Health Services for People with Haemoglobin Disorders

Birmingham Women's and Children's NHS Foundation Trust

Visit Date: 19th December 2019

Report Date: March 2020

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Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Birmingham Women's and Children's NHS Foundation Trust that took place on 19th December 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 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 Birmingham Women's and Children's 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:

- Birmingham Women's and Children's NHS Foundation Trust
- NHS England & NHS Improvement Lead Specialised Commissioning – Haemoglobinopathies
- NHS Birmingham and Solihull 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 Birmingham Women's and Children's 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

Birmingham Children's Hospital (BCH) was a Specialist Haemoglobinopathy Team (SHT) for children and young people residing across the West Midlands and surrounding counties, and was part of the West Midlands Paediatric Haemoglobinopathy network. The Trust was a large tertiary hospital that provided a vast range of specialised services.

The haemoglobinopathy service was an established and well-embedded service located within the Blood, Stem Cell Transplant and Cancer (BSC) clinical division. The service catered for a very large number of children (approximately 550 children and young people) with haemoglobin disorders, both sickle cell disease and thalassaemia, and had one of the largest numbers of children and young people on regular blood transfusions in the UK.

Formal designation by NHS England (NHSE) of the service as an SHT for Sickle Cell Disease and Thalassaemia had been agreed shortly before the review visit. The Trust was keen to support this development and was working with the team to implement the action plan agreed with NHSE.

As part of the national procurement exercise being conducted by NHSE during 2019, Birmingham Women's and Children's NHS Foundation Trust, together with Sandwell and West Birmingham Hospitals NHS Trust, had applied to become a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell Disease and Thalassaemia for the Midlands region. At the time of the visit, discussions concerning the designation as an HCC were ongoing with NHSE specialist commissioners.

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
Birmingham Women's and Children's NHS Foundation Trust –– Birmingham Children's Hospital	SHT	438	114	79

Support Groups	Yes /No
Sickle Cell Disease – Children and Young People	Y
Thalassaemia – Children and Young People	Y

Specialist Team (Children and Young People Services): Birmingham Women's and Children's NHS Foundation Trust

General Comments and Achievements

This was an experienced team with strong medical and nursing leadership evident throughout. The team as a whole were extremely proud of the service that they provided, and it was clear to the reviewers that the team were highly committed and enthusiastic.

Following the formal designation by NHSE as an SHT, the team, which had always provided specialist care with limited resources, had received additional funding that would enable them to develop a comprehensive specialist haemoglobin disorder service. Agreement had been reached to appoint, in early 2020, to two WTE clinical nurse specialist (CNS) posts, for outreach work and the care of children and young people with thalassaemia, additional consultant time (1 WTE), a network co-ordinator (1 WTE), and a psychologist (1 WTE) specifically for the care of children and young people with haemoglobinopathies and their families. The team recognised that the next 12 months would be a time of great change as they developed the service.

In August 2018 the service had been relocated to a newly built department in Waterfall House and it was now collocated with the oncology, haemophilia, and stem cell transplant services. Facilities at Waterfall House were well designed, and included the provision of dedicated day units and, inpatient and outpatient facilities for this group of children and young people.

The haemoglobinopathy service was overseen by three consultants with a total of six programmed activities (PA) allocated for haemoglobinopathy work. A weekly haemoglobinopathy clinic (by each consultant) was held in BCH. Weekly nurse-led hydroxycarbamide clinics were in place. Recruitment of a network co-ordinator to support the SHT was in progress.

The team had a good oversight of regional caseloads, and each of the three consultants provided an outreach clinic service to a number of local hospitals across the region two or three times a year (Sandwell and West Birmingham Hospitals NHS Trust, The Royal Wolverhampton NHS Trust, Shrewsbury and Telford Hospital NHS Trust, University Hospitals Coventry & Warwickshire NHS Trust, and University Hospitals of North Midlands NHS Trust).

There were good working relationships with the community children's teams across the network, who considered that engagement and involvement with the SHT was extremely positive, with timely access to advice and support.

The network meetings were well attended and provided a good forum for review and learning, although meetings had been temporarily suspended in the summer of 2019 whilst the service was waiting for formal confirmation that it had been designated as an SHT for the region.

