Health services for people with haemoglobin disorders

Nottingham University Hospitals NHS Trust

Visit Date: 4th February 2020

Report Date: May 2020

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Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Nottingham University Hospitals NHS Trust that took place on 4th February 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

The 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 Nottingham University Hospitals NHS Trust. Appendix 2 contains the details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- Nottingham University Hospitals NHS Trust
- NHS England & NHS Improvement Specialised Commissioning – Haemoglobinopathies
- NHS Nottingham City Clinical Commissioning Group

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, 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 Nottingham University Hospitals NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are also grateful to the users and carers who took 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 health services provided for adults with haemoglobin disorders. During the course of the visit, reviewers met with patients, and with staff providing the services, and visited the Specialist Receiving Unit (SRU), Bethell Haematology Day Unit and Burns and Gillies in-patient wards at Nottingham City Hospital (NCH). Reviewers also spoke to a representative from the emergency department (ED) based at the Queen's Medical Centre (QMC), and to the regional NHS England (NHSE) specialist commissioner.

Nottingham University Hospitals NHS Trust (NUH) comprised QMC and NCH, which together had 87 wards and around 1,700 beds. The Trust provided local services to around 2.5 million people in Nottingham and the surrounding areas, and specialist services to a further 3 or 4 million people from neighbouring counties each year.

All in-patient, and the majority of out-patient, haematology activity was based in the Russell Centre for Clinical Haematology at NCH. The non-malignant consultant haematologists were primarily based at QMC, and the haematologist-oncologists at NCH.

The Trust had been formally recognised as a Specialist Haemoglobinopathy Team (SHT) for adults with sickle cell disease and thalassaemia in April 2019 following the national procurement exercise conducted by NHSE. The SHT was working towards expanding staffing to meet the requirements of a comprehensive SHT, and an action plan had been submitted to NHSE.

The Trust was also working with the University Hospitals of Leicester NHS Trust (UHL) to provide a Haemoglobinopathy Coordinating Centre (HCC) function for sickle cell disease. Due to ongoing national re-commissioning, a designated HCC for the East and West Midlands for patients with thalassaemia had not been agreed.

The SHT was part of the East Midlands Sickle Cell and Thalassaemia Network. The network had regular network-wide MDT meetings, education days and business meetings.

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
Nottingham University Hospitals NHS Trust – Nottingham City Hospital	SHT	123	19	32

Support Groups	
Sickle Cell Disease – Adults	Y
Thalassaemia – Adults	Y

Specialist Team (Adult Services): Nottingham University Hospitals NHS 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 SHT. A new consultant had joined the well-established nurse specialist team in August 2019. The service was well organised, with strong leadership from the lead clinician. Network-wide multi-disciplinary team (MDT) meetings, led by the lead clinician at NUH, were held every two months, with good engagement from the specialist and local teams across the network. Communication between local referring teams was reported to be working well, and link nurses were in place in the key areas to which patients with haemoglobin disorders were usually admitted. However, it was clear to the reviewers from discussions with staff that the team were working under extreme pressure and that the SHT was very reliant on key individuals.

Since the previous peer review visit in 2015 there had been some significant challenges for the service. The retirement of the long-serving lead consultant in April 2018 had left the service without a substantive lead consultant until late August 2019 (14 months). During this time, three different agency locum consultants had helped to provide services, which had led to a lack of continuity of consultant care for patients. In addition, none of the locums had had a sub-specialist interest in haemoglobin disorders. The specialist nursing team had worked hard to mitigate the impact of not having a substantive lead consultant and to provide continuity of care for patients. The team were extremely grateful for the assistance that had been available during this time from the lead consultant based at UHL, who had provided advice and support in the management of patients with complex needs.

As part of the development of the SHT, work was in progress to develop the specialist nursing roles to enable more nurse-led activities such as undertaking annual reviews, blood transfusion and chelation monitoring. Recruitment to the vacant Band 6 nursing post had been successful and the new postholder was due to commence in April 2020. The Band 6 post would focus on the support available to young people transitioning to adult care, as well as those young people up to 24 years of age who had already transitioned.

