Health services for people with haemoglobin disorders

London North West University Healthcare NHS Trust

Visit Date: 22nd January 2020

Report Date: May 2020

8831

Contents

Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in London North West University Healthcare NHS Trust that took place on 22nd January 2020. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V4, 2018 which were developed by the UK Forum on Haemoglobin Disorders working with the Quality Review Service (QRS). The peer review visit was organised by QRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

- Specialist Haemoglobinopathy Team (SHT)
- Local Haemoglobinopathy Teams (LHT) or linked providers

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

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

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

- London North West University Healthcare NHS Trust
- NHS England Specialised Commissioning – Haemoglobinopathies
- NHS Brent 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, NHS Brent Clinical Commissioning Group.

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 London North West University 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.

Return to Index

Review Visit Findings

Trust-wide

General comments

This review looked at the health services provided for children, young people and adults with haemoglobin disorders. During the course of the visit, reviewers met with patients, parents and carers, and with staff providing the services. They visited the adult day unit and the adult and paediatric out-patients services based at Central Middlesex Hospital (CMH), and the emergency department (ED), paediatric day unit, and adult and paediatric in-patient wards at Northwick Park Hospital (NPH).

In the years leading up to the review visit, there had been a significant infrastructural change within the Trust, with the closure of the CMH ED and acute wards and the subsequent relocation of these services to NPH. Both the adult and the paediatric teams had continued to meet the challenges of providing multi-site care: day care and out-patient care were provided at CMH and Ealing Hospital and emergency and in-patient care on the NPH site. The Brent Sickle Cell and Thalassaemia Centre, based at CMH, had celebrated its 40th anniversary as a community centre for sickle cell disease and thalassaemia patients in 2019.

In April 2019, following the national procurement exercise conducted by NHS England (NHSE), the Trust had been formally designated to provide Specialist Haemoglobinopathy Team (SHT) functions for both adults and children, and both teams were working towards meeting the requirements to provide this level of specialist service.

At the time of the visit, London North West University Healthcare NHS Trust (LNWUHT) was part of the North West London Network, which also included Imperial College Healthcare NHS Trust. Both Trusts were Specialist Haemoglobinopathy Teams.

In October 2019, following the national procurement exercise conducted by NHS England (NHSE), the Trust, in partnership with Imperial College Healthcare NHS Trust and St George's University Hospitals NHS Foundation Trust, had been formally designated as a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell Disease, and, with University College London Hospitals NHS Foundation Trust, Imperial College Healthcare NHS Trust, and St George's University Hospitals NHS Foundation Trust, a Haemoglobinopathy Coordinating Centre (HCC) for Thalassaemia.

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
London North West University Healthcare NHS Trust (Central Middlesex Hospital, Ealing Hospital and Northwick Park Hospital)	SHT	340	29	27

CHILDREN AND YOUNG PEOPLE

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long-term red cell transfusions
London North West University Healthcare NHS Trust (Central Middlesex Hospital, Ealing Hospital and Northwick Park Hospital)	SHT	157	18	19

Support Groups	
Sickle Cell Disease – Adults	Y
Thalassaemia – Adults	Y
Sickle Cell Disease – Children and families	Y
Thalassaemia – Children and families	Y

Some issues in this report relate specifically to the Trust as a whole and have been included in the Trust-wide section of the report. Other issues that are the same for both the adult service and the children and young people service have been repeated in each section.

Trust-wide Concern

1. **Users' and carers' views**

   Reviewers were concerned at the level of disquiet and concern expressed by the services users and carers about their experiences of emergency and in-patient care at the Trust (see the section on 'Views of service users and carers' on pages 8-10), which contrasted strongly with what reviewers heard in their discussions with staff during the visit. Reviewers considered that, in the light of the seriousness of some of the comments, it would be important for the Trust to engage with the service users and carers to address their immediate concerns, and also to work with them to understand more about their perceptions and expectations of the Trust services, and how the Trust could best meet their needs.

Trust-wide Further Consideration

1. At the time of the visit, the haemoglobinopathy service was provided across three sites. Reviewers acknowledged that this reflected the local restructuring of services, including the merger of three Trusts and the closure of the ED in CMH and the paediatric ED in Ealing Hospital. Whilst provision of out-patient services at CMH and Ealing ensured that high quality senior-led out-patient care was being provided at a local level, reviewers were concerned that this resulted in patients attending multiple sites for different aspects of their care. Further fragmentation of care for children with sickle cell disease was predicted in the near future when the Trans-Cranial Doppler (TCD) service moves to NPH. Reviewers identified that some rationalisation of services might be possible to reduce the impact on patients of travelling, for example. However, reviewers also acknowledged that any structural reforms to the service should only be carried out following consultation with users. From discussions with staff it was not clear if there was a long -term strategy for the future development of the SHTs to ensure that there was enough capacity to provide comprehensive specialist haemoglobin disorder services for adults, children, young people and their families.