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
Birmingham Women's and Children's NHS Foundation Trust – Birmingham Children's Hospital	• Sandwell and West Birmingham Hospitals NHS Trust • The Royal Wolverhampton NHS Trust • Shrewsbury and Telford Hospital NHS Trust • University Hospitals Coventry & Warwickshire NHS Trust • University Hospitals of North Midlands NHS Trust

Staffing

Staffing for the SHC Paediatric Haemoglobinopathy Service [1]	Number of patients	Actual WTE (at time of visit)	Staffing required as recommended by NHSE (WTE)
Consultant haematologist/paediatrician with >0.6 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	552	0.6	2.2
0.25 WTE allocated to haemoglobinopathies CPD in the paediatric consultant job plan	552	0	-
Clinical psychologist for paediatric patients who has >0.5 WTE per 150 patients dedicated to work with patients with haemoglobinopathies.	552	0	1.84

Emergency Care

All children with haemoglobinopathies attended the emergency department (ED) and were triaged according to clinical need. The triage team had patient group directions (PGDs) in place for the administration of paracetamol and ibuprofen for children who were admitted with pain. During normal working hours the ED medical and nursing team provided immediate clinical care, although there were a group of patients who would be directly referred to the haematology team. During normal working hours the advanced nurse practitioner (ANP) for haemoglobinopathies and the middle grade doctor could also be contacted to review some cases needing admission. A named haematology consultant was rostered to review all patient admissions.

Out of hours the ED medical team assessed the patients and referred to the haematology middle grade doctor until 9.30pm and directly to the on-call Haematology Consultant after this time.

Inpatient Care

Ward 18 was the dedicated haematology/ oncology ward. In practice most patients with haemoglobin disorders requiring admission were admitted to other wards with data showing that only 17% of emergency admissions were admitted to the haematology ward. An outreach intensive care team (HDU plus/PACE) supported any ill children on the wards. The intensive care unit (ITU) was a very large open plan unit where children were managed when they needed intensification of treatment, including emergency and manual red cell exchanges. Automated red cell exchanges were undertaken, during normal working hours, by the apheresis team.

Day Care

Children and young people could attend the day care unit for blood transfusions four days a week. On Thursdays the day care area was converted to an out-patient waiting area and children attended for phlebotomy prior to their transfusions which had reduced the number of separate visits to hospital. Children attending the day unit for transfusions were visited by the hospital schoolteachers regularly and were registered as 'present' in hospital school, thereby maintaining school attendance. The day care team worked hard to ensure that appointments met patient and family needs and rescheduling was relatively easy. All venepunctures and cannulations were undertaken by trained nurses. The latest audit of waiting times (21 patients) for blood sampling showed that 95% of patients had venepuncture undertaken within 30 mins, and all patients commenced their transfusions within 90mins of arrival.

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

Outpatients

Weekly Consultant led haemoglobinopathy clinics took place on a Thursday morning. Transcranial Doppler (TCD) ultrasound scanning was provided three times per month and occurred alongside the Thursday morning clinics. An ANP led hydroxycarbamide clinic was held every week on a Wednesday morning, and dedicated endocrine, neurology and post-transplant clinics were held quarterly. The team had also commenced a weekly nurse-led pre- transition clinic.

Community-based Care

Across the network there was no specific community nursing support for children, young people and their families residing in Sandwell, Stoke, Telford, Wolverhampton or Worcester, though the BWC outreach nursing team (1WTE) provided some support across the region. Community support was in place for children and young people residing in Dudley and Coventry areas, and for those residing in the Birmingham area, additional support and advice was available from the community children's team based at Soho Road medical centre.

Progress from Last Visit

- Funding had been agreed for additional staffing, which included one WTE consultant, one WTE psychologist, one WTE Band 7 CNS for outreach work and a 1WTE Band 7 CNS specifically for children a young people with thalassaemia/rare anaemias and a 1WTE Band 6 network coordinator post.
- A nurse-led transition programme had been developed, supported by the multidisciplinary team (MDT) at both the Trust and the adult service based at Sandwell and West Birmingham Hospitals NHS Trust
- The service had moved into new facilities which were now co-located with the rest of the haematology/oncology service.
- An in-house regional haemoglobinopathy database had been developed.
- The service had Increased their level of research activity.
- The nurse led hydroxycarbamide monitoring clinics had been increased from monthly to weekly to accommodate the increased numbers of children and young people on hydroxycarbamide therapy.