The introduction of 24/7 HbSS testing was due to take place in spring 2020. The lead clinician was also considering the development of an electronic single-page digitalised admission analgesia plan for each patient to improve the process by which staff carrying out admissions accessed relevant patient information.

A business case to fund additional psychology time for both the adult and the paediatric SHTs (0.4 WTE) was in the process of being agreed.

The SHT also had a number of other ideas and plans to improve the service. These included the development of a 24/7 automated red cell apheresis service, the reduction in the femoral line rate for those requiring red cell exchange, the introduction of peripheral deep vein cannulation (ultrasound guided), alternative intravenous access options for patients, and increased patient involvement in clinical research trials.

Specialist Haemoglobinopathy Team	Local Haemoglobinopathy Teams
Nottingham University Hospitals NHS Trust – Nottingham City Hospital	• University Hospitals of Derby and Burton NHS Foundation Trust (UHDB), Royal Derby Hospital • Sherwood Forest Hospitals NHS Foundation Trust, King's Mill Hospital (SFH-KMH) • United Lincolnshire Hospitals NHS Trust, Grantham and District Hospital, Lincoln County Hospital, Pilgrim Hospital Boston (ULH)

Patients at SFH-KMH and ULH had shared care arrangements in place, with annual reviews undertaken by the SHT at NUH.
UHDB undertook all annual reviews for their patients and the only shared care arrangements in place were for those who attended NUH for red cell exchange transfusions.

Staffing

Staffing for the Adult Specialist Haemoglobinopathy Service (SHT)[1]	Number of patients	Actual WTE (at time of the visit)	NHSE recommended staffing WTE
Consultant haematologist with >0.6 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	142	0.45	0.57
At least 0.25 WTE allocated to haemoglobinopathies CPD in the adult consultant job plan	142	-	-
A clinical psychologist for adult patients with >0.5 WTE per 200 patients dedicated to work with patients with haemoglobinopathies	235 (adults & children)	0.4 (adults & children)	0.35 (adults) 0.4 (children)

Emergency Care

The Trust provided services on two sites. The ED was based at QMC, with a Specialist Receiving Unit (SRU) based at NCH. Patients requiring emergency assessment were asked to contact the Haematology Triage Line, which was in operation 24/7, and, if it was appropriate, they were admitted directly to the SRU.

Arrangements were in place with the ambulance service to bring patients to the SRU where possible; those patients with more life-threatening symptoms were taken directly to the ED at QMC.

Between 9am and 5pm Monday to Friday, patients could also contact the acute haematology service nurses who held the triage phone in the daytime. In these circumstances the triage nurses would assess whether the patient could attend the haematology day unit for assessment or required direct admission to the SRU. Out of hours, the triage phone was held by the senior nurse on one of the two in-patient wards, and patients were directed to the SRU or the ED for admission. If admission was not required, appropriate arrangements were made for staff to contact and review the patient on the next working day.

In-patient Care

The majority of acute haemoglobinopathy admissions were to the SRU, directly by ambulance transfer, or from the Haematology Day Unit, or occasionally from the ED. Patients were admitted for a maximum of 18 hours. If patients required ongoing care or access to patient-controlled analgesia they were transferred to one of the designated 'Cancer and Associated Specialties' (CAS) wards (Gillies, Burns and Loxley) or another outlying ward (usually one of the surgical wards, Barclay, Harvey or Winifred). Patient-controlled analgesia was available on the surgical wards with support from the on-call anaesthetist. All admitted patients with sickle cell disease were reviewed daily by the ward-attending haematology team, and were looked after by the 'hospital at night' team out of hours.

The main haematology wards (Toghill and Fletcher) were situated in the Russell Centre for Clinical Haematology. The wards had a total of 40 in-patient beds, but patients with haemoglobin disorders were rarely transferred to these wards (2% of all patients had HD) because of the number of haemato-oncology admissions. Discussions were ongoing to agree whether patients with suspected sickle acute chest syndrome or delayed haemolytic transfusion reactions could be prioritised for admission to either Toghill or Fletcher ward.

