local Haemoglobinopathy Team	Links with Specialist Haemoglobinopathy Teams
Bradford Teaching Hospitals NHS Foundation Trust	• Leeds Teaching Hospitals NHS Trust • Manchester University NHS Foundation Trust • Sheffield Teaching Hospitals NHS Foundation Trust • Whittington Health NHS Trust

Staffing

Staffing for the Adult Local Haemoglobinopathy Service (LHT)	Number of patients	Actual WTE (at time of visit)
Consultant haematologist dedicated to work with patients with haemoglobinopathies	42	0.2
Clinical psychologist for adult patients dedicated to work with patients with haemoglobinopathies	42	0

Emergency Care

All patients requiring emergency care attended the emergency department (ED) and were triaged according to clinical need. All known patients with sickle cell disease had an electronic flag on their medical records so that they could be assessed quickly and receive timely analgesia. Patients known to the haemoglobinopathy team had individual written pain management plans, which were kept in a folder in the ED central office. During normal working hours, the CNS and consultant haematologist were also notified of patients who attended the ED. Out of hours, the ED medical team assessed the patient and then referred to the haematology middle grade doctor for advice. Following triage assessment, and depending on bed capacity, patients who required in-patient care were admitted to one of the haematology wards, Ward 33 or Ward 24.

Advice and training on the care of patients with haemoglobin disorders was also available from one of the ED sisters who had a special interest in sickle cell and thalassaemia. The ED sister also attended MDT meetings, and had actively been involved in improving the access to timely analgesia for patients with acute pain attending the ED. Additional training sessions for ED staff were also planned.

In-patient Care

In-patient care was primarily provided on the haematology/oncology wards (33 and 24). Annette Fox ward (Ward 33) was a 12-bedded dedicated haematology ward, and the oncology ward (Ward 24) also had 12 beds. Admissions to these two wards were prioritised for patients who required management of sickle cell crisis or urgent transfusions or who had other complications relating to their haemoglobinopathy condition.

If a bed was not available then patients would usually be admitted to the acute medical unit (AMU), which consisted of two wards (Wards 1 and 4) and had 42 beds.

The haemoglobinopathy specialist nurses were available for patient, carer and staff support Monday to Friday during normal working hours. Out-of-hours advice and support was provided by the on-call consultant haematologist and specialty haematology registrar.

Day Care

The haematology/oncology day unit was based on Ward 16 at BRI and had recently been refurbished. The day unit was operational Monday to Friday between the hours of 8.30 am and 7.00 pm (excluding bank holidays). Patients attended for elective blood transfusions and could also attend for a non-urgent review if pre-arranged with the specialist haemoglobinopathy CNS. All patients who attended had treatment monitoring and management plans in place, and these were updated following each visit. An electronic booking system had also been implemented to enable scheduling of patients requiring elective care. Medical cover to patients attending the day unit was provided by the haematology team.

Out-patient Care

Consultant-led haemoglobinopathy clinics were held at BRI on the second and fourth Friday of each month. The specialist nurse and haemoglobinopathy counsellor were also available during this time to see patients attending for their annual reviews, for follow-up and for general out-patient appointments.

Community-based Care

Community integrated services for patients with haemoglobin disorders were managed by BTHFT and based at the Manningham Clinic near the city centre. The service consisted of 1.75 WTE haemoglobinopathy counsellors and 0.64 WTE administration support, and provided support for paediatric and adult patients, and counselling for families of affected new-born babies and ‘at risk’ couples identified by the antenatal screening programme. The counsellors also attended the haemoglobinopathy out-patient clinics, and saw patients with sickle cell disease when they were admitted for acute care and thalassaemia patients who attended regularly for their blood transfusions on the day unit. The haemoglobinopathy counsellors also provided education and training for medical and nursing staff, GPs, midwives, and school and nursery staff across the local area.

Support groups were also held in the community for people with haemoglobin disorders and their families.

Progress since Last Visit in 2015

- Refurbishment of the haematology and oncology combined day unit.
- Work was in progress for the adult and paediatric CNSs and community counsellors to be co-located.
- Discussion had commenced with the Leeds Teaching Hospitals NHS Trust to ensure that patients received specialist care and that their annual reviews were undertaken.
- Regular local MDT meetings had been implemented, and the team attended the quarterly Yorkshire and Humber Haemoglobinopathy Network meetings.
- Meetings with service users had been implemented and were being held on a quarterly basis.
- The service had engaged with the NHS Improvement collaboration on improving the care of young people transitioning to adult services.
- Processes for monitoring, and actions to be taken for, those patients who did not attend regular reviews had been strengthened.