Views of Service Users and Carers

The visiting team met with eight families attending with children and young people during the course of the day who were attending the clinic for review or blood investigations. Overall, the patients and carers were highly complimentary about the care they received at the hospital, and they were particularly appreciative about the support from the haemoglobinopathy team. In addition:

- The pathway for accessing advice if their child was unwell worked well. Parents would call for advice and then if asked to attend the hospital were then seen quickly.
- Children and their parents told reviewers that Ward 18 was the 'best ward', staff had a good understanding of their child's condition, they did not have the same confidence that staff had sufficient understanding of their child's needs if they were admitted to other wards.
- Parents felt that they were well cared for when accessing services at the Trust.
- All those who met with the reviewing team were clear about how to raise concerns or give feedback.
- Parents commented that support was always available if they raised issues relating to their child's education or school and there were good relationships with their child's schools and the Trust team.
- There was good access to education support on the day unit and when their child was an inpatient.
- A couple of the parents commented that they would like to be able to access some refresher training for delivering Desferal® to check their competences, as they had received training a long time ago.
- Some families that met with the reviewing team would like more flexibility in attending for treatments and reviews outside of school hours. Others commented that they had been able to make appointments during school holidays.

- Not all those who met with the reviewing team were clear about the support that was available to them in their local areas. Others commented that they were fully informed about local services and would actively seek support when required.
- There had been some issues with the lack of communication with the Trust team some time ago. These issues had been resolved and the arrangements for communicating with medical and nursing staff were working well.
- Some who met with the reviewers had commenced on the transition pathway though they were 'worried' about leaving the children's service. Another representative also commented that they had the same concerns about being transitioned to the adult service; they thought they would be one of the youngest patients but assured the other young people in the meeting that their experience was very positive, and care from their adult haemoglobinopathy team was very good.
- Some commented that the food menu had changed and that they were not keen on the food now being offered.
- Parents commented that there were no facilities on the ward for making drinks. Nursing staff would always make drinks if asked, but the parents felt uncomfortable about asking as they know that the staff are busy.
- All those who met with the reviewers liked the access to charging points available for them to use for their digital equipment, though some were not sure whether there was any access to Wi-Fi for their laptops.
- Not all those who spoke to the reviewers were clear about how to access benefits advice.

Good Practice

1. Reviewers were particularly impressed with the following guidelines: -
    a. The chelation guidelines were very comprehensive, easy to read and follow with clear advice for staff.
    b. The clinical guidelines for thalassemia guidelines were also very well written and comprehensive.
2. Reviewers were impressed with the approach to pain management and that the acute pain service was available to review patients from 8am to 5pm on weekdays and 8am to 2pm at weekends and bank holidays.
3. A very good network community nursing group was in operation with support from the SHT. From discussion with representatives from the group it was clear that they were working well together across a wide range of acute and community services. Reviewers were impressed by the empathic and efficient way in which the group had worked and liaised with services dealing with complex and challenging issues such as refugees and trafficked children.

Immediate Risks: None identified at the time of the visit

Concerns

1. **Consultant staffing**

    The service had insufficient consultant medical staff with time for the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care, clinics, and support and oversight to other LHTs across the network. At the time of the visit there were three consultant haematologists (3WTE) with only 0.6WTE time allocated for work with haemoglobin disorders (approx. 552 patients). As part the Trusts designation as SHT recruitment for an additional 1WTE Consultant Haematologist with 0.6WTE time allocated for work with haemoglobinopathies had been agreed, but was unlikely to be in post within the next 12 months. Reviewers were concerned that this would still only provide 1.2WTE time for the service, and would not meet the NHSE recommend staffing levels of 0.6WTE for every 150 patients. If designation as a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell Disease and Thalassemia was successful, this would also require an increase in the time available for leadership and support to other paediatric haemoglobinopathy services across the Midlands.

2. **Clinical nurse specialist**

    The CNS team had insufficient time available for the number of patients being cared for with haemoglobin disorders (approx. 552 pts being cared for across the region) to provide nurse led clinics, specialist nursing advice and education within the Trust, outreach work, and leadership for the service. At the time of the visit the CNSs team

consisted of two CNS with 0.6 and 0.4 WTE respectively, and an ANP (0.8 WTE) with time allocated for work with haemoglobinopathies. As part the Trusts designation as SHT, recruitment for two additional CNSs for outreach work and the care of children and young people with thalassemia were planned to take place in early 2020.