Views of Service Users and Carers

During the course of the visit the visiting team met with 16 service users and carers with sickle cell disease and three thalassaemia users and carers representing the adult and children services. The views of the users were extensive and wide-ranging. The review team would like to thank them for their openness and willingness to share their experiences.

- Overall, the users and carers were particularly appreciative about the support for adults, children and young people from the specialist haemoglobinopathy teams (consultants, the psychologist, acute and community-based haemoglobinopathy CNSs and haemoglobinopathy day unit staff).
- Patients and parents unanimously agreed that the care they received on the haematology day units was very good. They commented about the confidence they had in the day unit staff, and praised the support from the day unit manager.
- Parents commented that support was always available if they raised issues relating to their child's education or school care plan, and said that the community nursing team were very supportive.
- The arrangements in place to attend either the adult or the paediatric day unit at CMH for a clinical assessment and treatment if a patient was unwell were working well, and those who had attended for assessment commented that their attendance had avoided the need for them to visit the ED at NPH.
- There was agreement from service users that, once members of the SHT had become involved in their care, they felt well supported, but they recognised that before this time they did not understand enough about what services were available and how to access them.
- The local support group was active, supportive and keen to drive change. In the past they had written to the Chief Medical Officer for NHS England about their concerns about the level of services available locally.
- Patients with thalassaemia were happy with the care they received as out-patients and on the day care units for adults and children.
- Patients with thalassaemia raised concerns about the monitoring processes in place for regular endocrinology reviews, and had concerns about the long-term effects of their disease on their bone health. They also commented that they were not routinely given all the options available for chelation therapy, including information about the long-term side effects.
- A few of the young people who met with the reviewing team, who were between the ages of 13 to 16 years, had commenced on the transition pathway.
- A number of very discerning comments were made by service users about the emergency care pathway. Most who attended the meeting had no confidence in the staff in the ED at NPH, commenting that: -
    - Staff had limited knowledge of haemoglobin disorders, so that even when patients informed the reception, there was no clear priority pathway for them.
    - Patients were waiting very long times to be seen and then receive analgesia. The fastest time anyone in the meeting had received analgesia was 1.5 hours for adults and two hours for children; the consensus was that it was usually about six hours before analgesia was administered.
    - Accommodation in the ED was poor and usually overcrowded and chaotic. Service users said they would often spend a long time sitting on plastic chairs, with one patient reporting that they had sat for over 24 hours before a trolley / bed had been available.
    - None of the service users who met with the visiting team had an agreed plan for their management in the ED.
    - Service users considered that, in general, attending the ED at NPH was a traumatic experience, with language such as 'atrocious' and 'disgraceful' being used to describe their experiences.
- When asked about 'chest crisis', the service users were not aware of what a spirometer was or the benefits of using incentive spirometry to help improve lung function and reduce the complications associated with acute chest syndrome.

- Service users' experiences of the care they received when an in-patient, on both the adult and the paediatric wards, were also mixed. Patients considered that some staff, including nurses, doctors and, especially, junior doctors, had very limited knowledge of haemoglobin disorders, and several comments were made by those who met with the reviewers about the lack of care and compassion. For many services users, being an in-patient at NPH had not been a pleasant experience.
  - Comments specifically about the adult wards included: -
    - Some of the nurses on Carroll Ward were 'great' and had a good understanding and knowledge of haemoglobin disorders, but others were not so competent or caring, and it was just 'luck' whether someone knowledgeable and caring was on duty.
    - When the service users had been in-patients, they had felt unsupported and isolated, which had led to the development of a women's group. Those who met with the reviewing team commented that this group had been useful for moral support when the users had been in-patients or had been contacted to provide support to others.
  - Comments specifically about the paediatric wards included: -
    - Junior medical staff often attempted multiple cannulations on their child.
    - There was a lack of understanding of haemoglobinopathies, with one nurse asking, 'how long has your child had sickle cell disease?' and then commenting that 'hopefully they will grow out of it'.
- Extending the time that the community CNS was at CMH to the occasional afternoon would be helpful for those who attended afternoon sessions.
- Access to benefits and other social care support was limited. Many who met with the visiting team were not aware of any entitlement to benefits or of how to access a social worker. Few were aware of the service 'fact sheet' covering benefits advice and how to access social support locally.
- Those who were aware of the benefits and entitlements they could access were struggling with the claims process, and were extremely appreciative of the support from the psychologist and others to help them, especially when benefit claims had been rejected.
- When asked, some service users who met with the visiting team were not clear who to contact in an emergency or about the vaccinations they should have. Some also commented that they had not had any vaccinations and were not aware of any specific information and preparations they needed to undertake before travelling.
- Several comments were received about not knowing what services were available. Those who met with the reviewing team commented that the processes for communication to services users about services and key information could be improved.
- Some service users were still upset about the closure in 2014 of the CMH ED.
- The service users and families who met with the visiting team felt disheartened about the lack of response from the Trust and the failure of the Trust to register the significance of their complaints. Others commented that they felt that when they had raised concerns about treatment it had then affected the way they were treated by staff.
- The service users and carers requested that the peer review visit report be shared with them, and were keen to work with the Trust to improve the services available.