Views of Service Users and Carers

The visiting team met with one person with sickle cell disease, one parent of a young adult, and two patients receiving care on the day unit. The comments received from the users and carers covered the following matters:

- Patients all had access to their blood results.
- The patients who were on chelation therapies reported that they were having regular MRI scans, although they were not always informed of the results when they attended for their appointments. Those who spoke to the reviewers were not sure about what other monitoring they were receiving with regards to the possible side effects of iron chelation.
- Not all those who met with the visiting team considered that there was easy access to advice from the adult consultant team. One example was of a service user who said it had taken eight months for them to arrange to see their consultant, despite contacting the service on a number of occasions.
- Patients attending the refurbished adult day unit were unsettled by the fact that when they were receiving their blood transfusions a member of staff was not always visible.
- Some patients commented that they often had to chase staff for appointments for their transfusions.
- Those who had been with the service for a few years commented that it had been an unsettling time with all the staff changes. They did not feel that their concerns were always listened to, and did not always have confidence that staff who they saw had sufficient knowledge about their condition.
- Some patients commented that within their social network groups they were aware that they would need to be monitored regularly by a specialist haemoglobinopathy team. Some patients with thalassaemia with whom they were in contact were already being seen by other SHTs in London, and the patients who spoke to reviewers were concerned that they were not being offered similar opportunities to access specialist care.
- Service users would value access to psychology support.
- The option to access elective care outside normal working hours would help reduce the time they needed to take off from their working day.
- The waiting time for phlebotomy was long and reviewers were told that patients often had to wait for several hours and attend the hospital multiple times. Patients who met with the visiting team commented that they would value working with the Trust teams to see if the pathway for phlebotomy could be streamlined.

See also Trust-wide concern: User and Carer Views on page 5.

Good Practice

1. Reviewers were impressed that all patients had access to welfare support and advice from a team based at the BRI.
2. The Trust was participating in an NHS Improvement collaboration for transition, and had identified the adult and paediatric haemoglobinopathy services as implementer sites. Reviewers were impressed with the work that had been undertaken to redesign the transition pathway and the documentation available for young people and their families as part of this initiative.

Immediate Risks: None were identified during the course of the visit.

Serious Concern

1. **Guidelines**

   Reviewers were seriously concerned about the process for the development and governance of guidelines. The content of many of the guidelines was variable, and many guidelines had elements omitted. Some of the guidelines that were presented in paper format were uncontrolled documents with slightly different information (some dating back to 2012/15).

   Reviewers were concerned that most of the guidelines would be unclear to staff who were unfamiliar with haemoglobin disorders or new to the Trust, and felt that it was important that all staff were able to access comprehensive and evidence-based guidance at all times. As a matter of urgency, the Trust should consider, as a minimum, adopting and implementing SHT or Haemoglobinopathy Coordinating Centre Guidelines. Otherwise, the Trust should revisit each of the guidelines individually and address areas that had deficiencies or concerns.

   Reviewers had the following comments about the guidelines that were in place:

   a. The Trust-wide pre-operative care guidelines did not include any specific requirements for patients with haemoglobin disorders.

   b. The Trust-wide transfusion guidelines:

      i. Did not include specific reference to the care of adults with haemoglobin disorders. For example, 'group and save' was stated, but the guidelines did not advise alerting the blood transfusion service to any specific requirements. During discussions with staff at the time of the visit, reviewers were told that the service would be alerted if the patient was seen at an out-patient appointment but not necessarily if he or she was seen via any other pathway, which may result in suboptimal transfusion.

      ii. The guidance suggested that in the acute setting a 'top-up' transfusion was recommended. However, the guidance did not say that the baseline haemoglobin (Hb) should be taken into account, as a baseline Hb of more than 100g/l may be a contraindication for a 'top-up' transfusion.

      iii. The maximum recommended number of cannulation attempts was not included in the guidance seen.