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

Day Care

The Bethell Haematology Day Unit was open between 8.30am and 8.00pm Monday to Friday. The unit provided a blood transfusion service, automated red cell apheresis (Monday to Friday within normal working hours, provided capacity and sufficient trained staff were available), and a service for the management of acute painful crises. Patients could also attend to receive a clinical review from the day unit team. On Saturdays the unit was open between the hours of 8.30am and 3.00pm, when top up transfusions and phlebotomy services were available.

Facilities included 16 stations with recliner chairs for infusional treatments, phlebotomy or ambulatory review. There were two apheresis rooms housing three Spectra Optia® apheresis system and three Therakos Cellex® photopheresis system machines. There was a separate procedure room and a doctor's office where patients could be reviewed and examined privately.

Out-patient care

The dedicated out-patient suite was on the ground floor at the Centre for Clinical Haematology, adjacent to the day unit. It had its own phlebotomy area and blood analyser for processing blood counts. A walk-in service for phlebotomy was available on Wednesday and Friday afternoons or by specific arrangement outside these times. Consultant-led adult specialist sickle cell and thalassaemia clinics were run every Wednesday afternoon and alternate Friday afternoons for new patients and patients requiring their annual reviews. A nurse-led hydroxycarbamide monitoring clinic was also held on the second and fourth Friday of each month.

Transition clinics had been re-established in January 2020, and these were going to be held four times a year with the paediatric team based at Nottingham Children's Hospital.

A joint obstetric haematology clinic was held each week with the clinical lead for the SHT and the lead for obstetric haematology.

Community-based Care

A nurse-led service was based at the Mary Potter Centre and was available between 9am and 5pm, from Monday to Friday. Patients had direct access to this service and could attend as drop-in patients or make an appointment. The clinical psychologist could see patients at the centre by arrangement, and any patients requiring access to the leg ulcer service could also be seen at the centre.

Progress since Last Visit in 2015

- Since September 2019, the Trust had been able to provide T2* Cardiac MRI, which had reduced the need for patients to travel to UHL for specialist imaging.
- Depletion automated red cell exchange had been available since December 2019
- The Haematology Outreach Service had established a home visiting service and could also undertake pre-transfusion cross match samples.

Views of Service Users and Carers

The visiting team met with five patients during the visit who had sickle cell or thalassaemia. The comments received from the users and carers covered the following matters:

- Overall, the users and carers were highly complimentary about the care and support available from the new lead consultant and the CNS.
- Care on the day unit was very good. Service users felt that staff were supportive and that care on the unit was well organised.

- The service users with thalassaemia considered that the service was very well run and that the relevant monitoring of their condition had occurred. They felt 'very well looked after'. They were extremely appreciative that they could access top up transfusions and phlebotomy in the evenings and on a Saturday.
- There were mixed views about care on the SRU. Service users were happier about the care they received during normal working days, but they were not confident that, out of hours and at weekends, staff in the SRU had sufficient understanding of haemoglobin disorders. The service users commented that staff were often not clear about the medication they needed, and they felt that their agreed care plans were not always followed.
- The service users preferred to follow the admission route to be seen on the SRU rather than attending the ED at QMC, and they only wanted to attend the ED if they considered that they were seriously ill. The service users commented that staff in the ED did not access their emergency care plans, and they reported waiting up to two hours for analgesia; on occasions they were only offered paracetamol.
- On the admitting wards, staff did not always understand the service users' needs. The service users commented that they wanted to be admitted to wards where the nurses and junior doctors had some knowledge and understanding of their condition. When they were in-patients on Gillies Ward, Burns Ward or the haematology wards then they felt slightly more confident that staff understood their needs.
- Not all ambulance crews would administer analgesia, but this was appreciated when it was possible.
- Not all those present were aware of the local support group or how to access the psychologist.
- Those who had been with the service for a few years commented that it had been an unsettling time with all the staff changes.