Return to Index

Specialist Team (Adult Services): London North West University Healthcare NHS Trust

General Comments and Achievements

This was an enthusiastic and well-established team providing acute and community care for the local population of the boroughs of Brent, Harrow and Ealing. A second consultant haematologist with time allocated for the care of people with haemoglobin disorders had joined the Trust.

The SHT had good links with the paediatric SHT in providing support for young people transitioning into adult care, and the CNS team had plans to develop nurse-led clinics in the future. Other plans included increasing the patient involvement mechanisms and more involvement in investigator-initiated research.

Average length of stay for patients admitted to the wards had remained stable at approximately four days for the last four years.

Specialist Haemoglobinopathy Team	Local Haemoglobinopathy Teams
London North West University Healthcare NHS Trust	None

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.	369	0.7 Provided by two consultant haematologists	1.48
At least 0.25 WTE allocated to haemoglobinopathies CPD in the adult consultant job plan.	369	-	-
Clinical psychologist for adult patients with >0.5 WTE per 200 patients dedicated to work with patients with haemoglobinopathies.	554 (total number of adults and children)	1 Covering both the paediatric and adult services	0.9 for adults 0.6 for children

Emergency Care

Adults requiring emergency care were seen at the ED at NPH. Following feedback from service users, a new emergency care pathway had been introduced in December 2019, to reduce the time patients waited for analgesia and emergency assessment when attending the ED at NPH.

The haematology team were primarily responsible for patient care and were supported by other general medical teams. The on-call haematology specialist registrar, who was resident until 6pm each day, was called to assess and admit patients if necessary. After 6pm, the on-call medical team would assess patients and discuss with the on-call haematology registrar who would review the patient if clinically indicated.

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

Adult patients with uncomplicated pain episodes were also treated in the medical day care unit at CMH. Patients who then required further management would be transferred to NPH for admission via the ED.

Adult patients who presented to the ED at Ealing Hospital (EH) with severe pain would receive analgesia prior to being transferred to the NPH ED.

In-patient Care

Adults requiring admission were admitted to an acute medical ward (Carroll Ward) at NPH, which had 22 beds, with four of them being dedicated to patients with haemoglobinopathies. Patients were reviewed daily by the haematology SHO and/or red cell consultant haematologist and the adult CNS, and three times a week by the psychologist. The Wednesday afternoon ward round included attendance by the community CNS. Patients were notified to the community CNS, who would ensure appropriate follow-up in the community following discharge. Medical support out of hours was provided by the haematology specialist registrar, who was resident until 6pm. Out of hours, specialist support was provided by the red cell haematology consultants who worked a 1:4 on-call rota.

Day Care

Day care for adult patients was provided on the medical day unit at CMH. Patients attended for blood transfusions including apheresis and management of uncomplicated sickle cell pain. Patients who spoke to the reviewing team were appreciative of this service, although the data showed that relatively low numbers of patients (an average of six patients a month) were accessing the acute management service provided by the day unit staff.

Community-based Care

The Brent Sickle Cell and Thalassaemia Centre based at CMH was part of the LNWUHT haematology department and managed the regional newborn screening programme, pre-conception antenatal screening, and community support services including genetic testing and counselling, health monitoring, health promotion for individuals including parental and patient education, and community support for patients and their families.

Progress since the Last Visit -2015

- An elective and 24-hour emergency automated red cell exchange transfusion service was available at the Trust, provided through a service level agreement with NHS Blood and Transplant.
- The Trust had recruited a second consultant haematologist with time allocated for the care of people with haemoglobin disorders.
- A transition pathway with the orthopaedic service had been implemented to improve the care for adult patients requiring orthopaedic surgery.
- Ferriscans were now undertaken at the Trust.
- As part of a Commissioning for Quality and Innovation (CQUIN) project, funding had been received to enable the recruitment of a data manager.

