Health Services for People with Haemoglobin Disorders

Imperial College Healthcare NHS Trust

Visit Date: 27th September 2019

Report Date: January 2020

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Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Imperial College Healthcare NHS Trust that took place on 27th September 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 reviewers did enquire about the local network and commissioning arrangements during the course of the review visit.

The aim of the standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Any immediate risk identified includes the Trust's proposed actions to mitigate the risk and QRS's response to those proposals. Appendix 1 lists the visiting team that reviewed the services at Imperial College Healthcare 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:

- Imperial College Healthcare NHS Trust
- NHS England Specialised Commissioning – Haemoglobinopathies
- NHS West London and Central London 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 Imperial College Healthcare NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are also grateful to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

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Review Visit Findings

Trust-wide

General Comments

This review looked at the care of adults with haemoglobin disorders. During the course of the visit, reviewers met with patients and carers, and with staff providing the services, and visited the triage unit, the day and apheresis unit, and wards.

At the time of the visit, Imperial College Healthcare NHS Trust was one of the largest acute Trusts in the country. The Trust comprised Charing Cross, Hammersmith, Queen Charlotte's and Chelsea, St Mary's, and Western Eye Hospitals. Clinical Haematology was part of the Division of Surgery, Cancer and Cardiovascular Sciences and was centralised on the Hammersmith Hospital site. The Trust was a provider of specialist services for haemoglobin disorders and had been formally recognised as a Specialist Haemoglobinopathy Team in April 2019 following the national compliance exercise conducted by NHS England (NHSE).

The red cell team delivered secondary and tertiary care to over 500 adults with haemoglobin and other inherited red cell disorders.

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
Imperial College Healthcare NHS Trust	SHT	355	65	96

Specialist Team (Adult Services): Imperial College Healthcare NHS Trust

General Comments and Achievements

This was an experienced service with strong leadership evident throughout. The team were extremely proud of what they had achieved since the last visit in 2015, and it was clear to the reviewers that they were highly committed and enthusiastic.

In addition to a comprehensive medical and nursing workforce, the red cell team included a designated clinical psychologist, a designated physiotherapist, a designated social worker and a quality team.

The team were well supported by the Trust executive team, and there were good working relationships with the community team, who considered that engagement and involvement with the team was very positive.

A monthly network-wide multidisciplinary team (MDT) meeting was held with representatives from the Trust and community teams; patients for whom urgent decisions needed to be made in between meetings were discussed at the weekly red cell haematology MDT.

Weekly 'red cell' clinics were held at both the Hammersmith Hospital and St Mary's Hospital (Paddington). A joint obstetric clinic was run with staff from Queen Charlotte's and Chelsea Hospital.

Clinics for young people transitioning to adult services were in place with staff from the paediatric service (based at St Mary's Hospital), and a CNS, with responsibility for transition, was able to provide additional support for young people when they attended the adult services based at Hammersmith Hospital.

The most recent audit on the management of acute pain for all areas (Renal and Haematology Triage Unit (RHTU) and in-patient wards) showed that 61% of patients received analgesia within 30 minutes of arrival.

At the time of the visit, 88% of patients were registered on the National Haemoglobinopathy Register (NHR).

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
Imperial College Healthcare NHS Trust	• West Middlesex University Hospital and Chelsea and Westminster Hospital (Chelsea and Westminster Hospital NHS Foundation Trust) • Hillingdon Hospital (The Hillingdon Hospitals NHS Foundation Trust)

Staffing for an SHT Adult Haemoglobinopathy Service [1]	Number of patients[2]	Actual WTE	Staffing required as recommended by NHSE
Consultant haematologist with >0.6 wte per 150 patients dedicated to work with patients with haemoglobinopathies	464	3.25	1.85
At least 0.25 wte allocated to haemoglobinopathy CPD in the consultant's job plan	464	1.25	-
Clinical psychologist for adult patients with >0.5 wte per 200 patients dedicated to work with patients with haemoglobinopathies[3]	464	1.0	1.16

Support groups available for patients and carers	Y/N
Sickle Cell Disease	Y
Thalassemia	Y

Emergency Care

Since the closure of the A&E department on the Hammersmith site in 2014, clinical pathways for the direct admission of patients under designated clinical specialties had been agreed. Patients requiring an emergency assessment were seen in the RHTU, a dedicated 24-hour facility for urgent assessment, where they were managed directly by their specialist team. Patients were reviewed by the admitting consultant on a daily basis, and at other times by the on-call haematology middle grade doctor for the RHTU. The expansion of ambulatory care for haematological disorders, with a nurse-led day care service for the management of uncomplicated acute painful crises in sickle cell disease, had also mitigated the impact of the A&E closure, had improved patient experience and had led to a reduction in in-patient admissions.