Good Practice

1. Reviewers were impressed with the leadership, compassion and enthusiasm for the service demonstrated by the lead clinician, who had only been in post for five months. The lead clinician clearly had a vision for the service, and significant changes had been made to the operational delivery of the service, with links being built with referring and specialist services. The lead clinician was also in the process of reviewing all the clinical guidelines.

2. The competence framework developed to enable staff to deliver Entonox® to patients in pain on the SRU was very good. The framework was comprehensive and provided a good balance between the theory and practice to support staff in gaining the relevant competences. The framework also included opportunities for staff to reassess their ongoing knowledge and competence.

3. Reviewers were also impressed with other documentation that had been developed to support staff caring for patients with haemoglobin disorders, such as: -

    a. the nursing review and care plan leaflet, which provided key advice to staff caring for patients with sickle cell disease;

    b. the care plan in place for patients undergoing surgery; and

    c. individualised care plans for supporting patients who needed a femoral line insertion and red cell exchange. These plans covered relevant patient history, including whether the patient had experienced any anxiety during previous procedures, patient preferences in terms of the procedure, and advice to staff about preparing patients who required a femoral line to be inserted.

4. The patient information booklet for people with sickle cell disease was very good. The booklet listed all the possible crises that patients could experience, and categorised them using a traffic light system so that patients could easily see when to seek urgent medical advice. The patient representatives on the reviewing team were so impressed that they suggested that the team should consider making the document available nationally.

5. The annual review template in use for patients with sickle cell disease and those with thalassaemia were well designed and based on the version in use by UHL. From the evidence seen of completed reviews, the documentation was very detailed, including updates on any investigations undertaken or needed and listing any side effects from any medication that had been discussed with the patient.

6. All patients had access to the haematology complementary therapy service.

7. Reviewers were impressed with the pathway in place for people with thalassaemia, who were able to get appointments so they could be seen on the day unit, and with the availability of evening and weekend times to attend for blood transfusions.

8. The lead clinician at NUH was the designated network lead for the MDT. Network-wide video conference linked MDT meetings were held every two months, and the minutes demonstrated that the process for the discussion of patients and actions following the MDT meetings was very comprehensive. The meetings were highly valued by those who spoke to the reviewing team, and were well attended by representatives across the network.

9. The process for collecting data centrally through the East Midlands Network was very robust. The data manager visited all sites on a regular basis to ensure that data collection was timely and comprehensive. Service level agreements were in place in each Trust to enable the data manager to access clinical information, prepare network and service data reports and ensure that data for each site was submitted to the National Haemoglobinopathy Register (NHR).

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

Serious Concerns

1. **Senior medical out-of-hours arrangements**[2]

   Reviewers were seriously concerned about the out-of-hours arrangements for senior medical review for people with haemoglobin disorders being cared for on the general wards. Reviewers considered that there was the potential for the condition of some patients to deteriorate, as a review by a consultant with competence in caring for patients with haemoglobin disorders was not usually possible for all in-patients within 14 hours of admission out of hours or at weekends.

   At weekends, new patients were reviewed by the on-call malignant haematology consultant (who conducted a ward round each weekend morning on the SRU). However, patients were only seen if they remained on the SRU from the time of their admission. If a patient was admitted and reviewed by the on-call haematology registrar and transferred to another ward, or admitted directly to another ward, then they would not have a consultant's review over the weekend, as local departmental arrangements did not include the requirement for the on-call haematology consultant to review patients outside the SRU or intensive care. The responsible consultant at weekends for these patients was the on-call non-malignant haematology consultant (normally based at QMC) who was non-resident out of hours. This consultant could be contacted for advice, and would attend if the patient was significantly unwell or had complex needs, or if attendance was requested by the registrar or the on-call malignant haematology consultant.