Views of Service Users and Carers

The visiting team met with a group of adults with sickle cell disease and thalassaemia during the visit. See their feedback about the services provided by the Trust on pages 8 to 10.

Good Practice

1. Reviewers were impressed with the outreach work delivered by both the SHT and the community team to raise awareness and provide information about haemoglobin disorders across the community, especially the work with the local councils and churches.
2. The acute management pathway for patients attending the day unit at CMH was very well organised. A clear process was in place covering the criteria for managing telephone advice, accepting patients for assessment by the medical staff on the day unit, and transferring patients to NPH if necessary. The time patients waited for analgesia was short, with most patients receiving appropriate analgesia within ten minutes of arrival.
3. Considerable work had taken place to improve the emergency care pathway at NPH. Arrangements had been made for patients to show their NHR card at the ED reception so that they could be fast tracked for assessment and analgesia if required. An audit of the first month of the implementation of the pathway had shown that, for those patients who were fast tracked, there had been some improvement in the length of time they had waited for analgesia.
4. The team had started sharing patient stories with ED staff as part of the ED team's review and learning sessions.
5. The antenatal fail-safe process was very robust. If women did not attend their appointments, the community midwife was notified and would then liaise with and see the patient as necessary.
6. A good pathway for those patients with haemoglobin disorders who required orthopaedic surgery had been implemented in June 2019. A joint protocol had been agreed between the orthopaedic service and the SHT which covered responsibilities and shared care arrangements for patients before and after their orthopaedic surgery.

Immediate Risks: None were identified during the visit.

Concerns

1. **Care in the Emergency Department at NPH**

   Reviewers were concerned about the care provided for patients attending the ED for the following reasons:

   a. Patients reported long delays in being seen by reception staff on arrival and then further delays while waiting for an initial assessment of their condition.

   b. Reviewers heard feedback from several service users about the poor attitudes of staff when the service users attended the ED. Patients also raised concerns at the lack of knowledge of haemoglobin disorders among staff throughout the ED and about the need for patients to receive timely analgesia.

   c. Eight months of data from April to November 2019, prior to the new pathway being introduced, showed that the number of patients who received analgesia within 30 minutes of arrival at the ED was significantly low, and ranged from between 4 and 17% each month.

   d. Patients who met with the visiting team who had attended the ED since the new pathway had been implemented (December 2019) commented that either staff had not been aware of the new fast track process (so the patients had still had to queue in reception and for triage), or they themselves had not been told that they could present their NHR card to be fast tracked for an urgent assessment.

e. The environment and capacity within the ED meant that patients, even when very unwell, spent long periods of time sitting in waiting areas.

Reviewers considered that prompt action will be required to address staff attitudes and behaviour and that there needed to be a plan to deliver a programme of training for ED staff covering the new emergency care fast track pathway and care for patients with haemoglobin disorders.

2. **Consultant staffing**

Reviewers were concerned that the service had insufficient consultant medical staff with time available for the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care and clinics. At the time of the visit the SHT had two consultants, with a total 0.7 WTE allocated for the care of 369 patients with haemoglobin disorders. Cover for the SHT consultants was from other adult consultant haematologists who may not always have up to date competences in caring for people with haemoglobin disorders.

3. **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. A competence framework was in place, but patients who met with the reviewing team lacked confidence in some staff because of their attitude towards them when an in-patient and their knowledge about their condition. Reviewers were concerned that unless staff training addressed these issues with a more robust process for the assessment and ongoing monitoring of staff competences and attitudes, the patients' experience and the care they received was unlikely to improve.

4. **Access to psychology**

One full-time psychologist 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 554 adults, children and young people) being cared for by the service. The psychologist also undertook all neuropsychology assessments, was the lead for transition across both services and had no cover for absences. The provision in place did not meet the national workforce recommendations of 1 WTE clinical psychologist for every 300 patients.

5. **Patients who may be lost to follow up and routine monitoring**

Reviewers were concerned that there may be adults from the Bedford catchment area who, at the time of the visit, were not accessing follow-up care and routine monitoring. The LNWUHT service did not provide an SHT function for any adult patients residing in the Bedford area, despite a number of children and young people from Bedford who were linked to the paediatric SHT at the Trust. The reasons for patients not transitioning to the adult service at LNWUHT were not clear, and neither was it clear where the local adult population residing in Bedford with haemoglobinopathy disorders were cared for.