In-patient Care

In-patient services for haemoglobin disorders were predominately based on Fraser Gamble ward, which provided 29 beds including five single rooms.

Day Care

Day care and ambulatory care facilities were co-located adjacent to the out-patient clinic on the ground floor of the Catherine Lewis Centre, a dedicated facility for the care of haematology patients that had opened in 2002. These facilities consisted of several bays that included three beds for apheresis procedures, six beds for the care of patients who were acutely unwell, including those with acute pain crisis, and 14 reclining chairs (six for the administration of blood products).

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[1] *Recommended staffing: national NHS England compliance exercise for designations of SHTs 2019.*
[2] *Figure excludes other patients with inherited red cell disorders cared for by the team.*
[3] *The Quality Standards for psychology staffing (HN-205) references the recommendation from the British Psychology Society Special Interest Group for Psychologists working in Sickle Cell and Thalassaemia (2017) which suggests 1WTE for every 300 patients.*

The day care and ambulatory care facility was in operation 12 hours a day, seven days a week. A team of eight specialist operators (three permanent apheresis staff and five additional trained staff) provided a 24/7 apheresis service. At the time of the visit there were four available apheresis machines on the Hammersmith site. Equipment was transported to in-patient areas for patients unfit for transfer to the apheresis unit in day care. In 2018, 732 red automated erythrocytapheresis procedures were performed. Between January and July 2019, 477 procedures had been performed.

Community-based Care

Community haemoglobinopathy services were provided through a service level agreement (SLA) with Central London Community Healthcare NHS Trust whose specialist nurses attended the haemoglobinopathy clinic and MDT meetings on a regular basis.

Progress since last visit

The previous review had taken place in 2015, and since this time there had been significant progress and a number of improvements:-

- Improvements in the management of iron overload in haemoglobin disorders, with the appointment of a clinical nurse specialist to provide a nurse-led iron overload clinic.
- Development of a comprehensive pain management programme in sickle cell disease led by the health psychologist and physiotherapist.
- The continuing delivery by haemoglobin disorders staff of an expanding portfolio of clinical research.
- The expansion of the apheresis service to provide a 24 hour, seven day a week service.
- The reconfiguration of the clinical network arrangements in North West London and the Imperial Healthcare NHS Trust paediatric red cell disorders network to provide a unified network for haemoglobin disorders in North West London.
- The appointment of a specialist physiotherapist to join the team.
- The appointment of an additional consultant with a special interest in haemoglobin disorders, who was due to commence in post in the autumn of 2019.
- As part of the national programme for reconfiguration of haemoglobinopathy services, the submission by the Trust, in conjunction with other west London specialist haemoglobinopathy teams (SHTs), of a proposal to become a Haemoglobinopathy Coordinating Centre (HCC).

Views of Service Users and Carers

The visiting team met with seven patients and carers during the course of the visit. 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 walk-in/triage centre was ‘amazing’. Users would contact the unit to let them know that they needed to be assessed, and would show their patient passport to the ambulance service so they were taken directly to the unit. Pain relief was usually given within 15 minutes of arrival.
- Users reported that when they were admitted to the wards, their pain was managed well.
- All but one of the users had a patient passport.
- All those who met with the visiting team thought that the apheresis service was well-coordinated, and they held the staff in high regard. They liked the flexibility of appointments and the availability of a Saturday service. The patients were slightly concerned that the success of the Saturday service meant that access was becoming more limited as there was only capacity for four procedures on Saturdays.
- The users and carers considered that the psychology service was easy to access and met their needs. They were particularly appreciative that they ‘did not feel judged’ by members of the team when accessing support.
- One patient was using the ‘Patient knows best’ app, which enabled access to key medical records and results.