   c. The emergency automated exchange policy referred to NHS Blood Transfusion but did not cover the method for obtaining venous access. A pathway was in place, and reviewers suggested that this should be documented formally.

   d. The protocol for manual exchange did not include the baseline Hb, and therefore did not provide any additional guidance for patients who were anaemic.

e. The clinical guidelines for acute complications:

   i. Did not include any monitoring of the acutely unwell patient with sickle cell disease.

   ii. Were unclear throughout that oxygen saturation should be measured on air, monitoring frequency and criteria for escalation of care.

f. The annual review template in use for patients with thalassaemia did not cover any endocrine issues, and therefore it was not clear that patients were receiving the recommended specialist reviews. The template was included in the standard operating procedure but not in the actual guideline.

g. No guidelines were in place for transfusion-dependent thalassaemia (apart from the guidelines for acute complications, which did not include any transfusion targets). The South Thames Sickle Cell and Thalassaemia network (STSTN) guideline for non-transfusion-dependent thalassaemia was available.

h. The section on hydroxycarbamide use did not reflect the latest British Society for Haematology (BSH) 2018 guideline and criteria for initiation of treatment. There was also no mention of fertility preservation for males.

i. The iron chelation policy did not specify the frequency of monitoring for adverse effects and for follow-up imaging.

j. The pregnancy guideline did not include specific information for induction and whether to proceed when a patient was in an acute crisis. Thromboprophylaxis was not mentioned in detail.

k. Guidelines covering chronic complications for adults were minimal; for example, hepatic sequestration was covered in only one or two lines and there was no mention of specific findings.

Concerns

1. **Consultant staffing**

   Reviewers were concerned that the adult LHT was reliant on a locum consultant haematologist and that there had been delays in recruitment to a substantive post. The locum consultant, who was also the lead for the service, was providing support for the day unit and clinics, and was also undertaking annual reviews for patients because there was no formal agreement with an SHT to undertake this work. Furthermore, the locum consultant had no time allocated in their job plan for professional development. Cover for the lead consultant was from other adult consultant haematologists.

2. **Access to psychology**

   Psychology staff with appropriate competences in the care of people with haemoglobin disorders were not available. Patients could be referred by their GP to the community psychology service, but staff in this service would not have the relevant experience in caring for patients and families with haemoglobin disorders, particularly in relation to issues with adherence to medication. Reviewers were also told that the waiting times to be seen by the community team were very long. The Trust teams had submitted a business case to increase the level of psychology support for patients being cared for by the adult and paediatric services.

3. **Specialist nursing**

   The CNSs did not have sufficient time available for professional development, and had not completed any specialist training in the care of patients with haemoglobin disorders. The CNSs attended the Northern Nurses Group and UK Forum on Haemoglobin Disorders meetings, but reviewers considered that these events would not provide the level of specialist training required for them to develop their CNS role.

4. **Nursing staff competences and staff training plan**

   Reviewers were concerned that staff on the wards to which people with haemoglobin disorders were usually admitted did not have appropriate competences to care for patients with haemoglobin disorders. Some training was provided by the community nurse counsellors, but competence-based training to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders was not in place.

5. **Audit**

   Audits as expected by the Quality Standards had not yet been undertaken (QS HN-705 and 706). Reviewers considered that it would be important to develop an audit programme to ensure that audits were completed and that there was a clear process for reviewing the practical implementation of any resulting action plans.

Further Consideration

1. Reviewers commented that the Trust should work urgently in collaboration with commissioners and regional specialist providers to address the various aspects of service provision outlined above and in the recent NHSE-led external review. The reviewers emphasised that the Trust should acknowledge that significant time and effort will be needed to rebuild trust with patients following the many changes in the service personnel over the last couple of years.
2. There would be a benefit in streamlining the elective blood transfusion pathway for adults, to reduce delays that at each stage were small but were experienced by service users on a regular basis. Reviewers were told by patients that they often had to wait for investigation results, to wait to be cannulated, and often to wait for blood to be available prior to and during the transfusion. The combination of these issues meant that patients felt they were spending more time on the unit than was necessary.
3. Out-of-hours provision for routine transfusions or phlebotomy was not available. Patients who met with the reviewing team considered that access to out-of-hours elective care would be helpful and would reduce the length of time they needed to take away from their working day.
4. The process for receiving T2* scan results from Leeds Teaching Hospitals NHS Trust (LTHT) would benefit from being more formalised to ensure that timely results were received from LTHT, and then the process for managing the results and action by the LTHT at Bradford.
5. Limited support was available for data collection, and clinical staff were spending time on data administration. Reviewers were told that some funding had been identified and that some additional data management support would be available.
6. Reviewers observed delays in nursing staff attending to patients on the day unit, and one of the reviewers was mistaken for a patient and told to ‘go back and sit and wait‘ when they reminded staff that a patient’s unit of blood had finished and that they had still not been seen 30 minutes after they had notified staff. Reviewers also observed that on the day of the visit the call bell in the day unit for patients to use in emergencies was not easily accessible for those who were receiving intravenous therapies.