   Reviewers considered that the combination of the consultant out-of-hours cover arrangements, and the reliance on the general wards on junior medical staff and nursing teams who had limited experience in caring for acutely unwell patients with haemoglobin disorders, required further attention in order to

[2] **Trust response to Serious Concern:** It has been agreed that the on on-call non-malignant Haematology Consultant will conduct a virtual board round at a pre-agreed time at the weekend to ensure that a systematic review of patients clinical observations, blood results and management plan is completed, rather than only giving advice if specifically called by the Registrar.

reduce the risk to those patients who were acutely unwell and were being cared for in general wards out of hours and at weekends.

Concerns

1. **Consultant staffing**

   Reviewers were concerned that the service had insufficient consultant medical staff time available for the care of people with haemoglobin disorders in order to carry out reviews of new patients within 14 hours of admission, to carry out regular reviews (annual reviews, and hydroxycarbamide and routine monitoring) and to provide support to the local haemoglobin teams across the network. At the time of the visit, the lead consultant had only 0.45 WTE time allocated for work with the haemoglobinopathy service, with no deputy in place or cover for absences. When the lead clinician was absent, clinics were not held, and on occasions the lead consultant had been contacted for advice when not on call.

2. **Ward staff training**

   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. Since the last visit the number of wards who accepted admissions had been consolidated, with the intention being that the staff would have more experience in caring for patients with haemoglobin disorders. However, staff (on Burns and Gillies wards and the SRU) and patients who met with the reviewing team both expressed concerns about the availability of sufficient staff with confidence and knowledge in caring for patients with haemoglobin disorders.

   Reviewers were also told that some of the wards were moving away from delivering patient-controlled analgesia, and therefore would not have staff with the relevant competences to continue to provide this method of analgesia for patients with sickle cell disease admitted in severe pain.

   Education days were held twice a year, but reviewers were told that staff were often unable to attend because of their workload. The training did not include a process for the assessment or ongoing monitoring of staff competence. As patients were admitted to a number of different wards, training and involvement of the practice development nurses (PDN) in supporting the training of ward staff in haemoglobin disorders may be a helpful way forward.

3. **Specialist nursing structure**

   It was not clear who had responsibility and oversight for ensuring that staff on the wards to which people with haemoglobin disorders were usually admitted (Burns, Gillies, the SRU and other general wards) had appropriate knowledge and competences to care for patients with haemoglobin disorders.

   A competence framework was not in place, and the specialist nursing team for haemoglobin disorders did not have easy access to data to assure them that staff on the wards had competences in cannulation and transfusion when patients were admitted for blood transfusions.

   Reviewers learned from their discussions with staff that the lead nurse was based mainly in the community, with one day allocated to the acute Trust for general nursing management but not management of the acute haemoglobinopathy service. The CNS who provided some educational days did not have capacity to provide ongoing assessment and monitoring of ward staff competences across all the wards where patients were admitted.

4. **Access to automated red cell exchange**

   Staff providing the apheresis service also rotated to cover the day unit, and reviewers were told that on occasions automated and emergency red cell exchanges could not be undertaken during normal working hours because staff who were trained to provide the service were not available. 24/7 access to

automated red cell exchange was also not possible, although the SHT was considering options to develop a 24/7 service.

5. **Access to psychology**

   One psychologist (0.4 WTE) provided support for both the adult's and the children's haemoglobinopathy services Reviewers considered that this was insufficient to provide a comprehensive psychology service for the number of adults, children and young people (approximately 235 adults, children and young people) being cared for by both services. The provision in place did not meet the national workforce recommendations of 1 WTE clinical psychologist for every 300 patients.