- Experiences around transition were mixed: some patients thought the process worked well, whereas others did not consider that they had sufficient support. Some patients had felt vulnerable following their transition to the adult service from other paediatric services, and had been 'unsettled' for some months.
- Patients with thalassaemia who spoke to the reviewing team considered that there were long waiting times for follow-up appointments with consultant medical staff, and said that they often had to contact the service to chase appointments.
- Some users who met with the visiting team expressed their concerns around the following:-
    - A perceived lack of communication between the MDT members: messages were not always communicated or documented. This meant that, for example, they got different opinions from different doctors, and care decisions felt like a 'lottery' and depended on who you saw.
    - The increased size of the team meant that they were sometimes unclear who to contact for queries and advice.
    - Patients commented that, being experts in their condition, they felt less confident when dealing with junior medical staff who they considered were not always as knowledgeable about their condition as other members of the team.
- Users and carers were asked about the new physiotherapy service for patients with sickle cell disease. None of those who met with the visiting team had been made aware that they could access the service; however, they did comment that better access to physiotherapy would be extremely helpful in managing their mobility and pain.

Good Practice

1. Reviewers were extremely impressed with the range of patient information that was available and highlighted the following patient information in particular:-

    a. The information on how to manage symptoms and the range of the treatments that may help, including complementary therapies. Reviewers commented that the advice covering how to manage fatigue was very helpful and well written.

    b. The iron chelation information pack for patients was excellent and the reviewers commented that it was the 'best information which they had seen'. The information covered all aspects from ordering and collecting medication through to drug administration.

    c. The patient management leaflet explained very clearly the different treatments available and the benefits of adherence to treatments. The section on the use of long-term opiates for pain control was very comprehensive, and covered advice for those driving (with a link to the Driver and Vehicle Licensing Agency for further information), general advice for patients in work, advice and information to give to employers and advice for those working with machinery.

    d. The patient information covering obstetric care was very well written and included possible complications before conception and during pregnancy.

2. Access to psychology support was very responsive. The team were able to respond within two days of the referral being received, and patients could be offered an appointment within a week.

3. The pathway in place to support patients with transfusional and non-transfusional iron overload was very good. A weekly nurse-led iron chelation clinic had been established to provide monitoring, education and support for patients and carers.

    A monthly apheresis MDT was also in operation which enabled patient review to ensure that targets for HbS were met, treatments were reviewed and any issues with vascular access resolved. The MDT included representation from a consultant haematologist, staff from both the adult and paediatric apheresis teams and the haemoglobinopathy and iron overload CNSs.

Audits had shown that the implementation of these initiatives had improved engagement with patients, had resulted in an increase in patients' compliance with iron chelation therapy and had ensured that timely investigations and monitoring took place.

4. A pain management programme (based on the St George's University Hospitals NHS Foundation Trust model), had commenced, with the aim of improving outcomes for patients with chronic or complex pain. Course and information materials had been developed by the clinical psychologist, and training was facilitated by the physiotherapist. The programme was delivered over eight weeks, with some individual sessions available for patients if required. Evaluation of the first programme (seven patients) demonstrated that patients had reported a measurably lower daily pain score, had less anxiety about pain, had improved mood and improved perceived health-related quality of life. A second eight week group course was planned for the late autumn of 2019.
5. The process for obtaining patient consent from patients to submit their data onto the NHR was very good, as the CNS who explained the process also signed the consent form.
6. The quality team were very well organised, and were clearly valued as members of the wider red cell multidisciplinary team. The quality team provided a wide range of support to the clinical team for data collection, audit and research, as well as providing a comprehensive administration service.
7. Reviewers were impressed with the strong commitment to research into red cell disorders. Since the last visit in 2015 the team had continued to expand their portfolio of prospective and observational research studies, with a good uptake in the number of patients who were willing to take part.
8. Away days for the non-malignant CNS were held regularly and included a range of invited speakers and refresher training on the care of people with haemoglobin disorders.
9. Patients who met with the visiting team were very impressed with the 'Patient knows best' app used by the Trust, which gave patients easy access to their investigation reports on their mobile devices.

Immediate Risks: None identified at the time of the visit

Concerns

1. **Annual Reviews**

   The full record of a patient's annual reviews was not accessible in the patient's electronic record. A summary was included in correspondence but, from the evidence seen at the time of the visit, this information did not include all the relevant detail. Reviewers were told that the annual reviews, once completed, were sent to the data manager, and the data were inputted into the NHR database. Reviewers were concerned that information from annual reviews was therefore not readily available to inform clinical decision-making in the clinic and ward environments if the healthcare professional was unable to access the NHR database.