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Specialist Team (Children and Young People Services): Bradford Teaching Hospitals NHS Foundation Trust

General Comments and Achievements

The team as a whole were extremely proud of the service that they provided, and it was clear to the reviewers that they were highly committed and enthusiastic.

Two CNSs (1 WTE) covered haemoglobin disorders and inherited and acquired bleeding disorders, and provided cross cover for both services. Two genetic counsellors provided a community service, including coordination of antenatal haemoglobinopathy screening results and support for children, young people and their families. Plans were being implemented to co-locate all the specialist nursing, community counselling and administrative team members to enhance collaborative working further.

Some shared care arrangements were in place with Whittington Health NHS Trust for some patients with thalassaemia.

A network-wide business case to fund some psychology time for both the adult LHT and the paediatric LHT was in the process of being agreed.

The team recognised that the next 12 months would be a time of great change as they developed the service.

Local Haemoglobinopathy Team	Links with Specialist Haemoglobinopathy Teams
Bradford Teaching Hospitals NHS Foundation Trust	• Leeds Teaching Hospitals NHS Trust • Whittington Health NHS Trust • University College London Hospitals NHS Foundation Trust

Staffing

Staffing for the Paediatric Local Haemoglobinopathy Service (LHT)	Number of patients	Actual WTE (at time of visit)
Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies	53	0.5 (for red cell disorders and bleeding disorders)
Clinical nurse specialist for paediatric patients dedicated to work with patients with haemoglobinopathies	53	0.5 for red cell conditions
Clinical psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies	53	0

Emergency Care

The majority of children and young people with sickle cell disease, transfusion-dependent red cell disorders, central venous access lines, or other individual reasons, had direct access to Ward 32 for acute health concerns. Any children and young people attending the paediatric ED with a red cell disorder were assessed initially by the ED team, who would liaise with the paediatric haematology team for advice.

In-patient Care

Children requiring admission were admitted to either the children's clinical decision area (CCDA) or the general children's ward (Ward 30) at BRI, both of which cared for paediatric medical and surgical patients. The CCDA had

five assessment cubicles and nine short stay beds (maximum of 24 hours), and Ward 30 had 41 beds, a school room, a playroom and an adolescent lounge.

Consultant paediatrician review on Ward 30 was provided daily by the lead consultant paediatrician for haemoglobin disorders. Out-of-hours cover was provided by the on-call paediatric consultant and team, who could contact the lead consultant for advice if required.

Day Care

Children and young people could attend the day care unit on Ward 2 at the BRI. The unit had 20 beds (15 for surgery and 5 for medicine), and had recently been refurbished. The unit was open from 7.30 am to 8pm Monday to Friday, with the exception of Tuesdays when it remained open till 9pm, and provided elective day case care, including for children who were transfusion-dependent. If treatments overran, then staff would occasionally be able keep the unit open or children could be transferred to the in-patient ward to complete their transfusions. Children attending the day unit for their regular transfusions were supported by the schoolteachers from Ward 30 who would also liaise with the child's school to make sure their time away from school did not affect their progress.

Out-patient Care

Paediatric out-patient care was provided at St Luke's Hospital, three miles from the BRI. Paediatric haemoglobinopathy clinics were held in the afternoon on every second and fourth Tuesday of the month. The paediatric haematology nurse and haemoglobinopathy counsellor were also available during this time to see children, young people and their families.