3. **Access to psychology**

   Access to psychology was very limited, referrals could be made to the general psychology service, however, the general psychology service would not have specific competences in caring for patients and families with haemoglobin disorders. As part of the development of the SHT, funding had been agreed for a 1 WTE psychologist to support children, young people with haemoglobin disorders and their families, though for the numbers of children and young people accessing the service (approx. 552 patients) this would still not be sufficient. Access to neuropsychology assessments was on a case by case basis.

4. **Ward 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 (83% of emergency admissions were to other wards). Families who met with the visiting team also raised concerns that some staff on the wards (other than the haematology ward) did not demonstrate sufficient knowledge and understanding of their child's condition. Staff did have competences in cannulation and transfusion skills.

   Some training was delivered to staff, but a training plan 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 *(see also further consideration section of the report re the development of the online training programme)*.

5. **National Haemoglobinopathy Register**

   Incomplete data was submitted to the NHR. Patients were registered on the NHR and serious incidents information completed but, due to capacity within the team, no other information such as patient annual reviews were submitted. Reviewers were told that once the network coordinator was in place in early January 2020, comprehensive data submission to the NHR would be possible.

Further Consideration

1. Access to a play specialist was not available for routine procedures. Patients had to be referred to the specialist play team to access any support.
2. The process for internal quality assurance for Transcranial Doppler Ultrasound would benefit from review as an internal audit had not been undertaken since 2017. A standard operating procedure was in place and practitioner numbers were collected annually and met the required standard of undertaking 40 scans per year.
3. At the time of the visit the capacity to provide any elective care outside of normal working hours was not possible. Patient feedback had identified that there was interest from children and families to have access to out of hours elective blood transfusions and other options for pre transfusion blood investigations to be completed outside of the school hours. Reviewers considered that a review of arrangements should take place, especially considering the feedback from families and as the Trust had one of the largest number of children and young people on regular blood transfusions in the UK.
4. Considering the diverse population cared for by the SHT, access to written information in languages other than English was not seen in any of the areas visited, or evident in the information provided to reviewers. In the first instance it might be useful to have the section on 'access to interpreters' on the information leaflets in languages other than English. As the SHT develops, it may also be helpful to undertake further work with the support group to consider how best to develop and provide appropriate written information to meet the needs of the changing local population.

5. Mechanisms for receiving feedback from patients and carers would benefit from being strengthened. The last comprehensive feedback exercise was undertaken in 2015. Some feedback was received from five young people who attend an event in 2019 but this would not be reflective of the population served.

6. Reviewers were encouraged to hear that an online training programme for staff covering haemoglobin disorders was in the process of being developed, but they commented that ensuring a robust process of how competences will be assessed and monitored will be imperative as part of the programme development.

7. As the SHT develops, service level agreements should be agreed with community services and LHTs across the network to formalise the shared care arrangements and level of advice provided by the SHT. Formalising contractual arrangements would ensure that there was Trust oversight and the service would have support to ensure that the service provision was correctly governed and managed.

8. Reviewers noted the ongoing work with commissioners to develop the service, to enable the team to function as a designated specialist haemoglobinopathy team, but commented that in order for the team to progress, ongoing Trust executive support will also be needed to ensure that there is timely implementation of the agreed action plan.

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Commissioning

Reviewers were unable to meet with a commissioner representative at the time of the visit. but noted the ongoing work with commissioners to develop the service, to enable the team to function as a designated specialist haemoglobinopathy team. However, several of the issue in this report will require active involvement of the Trust and commissioners in order to ensure that timely progress is made.