2. **Renal and Haematology Triage Unit (RHTU)**

   From discussion with staff at the time of the visit, reviewers heard conflicting views as to the length of stay for patients admitted to the RHTU. Reviewers were told that when the RHTU had been commissioned, the length of stay for patients had been envisaged to be comparable with that for patients attending other emergency portals. However, reviewers were told that on occasions patients were cared for in the RHTU for over 24 hours before being admitted to an in-patient ward. Reviewers were concerned that in these circumstances patients' privacy and dignity was compromised. The unit provided mixed-sex accommodation with some side rooms, but the majority of patients were cared for in cubicles with no access to appropriate toilet and washing facilities or hot food. The management of pain would also be suboptimal for some patients, as there was no access to patient controlled analgesia (PCA) on the RHTU.

Further Consideration

1. Considering the views from patients about communication/information issues and inconsistency in advice from MDT members, it may be helpful to work with patient groups around their perceptions and expectations of the MDT and how best to meet their needs.
2. Reviewers were told of the plans to develop a nurse-led hydroxycarbamide clinic to run alongside the nurse-led iron chelation clinic. As part of the development of these clinics, input from the psychologist may be helpful, to address any psychological barriers to medication adherence.
3. Some of the innovative practice such as the 'Patient knows best' app and the haemoglobin disorder physiotherapy service had the potential to improve patient care greatly, but at the time of the visit it was not widely known about by patients. Developing a communication and marketing strategy may be helpful to cover how patients will be made aware of new services.
4. The pain management programme and new physiotherapy service were tailored for patients with sickle cell disease. Extending support to patients with thalassaemia should be considered, as patients with thalassaemia would also benefit from access to pain management programmes and physiotherapy.
5. Access to neuropsychology was only via the neurology service, and reviewers supported the team's plans over the next few years to develop the adult neuropsychology service.
6. With the level of experience and engagement with research, the team should consider expanding the research portfolio to other members of the MDT.

Commissioning

Reviewers were unable to meet with any regional or local commissioners. Reviewers were able to have a conversation with the NHSE & NHSI Specialised Commissioning Lead for Haemoglobinopathies, who did not have any concerns about the service.

The service had submitted a bid to become a Haemoglobinopathy Coordinating Centre (HCC) for sickle cell disease and thalassaemia for the West London region.

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APPENDIX 1 Membership of Visiting Team

Clinical Lead		
Dr Rachel Kesse-Adu	Consultant Haematology and Sickle Cell Disease	Guy's and St Thomas' NHS Foundation Trust

Visiting Team		
Helen De Marco	Senior Clinical & Health Psychologist in Red Cell Haematology	University College London Hospitals NHS Foundation Trust
Roanna Maharaj	Patient representative	
Susie McKeown-Wade	Clinical Nurse Specialist – Red Cell	Leeds Teaching Hospitals NHS Trust
Julie Nicholson	Quality Manager for Transplant Services	St George's University Hospitals NHS Foundation Trust
June Okochi	Patient representative	
Dr David Simcox	Consultant Haematologist Clinical Lead for Haemoglobin Disorders Speciality Lead – Clinical Haematology	Royal Liverpool and Broadgreen University Hospitals NHS Trust.

QRS Team		
Sarah Broomhead	Assistant Director	Quality Review Service

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APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

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

Service	Number of applicable QS	Number of QS met	% met
Specialist Haemoglobinopathy Centre – Imperial College Healthcare NHS Trust	42	42	100
Total	42	42	100

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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	
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	See also Good Practice section of the main report.

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	The care plans were very clear, and recorded medical history separately from surgical history.
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	
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	Reviewers considered that including the patient's experience of the management of the care on the patient experience form may be helpful.

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	The lead had an extensive job plan and a business case to increase support was in the process of being developed.
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	Cover for absences was available from the CNS team.
HN-203	**Medical Staffing and Competences** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including: **All services:** a. Haematology or paediatric medical staffing for clinics and regular reviews b. 24/7 consultant and junior staffing for emergency care **SHCs only:** c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours d. If doctors in training are part of achieving 'a' or 'b' then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y	

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.	Y	
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.	Y	'c' was accessible through the neurology service, but reviewers considered that this process would not be sustainable in the future as patient numbers increased.
HN-206	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.	Y	

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.	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	
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	
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	See main report in relation to filing of annual reviews.
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	
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 there were no shared care arrangements in place with local 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.	N/A	
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	
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/A	

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.	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.	Y	In the SLA, 'b' could be more explicit about arrangements and agreement. In practice, the process was working well.
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	

Ref	Standard	Met?	Comments
HN-702	**Activity Data** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y	
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	

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	
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	

Ref	Standard	Met?	Comments
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

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