Community-based Care

The community service for patients with haemoglobin disorders was managed by BTHFT and was based at the Manningham Clinic near the city centre. The service consisted of 1.75 WTE haemoglobinopathy counsellors who provided support for paediatric and adult patients, and counselling for families of affected new-born babies and at risk couples identified by the antenatal screening programme. The counsellors also attended the haemoglobinopathy out-patient clinics and would see children and young people if they were admitted for acute care or were attending regularly for their blood transfusions on the day unit.

Progress since Last Visit

- The service had moved into the newly-built and refurbished paediatric in-patient ward and children's clinical decision area.
- An additional paediatric haematology CNS had been appointed (1 WTE for red cell and bleeding disorders).
- Staffing had been increased for the medical day care unit, which had released time for the paediatric clinical nurse specialist (CNS) to attend the out-patient haemoglobinopathy clinics.
- The Trust was participating in an NHS Improvement collaboration for transition, with the service focussing on the transition of haemoglobinopathy patients to the adult service. The transition pathway and documentation had been redesigned as part of this initiative.
- Quarterly paediatric telephone MDT meetings had commenced between BRI and the SHT at Leeds Teaching Hospitals NHS Trust.
- Regular local MDT red cell meetings had been implemented, and the team attended the quarterly Yorkshire and Humber Haemoglobinopathy Network meetings.
- Processes had been implemented to improve CNS liaison and support to children, young people and their families.
- The team had commenced submission of data for Specialised Services Quality Dashboards (SSQD) and agreed NHSE Commissioning for Quality and Innovation schemes (CQUINs). Administrative support had

also been increased, which had improved the quantity of data submitted to the National Haemoglobinopathy Registry (NHR).
- The paediatric consultant and paediatric haematology CNSs had attended additional training in motivational interviewing.

Views of Service Users and Carers

During the visit, the visiting team met with one young person and four parents of children with thalassaemia. Some families who had been invited were not able to attend on the day. The comments received from the users and carers covered the following matters:

- Parents were highly complimentary about the support from the paediatric lead consultant and CNS. Their concerns were always listened to and the arrangements for accessing advice or an urgent review worked well.
- Those parents whose children were on chelation therapies reported that the children were having regular iron monitoring investigations, though some reported that they had not seen an endocrinologist and had some concerns about their child's physical development.
- All those who met with the reviewing team had concerns about the waiting time for blood transfusions to commence. Children had to attend by 9am for a medical review of investigations and often their transfusion did not commence until late morning; the parents considered that this meant that they were in the unit for longer than necessary.
- Patients and parents were unsettled about transitioning to the adult service and had heard that access to advice was not so forthcoming, with one parent commenting that their child who had transitioned found it difficult to get the same level of support from the clinical team as they had received when cared for by the paediatric service. Not all the parents were aware of the work being undertaken by the Trust to implement a more robust transition process.
- Some disquiet was expressed about the new unit, with parents feeling that other children were accessing better facilities on the floor above. Parents raised concerns about the staffing on the day unit being shared with the ward, which, in their opinion, had resulted in staff with limited knowledge about haemoglobin disorders now caring for their children.
- They also commented that it was more difficult to find opportunities to meet with other families.
- Access to the schoolteacher was not always possible in the mornings, and some parents were concerned at the number of days of school missed by their child.
- The options for hot food were limited, especially if a child was attending later in the morning, as a decision to choose hot food needed to be made earlier in the day.
- All the parents would value more communication and opportunities to attend conferences and patient events.
- Some parents commented that they had been made aware from conversations within their social networks that their child would need to be monitored regularly by a specialist haemoglobinopathy team, and they were concerned that they had had little information about where and when this would occur.

Good Practice

1. A 'rapid access triage' process had been implemented so that children and young people with chronic conditions, including those with haemoglobin disorders, had direct access to the admissions unit for assessment and urgent care. Patients could either attend directly by phoning in advance or be referred by their GP.
2. Travel advice was comprehensive and included advice before travelling, and information on what to do in the event of requiring medical assistance when away from home.
3. School care plans were well designed and had been developed specifically to target the different educational age groups; for example, there were separate templates that could be used for nursery, primary or secondary school aged children.
4. The Trust was participating in an NHS Improvement collaboration for transition and had identified the adult and paediatric haemoglobinopathy services as implementer sites. Reviewers were impressed with the work that had been undertaken to redesign the transition pathway, and the documentation available for young people and their families as part of this initiative.

Immediate Risks: None were identified during the course of the visit.