Further Consideration

1. Reviewers were impressed with the progress made, especially by the lead clinician, and with the plans that the SHT wanted to implement in a relatively short timeframe. These plans would require time from staff in addition to their clinical commitments. Reviewers commented that the Trust should not underestimate the challenge and energy that would be required to progress some of these plans, and also the time needed to build trust with patients following the many changes in the service personnel over the last couple of years.
2. The information seen at the time of the visit for patients with thalassaemia was limited and appeared to be only from one drug company.
3. The Trust's unit for teenagers and young people did not accept teenagers and young people with haemoglobin disorders. Depending on their age, young people were admitted to either the paediatric or the adult ward.
4. The lack of a service level agreement (SLA) with University Hospitals of Derby and Burton NHS Foundation Trust (UHDB) was limiting the input that NUH could provide as the SHT for UHDB. At the time of the visit the LHT service at UHDB was provided by a locum consultant who was leaving the Trust on the day of the visit, and reviewers were told that interim arrangements meant that patients would not have access to a consultant with expertise in the care of haemoglobin disorders (see Concern 1 in the commissioning section of the report).
5. The electronic patient record system was comprehensive and held all the care plans and templates mentioned in the good practice section of this report, but the system was difficult to navigate and read, and there was often a delay in documents being uploaded to the system. Service users also reported that staff often did not access the key information held on the system. The issue had been recognised by the team, and the lead clinician was planning to develop a front sheet to guide staff. This development would be time-consuming and would require other relevant care documents to be updated simultaneously to ensure they were all up to date. Reviewers suggested that the issue could be raised again with the Trust records group and IT department to see if any electronic solutions could be implemented to improve staff access to key patient information.

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Commissioning

The review team had discussions with the regional NHSE specialist commissioner. Several of the issues in this report will require active involvement of the Trust and commissioners in order to ensure that timely progress is made.

Concerns

1. **Access to specialist care - University Hospitals Derby and Burton NHS Foundation Trust**

   Adult patients with sickle cell disease attending UHDB did not have access to specialist annual reviews, and arrangements for accessing specialist advice and support from the SHT at NUH had not been formalised. This issue had been highlighted at the last review in 2015 and had not been addressed at the time of this review. The lead clinician, who had commenced in post in August 2019, had begun a dialogue with the Trust, but the issue was still unresolved. Reviewers were concerned that the locum consultant based at the Royal Derby Hospital was leaving on the day of the review visit. They were told that cover arrangements from a consultant with expertise in the care of haemoglobin disorders had not been formalised by the Trust, and they considered that there was the potential that patients would receive suboptimal treatment.

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APPENDIX 1 Membership of Visiting Team

Clinical Lead		
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust

Visiting Team		
Karen Madgwick	Deputy Clinical Lead for Blood Transfusion	North Middlesex University Hospital NHS Trust
Roanna Maharaj	Patient Representative	UK Thalassaemia Society
Dr Mamta Sohal	Consultant Haematologist	Imperial College Healthcare NHS Trust
Deena Paul	Lead CNS, Non-malignant Haematology	Imperial College Healthcare NHS Trust
Halima Begum	Quality Manager for Clinical Haematology	Imperial College Healthcare NHS 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
Specialist Haemoglobinopathy Centre – Nottingham University Hospitals NHS Trust	42	34	81
Total	**42**	**34**	**81**

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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)	Y	Information on how to access immigration advice could be clearer in the information available for patients. In the information leaflets, it may be helpful for patients if additional sentences were included in other languages that explained how to access an interpreter and information in that language.
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	Y	

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).	Y	
HN-104	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on: i. Hydroxycarbamide and iron chelation therapy (if being prescribed by GPs) ii. Immunisations iii. Contraception and sexual health d. Indications and arrangements for seeking advice from the specialist service	Y	
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	

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)	N/A	
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	Young people were started on the 'Ready Steady Go' transition programme. At the time of the visit the lead nurse was the named coordinator for those young people transitioning to the adult service. A new Band 6 nurse had been appointed who would be taking the lead for transition. As part of the development of the service, reviewers suggested that planning for transition with young people would benefit from a more structured approach.
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	The support group had met for the first time shortly before the visit.

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.	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.	N	A lead nurse with responsibility and oversight of training for nursing staff within the acute Trust was not in place. The lead nurse was based mainly in the community, with one day allocated in the acute Trust for general nursing management but not management of the haemoglobinopathy service.