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APPENDIX 1 Membership of Visiting Team

Clinical Lead		
Dr Subarna Chakravorty	Consultant Paediatric Haematologist	King's College Hospital NHS Foundation Trust

Visiting Team		
Sajid Hussain	Service User	
Rachel Kemp	Clinical Psychologist	University Hospitals of Leicester NHS Trust
Hazel Marriott	Sickle Cell and Thalassaemia Nurse Specialist	Nottingham University Hospitals NHS Trust
Giselle Padmore-Payne	Senior Clinical Nurse Specialist for Haemoglobinopathies	King's College Hospital NHS Foundation Trust
Dr Indu Thakur	Consultant Paediatric Haematologist	Cardiff and Vale University Health Board
Cherryl Westfield	Patient Representative	

Quality Review Service		
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
Birmingham Women's and Children's NHS Foundation Trust - Children and Young People Services	51	33	65
Total	**51**	**33**	**65**

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Specialist Services for People with Haemoglobin Disorders

Ref	Standard	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)	N	Information did not appear to be available in languages other than English Written information covering access to benefits and advice was not seen at the time of the visit.
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 information seen at the time of the visit did not cover advice about travel, vaccinations or self-administration of medications. Information did cover the various medications that could be prescribed. The thalassaemia booklet could benefit from review to simplify the diagram showing carrier status.

Ref	Standard	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).	N	Care plans did not include a plan for management in the ED. All other aspects were met.
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	Information to the primary health care team did not include contraception and sexual health. 'c'(i) was not applicable, as hydroxycarbamide and iron chelation therapy were not prescribed by GPs. For other aspects of the QS the clinic letters were very comprehensive.
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	Y	

Ref	Standard	Met?	Comments
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)	Y	The template for the thalassaemia school care plan seen at the time of the visit only included two of the possible three chelators that could be used. Staff who spoke to the reviewers commented that the template included the most common chelators used, and could be amended to include other therapies as required.
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	
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 information for young people transitioning to the adult service was very comprehensive. Information had been developed to cover each stage of the transition process.
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	Feedback from 2019 was received only from five young people who had attended an event. The questions were fairly limited and did not reflect the service provided, nor did they cover the range of children and young people cared for by the SHT. Feedback from the patient survey undertaken in 2015 was seen.

Ref	Standard	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.	N	The lead clinician had only two PAs for work with the SHT and no additional time allocated for work across the network.
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	
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	Consultant time was insufficient for the number of patients cared for by the SHT. See Concerns section of the main report. All other aspects of the QS were met.

Ref	Standard	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	For 'c', ward-based nursing staff had not completed competences in the care of people with haemoglobin disorders. A competency framework was not in place. See Concerns section of the main report. All other aspects of the QS were met.
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. Neuropsychological assessments were on a case by case basis, though reviewers were told that there was no "ring fenced" funding for the service. Funding had been secured to appoint 1WTE psychologist for work with the SHT but this would not meet the British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) recommendations of 1 WTE for every 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.	N	A number of training sessions and study days were held, but no training plan was in place to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.

Ref	Standard	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.	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	Because of the capacity within the data team, information could not be submitted to the NHR. Clerical support was available, and the Trust was in the process of appointing a network coordinator.
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	
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	No regular training for ED staff was in place though staff had plans to address this. An audit of time to analgesia had been completed
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	

Ref	Standard	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	
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	

Ref	Standard	Met?	Comments
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	
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	
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	
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/A	

Ref	Standard	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 number of cannulation attempts was not clear in the policy. The number of attempts was documented on the transfusion checklist in the patients care records.
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	'f' was not applicable as no shared care arrangements were in place with GPs.
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	

Ref	Standard	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	Y	
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	
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.	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	
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	

Ref	Standard	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	The policy would benefit from review to include the role that administrative staff undertake as part of the pathway for the 'fail-safe' process for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated.
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	
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	Written agreements were not in place with LHTs.

Ref	Standard	Met?	Comments
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	Feedback from families had identified that they would be interested in being able to access elective care out of hours.
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	SLAs with community children's services employed by other Trusts were not yet agreed.
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	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	Network meetings had been suspended over the summer of 2019 whilst the Trust awaited formal SHT designation from NHSE.
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.	Y	

Ref	Standard	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.	N	Only registration of patients and any adverse events were entered onto the NHR. Reviewers were told this was due to capacity within the data team.
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	However data on readmission rates were not specifically collected. Data covering all other aspects of the QS were collected.
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	
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	Y	

Ref	Standard	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)	Y	
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	Y	
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	
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 review of the internal TCD quality assurance process had not been undertaken within the last year ('b'). 'c' was not applicable as a national quality assurance process had not been established.
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	
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

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