Concerns

1. **Consultant staffing**

   Reviewers were concerned that the service had insufficient paediatric consultant medical staff time available for the care of people with haemoglobin disorders in order to carry out regular reviews and routine monitoring. The lead consultant was providing support for the paediatric day unit and clinics, as well as undertaking annual reviews for patients because there was no formal agreement with an SHT to undertake this work. The lead consultant had 0.5 WTE time allocated for all non-malignant haematology, which included being the lead for the haemophilia service, and did not have a deputy in place or cover for absence. In the absence of the lead clinician, clinics were not held. Patients who were in-patients were cared for by the general paediatric consultant rostered to attend the ward.

2. **Audit**

   Audits as expected by the Quality Standards had not yet been undertaken (QS HN-705 and 706). Reviewers considered it would be important to develop an audit programme, to ensure that audits were completed and to put in place a clear process for reviewing the practical implementation of any resulting action plans.

3. **Access to psychology**

   Psychology staff with appropriate competences in the care of people with haemoglobin disorders were not available. Children and young people could be referred by their GP to the community psychology service, but staff in this service would not have the relevant experience in caring for patients with haemoglobin disorders and their families, particularly in relation to issues of adherence to medication. Reviewers were also told that the waiting times to be seen by the community team were very long. The Trust teams had submitted a business case to increase the level of psychology support for patients being cared for by the adult and paediatric services.

4. **Day unit**

   The new day unit was adjacent to a ward area and, since the refurbishment, staffing was shared between the two areas. Parents who met with the visiting team expressed a lack of confidence in staff who were unknown to them and their child, and were concerned about whether these staff had sufficient knowledge

in the care of patients with haemoglobin disorders. They were also worried that on occasions the unit was left unsupervised when staff had to collect blood for transfusions.

5. **Specialist nursing and cover arrangements**

   The CNSs did not have sufficient time available for professional development, and had not completed any specialist training in the care of patients with haemoglobin disorders. The CNSs did attend the Northern Nurses Group and UK Forum on Haemoglobin Disorders meetings, but reviewers considered that these events would not provide the level of specialist training required for them to develop their CNS role.

   Reviewers were also concerned that cover arrangements for the CNS who was due to commence maternity leave in the next few weeks were not in place.

Further Consideration

1. Patients had no access to an out-of-hours service for phlebotomy or routine blood transfusions.
2. Limited support was available for data collection, ongoing monitoring and coordination across the hospital sites, and clinical staff were spending time on data administration. Reviewers were told that some funding had been identified and that some data management support would be available.
3. There would be a benefit in streamlining the elective blood transfusion pathway for children and young people, to reduce delays that at each stage were small but were experienced by service users on a regular basis. Reviewers were told by parents that children often had to wait for investigation results, to wait for cannulation and then often to wait for blood availability prior to and during the transfusion. In combination this meant that parents felt they were spending more time on the unit than was necessary.

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Commissioning

Reviewers met with the regional representative from NHSE specialist commissioning.

Reviewers acknowledged that considerable work had taken place with NHSE specialist commissioners, the Trust and the network to address some of the issues in this report. However, the ongoing involvement of the Trust and commissioners will be required to ensure that timely progress is made.

Serious Concern

1. **Organisational pathway**

   Following the formal designation exercise for commissioning SHTs for Sickle Cell Disease and Thalassaemia by NHS England (NHSE), the Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) had not been commissioned to continue to provide an SHT function. Reviewers were seriously concerned that agreements covering the pathway for accessing specialist advice, support, and care for patients with haemoglobin disorders had not been formalised, despite designations being assigned some time ago. Discussions had taken place with Leeds Teaching Hospitals NHS Trust (LTHT), and arrangements had been agreed in principle. At the time of the visit, children and young people with haemoglobin disorders were continuing to have their annual reviews at BTHFT under the care of the local team, with support available from the SHT. In addition, quarterly telephone MDT meetings between LTHT and BTHFT children's services had commenced. However, discussions were ongoing about the arrangements for outreach support from LTHT for adult patients cared for by BTHFT, and hence specialist-led annual reviews were not taking place. Reviewers were concerned that the ongoing delays in formalising the accountability and responsibilities for specialist access had the potential for patients to receive suboptimal treatment.