Ref	Standard	Met?	Comments
HN-203	**Medical Staffing and Competences** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including: **All services:** a. Haematology or paediatric medical staffing for clinics and regular reviews b. 24/7 consultant and junior staffing for emergency care **SHCs only:** c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours d. If doctors in training are part of achieving 'a' or 'b' then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	The service had insufficient consultant medical staff with appropriate competences in the care of adults with haemoglobin disorders to cover clinics and regular reviews in the absence of the lead clinician. Cover for the lead clinician was from other non-malignant haematology consultants based at QMC. 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	It was not clear who had responsibility and oversight for ensuring that staff on the wards to which people with haemoglobin disorders were usually admitted (Burns, Gillies, the SRU and other general wards) had appropriate competences to care for patients with haemoglobin disorders. Education days were held twice a year, but reviewers were told that staff were often unable to attend, and the training did not include a process for the assessment or ongoing monitoring of staff competence. As patients were admitted to a number of different wards, training and involvement of the practice development nurses in supporting the training of ward staff in haemoglobin disorders may be a helpful way forward. This QS was met for the CNS for the acute service and day unit staff.

Ref	Standard	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	There was insufficient psychology time for the number of people and families cared for by the service. At the time of the visit only 0.4 WTE psychology time was available for adults and children, young people and their families, and the psychologist did not have cover for absences. The Trust had plans to recruit an additional 0.4 WTE psychologist to support both services. The 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.	N	A training plan showing how staff developed and maintained appropriate competences for the care of adults with haemoglobin disorders was not in place. Some work had been undertaken to define the training need required. A range of training was provided for junior medical staff, and educational days for other staff were held twice a year.
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	
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.	Y	

Ref	Standard	Met?	Comments
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.	Y	The most recent audit showed that the percentage of people receiving analgesia within 30 mins of arrival to the SRU was 73%. The PDN from the SRU was keen to make progress with ongoing work in developing and delivering training and competencies for staff.
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	Outside normal working hours, only manual exchange transfusions were possible. These were usually performed by consultant medical staff or the SpR if they had completed the relevant training. Reviewers were also told that on occasions red cell exchanges could not be undertaken during normal working hours because staff with the relevant training were not available.

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	The lead consultant had liaised with all the relevant speciality services to identify a named lead contact.

Ref	Standard	Met?	Comments
HN-305	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
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	Trust guidelines were in use, as well as additional guidance for young people with haemoglobin disorders. The schematic pathway in the guidance presented the pathway very clearly.
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	Guidance was in place, and the clinic letters seen at the time of the visit were very detailed, with clear information and guidance for patients and staff.
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	This QS was not applicable to the SHT. However, discussions were ongoing around the arrangements for providing specialist support and advice to the LHT at UHDB.

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	However, the protocol for carrying out manual and automated exchange transfusions had been adopted from the Oxford University Hospitals NHS Foundation Trust protocol, and reviewers were unclear about the governance process for the adoption of other organisations' guidance for use within 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.	Y	

Ref	Standard	Met?	Comments
HN-506	**Clinical Guidelines: Acute Complications** Guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	
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.	N/A	

Ref	Standard	Met?	Comments
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	
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	However, in practice it was not always possible at weekends and on bank holidays for patients to be reviewed by a senior haematology decision maker. See serious concern in main report.

Ref	Standard	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	The team were also planning to implement team meetings to discuss and review patient care.
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	No written agreement with UHDB covering the delegation of annual reviews was in place. The lead clinician had commenced discussions with the LHT, but no agreement had been reached. This QS was not applicable to any other LHTs, as all annual reviews were undertaken by the specialist team.
HN-604	**Out of Hours Elective Care** Arrangements should be in place for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	
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	

Ref	Standard	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	
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	
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	
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	
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	Re-admission rates were not collected. All other aspects of the QS were met.

Ref	Standard	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	
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	
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	

Ref	Standard	Met?	Comments
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N	The team were in the process of exploring research opportunities.
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	
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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