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APPENDIX 1 Membership of Visiting Team

Clinical Leads		
Dr Subarna Chakravorty	Consultant Paediatric Haematologist	King's College Hospital NHS Foundation Trust
Prof Jo Howard	Consultant Haematologist / Honorary Professor in Haemoglobinopathies	Guy's and St Thomas' NHS Foundation Trust

Visiting Team		
Joanne Bloomfield	Lead Specialist Nurse and Manager	Nottingham University Hospitals NHS Trust
Dr Arne de Kreuk	Consultant Haematologist	North Middlesex University Hospital NHS Trust
Dr Rachel Kemp	Clinical Psychologist	University Hospitals of Leicester NHS Trust
Karen Madgwick	Deputy Clinical Lead for Blood Transfusion	North Middlesex University Hospital NHS Trust
Roanna Maharaj	Patient Representative	UK Thalassaemia Society
Giselle Padmore-Payne	Senior Clinical Nurse Specialist for Haemoglobinopathies	King's College Hospital NHS Foundation Trust
Louise Smith	Sickle Cell Clinical Nurse Specialist	Alder Hey Children's NHS Foundation Trust
Siobhan Westfield	Patient Representative	

QRS		
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 (SHT)	39	23	59
Children and Young People (SHT)	42	31	76
Total	**81**	**55**	**68**

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Specialist Services for People with Haemoglobin Disorders

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	The written information for patients did not include sufficient detail on the self-administration of infusions (i).	Y	Limited written information was available for children and young people with thalassaemia and their families, covering their condition and how it might affect them (a). The information covering self-administration of medication and infusions (i) was written mainly for use by adults.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	N	From the information available at the time of the visit, the information sent to the primary health care team did not cover contraception and sexual health, and the information on the use of hydroxycarbamide did not include sufficient detail on side effects.	N	From the information available at the time of the visit, the information sent to the primary health care team did not cover contraception and sexual health, and the information on the use of hydroxycarbamide did not include sufficient detail on side effects.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	This QS was not applicable to adult services.	N/A	This QS was not applicable to LHTs.
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	

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		Met?	Comments
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	However, from observation, the area where patients sat to receive their blood transfusions was not easily observable by staff, and the call bell for assistance was situated some way from the immediate area. Patients who met with the visiting team were also concerned that it was not easy to summon help if a member of staff was not in the immediate area.	Y	
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		Y	

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		Met?	Comments
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	Y		Y	
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	However, the locum lead consultant did not have any time allocated in their job plan for professional development.	Y	
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.	Y		Y	

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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.	Y	(c) and (d) were not applicable to LHTs.	Y	(c) and (d) were not applicable to LHTs.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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.	Y	Reviewers considered that, as the CNS role develops, more specific training in the care of people with haemoglobin disorders would be beneficial. The CNSs did attend the Northern Nurse Group and UK Forum on Haemoglobin Disorders meetings.	Y	Reviewers considered that, as the CNS role develops, more specific training in the care of people with haemoglobin disorders would be beneficial. The CNSs did attend the Northern Nurse Group and UK Forum on Haemoglobin Disorders meetings.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	No specific psychology support for people with haemoglobin disorders was available. (British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggests 1 WTE for 300 patients).	N	No specific psychology support for people with haemoglobin disorders was available. (British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggests 1 WTE for 300 patients).
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.	Y	The community-based nurse counsellors had developed a training package and delivered training for staff on the acute medical unit and wards.	Y	The community-based nurse counsellors had developed a training package and delivered training for ward staff. There were also plans were to deliver training for the rapid access triage team.
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		N/A	This QS was not applicable to LHTs. Children were referred to Leeds Children's Hospital for their TCD scans.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		Met?	Comments
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 service did not have sufficient support for data collection. Reviewers were made aware that there were plans to increase the level of administrative support, which would address the shortfall.	N	The service did not have sufficient support for NHR data collection, and staff were spending time on data collection, which was impacting on the clinical time available. Reviewers were made aware that there were plans to increase the level of administrative support, which would address the shortfall.
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		Y	

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	Competence-based training for ED staff had not taken place, but reviewers were told that sessions were planned. Some training had been provided for staff on the acute medical unit. A time to analgesia audit had not been undertaken.	N	Competence-based training for the staff providing the rapid access triage service had not taken place, but reviewers were told that sessions were planned.
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	N/A	This QS was not applicable to LHTs. Manual exchange transfusions (24/7) were not performed at the Trust, and patients who required erythrocytapheresis were seen at Leeds. All other services as defined in the QS were available locally.	N/A	This QS was not applicable to LHTs. Children requiring specialist support (as defined by the QS) were transferred to Leeds.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	N/A	This QS was not applicable to LHTs. Some specialist services were available locally and reviewers considered that once the specialist services pathways were agreed it would be helpful to document the arrangements.	N/A	This QS was not applicable to LHTs. Reviewers considered that once the specialist services pathways were agreed it would be helpful to document the arrangements.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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.	N	UKAS accreditation was in progress and reviewers were told that the service was waiting for their results.	N	UKAS accreditation was in progress and reviewers were told that the service was waiting for their results.
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	Allocation of a named coordinator for the transfer of care (c) was not explicit in the guidelines, but in practice a coordinator was allocated for those who were transitioning to an adult service.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	(a) was not applicable to LHTs.	Y	(a) was not applicable to LHTs.
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.	N	Guidelines had not been agreed with an SHT covering the details required by the QS. Staff who met with the reviewers commented that monitoring and management was undertaken locally, although meetings to agree arrangements with a specialist centre were planned to take place in the forthcoming weeks.	N	Guidelines had not been agreed covering the arrangements for escalation to an SHT, but in practice monitoring and management between annual reviews was in place.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		Met?	Comments
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	The guidelines would benefit from review to include specific reference to the care of adults with haemoglobin disorders (see main report).	Y	Automated exchange (a)(iii) was not applicable as not provided at the Trust.
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.	N	Guidelines did not cover the management and monitoring of iron overload, including management of chelator side effects. The policy did not specify the frequency of monitoring for adverse effects or the required follow-up imaging. From discussions with staff, reviewers were told that appropriate processes were in place to manage iron overload in patients on chelation therapy.	Y	However, in practice a different modality of iron load of the liver (e) was in use from what was documented in the guidance.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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	N	Clinical guidelines for acute complications did not include any monitoring of the acutely unwell patient with sickle cell disease. From the guidance that was available, measuring oxygen saturation on air and the monitoring frequency and criteria for escalation were not clear.	Y	The clinical guidelines were not clear on the management of patients with haematuria.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		Met?	Comments
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	N	The pre-operative guidelines did not include any specific requirements for patients with haemoglobin disorders. The section on hydroxycarbamide did not appear to reflect the latest BSH 2018 guideline and criteria for initiation of treatment. There was also no mention of fertility preservation for males. The pregnancy guideline did not include specific information for induction and whether to proceed when a patient was in an acute crisis. Thromboprophylaxis was not mentioned in detail.	Y	

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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)	N	The guidelines on the management of chronic complications for patients with thalassaemia lacked detail.	N	Guidelines were not available covering the management of renal and liver disease or chronic pain.
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		N/A	This QS is not applicable to LHTs.
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	N	The guidance did not include sufficient detail for any of the areas defined in the QS (a, b, or c).	N	The guidance did not include sufficient detail for any of the areas defined in the QS (a, b, or c).
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 - SHT		Children - SHT	
		Met?		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	Y		Y	

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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).	Y		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	However the LHT were undertaking all the annual reviews locally.	N/A	However the LHT were undertaking all the annual reviews locally.
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.	N	Out-of-hours elective care was not available.	Y	
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	Acute and community services were managed by the Trust.	N/A	Acute and community services were managed by the Trust.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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		N/A	
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	
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	

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		Met?	Comments
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	The 2018-19 Annual Report showed that 94% of patients had data entered on the NHR.	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	N	Some data were available showing contact episode numbers, but not specific data for each area as defined in (a). Data were not available for (b) or (c).	N	Data were not seen at the time of the visit covering the requirements of the QS.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		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 - SHT		Children - SHT	
		Met?		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		N	
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	N	However, the service was planning to participate in the agreed network audits.	N	The service had not participated in any agreed network audits.
HN-707	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	N/A		N/A	
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		N/A	This QS was not applicable to LHTs. Children were referred to Leeds Children's Hospital for their TCD scans.

Ref	Standard	Adults - SHT		Children - SHT	
		Met?		Met?	Comments
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)	Y		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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