6. **Manual Exchange Protocols**

Two different network protocols for carrying out manual and automated exchange transfusions had been adopted, but they included different criteria. Whilst both protocols were clinically appropriate, reviewers were concerned that having two protocols had the potential to cause confusion for staff, and that the SHT should work towards adopting one protocol.

Further Consideration

1. Patients did not have access to a social worker for advice on benefits and social care. Staff were spending considerable time providing social care advice and support, and this was having an impact on the time they had available for clinical work. A fact sheet had been developed for patients, although some of the

patients and families who met with the reviewing team commented that they were not aware of the services available in their local areas.

2. Out of hours provision for routine transfusions or phlebotomy was not available. Patients who met with the reviewing team considered that access to out of hours elective care would be helpful and would reduce the length of time they needed to take away from their working day.

3. Some of the information for patients with haemoglobin disorders filed and available on the trolleys in the unit at CMH included information that was not up to date, with dates between 2008 and 2005. Reviewers considered that it might be helpful for the service to work with the local user support groups to review the information available and check that it is appropriate to their current needs. For patients with thalassaemia, the information seen at the time of the visit was limited. Reviewers were told that the website for patients and families, which had included an information section, was no longer in operation. Funding had been agreed to develop a new website, although the website was unlikely to be operational for some time.

4. Reviewers acknowledged the rationale for the SHTs to develop patient group directions (PGDs) for immunisations, because of the poor level of patients' compliance with vaccinations in primary care, but considered that the teams should continue to work in collaboration with the primary health care teams to ensure that patients receive timely immunisations to reduce the risk of severe infections.

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

6. A data manager had been recruited as part of a CQUIN initiative, but reviewers were told that funding for data management support had not been secured after April 2020. The lack of data management support to the SHT would have an impact on clinical staff, who would then be spending time on data administration.

Return to Index

Specialist Team (Children and Young People Services): London North West University Healthcare NHS Trust

General Comments and Achievements

This was a hardworking and clearly enthusiastic team who worked well together. The team had shown themselves to be resilient in their continued work to develop the service and overcome the challenges of providing care with limited resources, across three hospital sites, as well as to the local team at Bedford Hospital NHS Trust (BH).

The SHT cared for the majority of children resident in the borough of Brent and Harrow who attended out-patient clinics at CMH. Some children from Hillingdon, Hounslow, Barnet and other boroughs were also cared for by the SHT. Children living in the borough of Ealing were seen at Ealing Hospital (EH) out-patient clinic, and arrangements were in place for children and young people on transfusion programmes to have their transfusions in the paediatric day unit or at Ealing Hospital.

The average length of stay for children and young people admitted to the wards had remained stable at approximately four days for the last four years.

The SHT had good links with the adult SHT in providing support for young people transitioning into adult care, and the CNS team had plans to develop nurse-led clinics in the future and to develop PGDs to administer simple analgesia. Other plans to develop the SHT included additional consultant paediatric time allocated for work with haemoglobinopathies, the provision of an elective paediatric automated exchange service and more involvement in investigator-initiated research.

Specialist Haemoglobinopathy Team	Local Haemoglobinopathy Teams
London North West University Healthcare NHS Trust	Bedford Hospital NHS Trust Luton & Dunstable University Hospital NHS Foundation Trust (newborn screening only)

Staffing

Staffing for the Paediatric Specialist Haemoglobinopathy Service (SHT) [2]	Number of patients	Actual WTE (at time of visit)	NHSE recommended staffing WTE
Consultant haematologist / paediatrician with >0.6 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	175	0.45	0.74
At least 0.25 WTE allocated to haemoglobinopathies CPD in the paediatric consultant job	175	-	-
Clinical psychologist for paediatric patients with >0.5 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	554 (total number of adults and children)	1 *Covering both the paediatric and adult services*	0.9 for adults 0.6 for children

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

Emergency Care

Children and young people requiring emergency assessment were seen in the dedicated paediatric ED at NPH. Following initial triage, children were then seen by the paediatric team in the ED. A paediatric emergency medicine consultant was available until 10pm each day. The attending paediatric team were primarily responsible for patient care, but the attending haematology consultant was available for advice and would review patients as required.

Children and young people residing in the Bedford area were asked to attend their local ED. The SHT at LNWUHT was available for advice during working hours. Out of hours, any queries were directed via the NPH switchboard to the on-call haematology registrar / haematology consultant.

In-patient Care

Children requiring admission were admitted to the children's ward (Jack's Place) at NPH, which was a 27-bedded unit. Consultant paediatrician review was provided daily by the attending paediatric team, who were primarily responsible for patient care, with support from the attending adult consultant haematologist, paediatric CNS and psychologist. In addition, the lead paediatric consultant and lead haematologist were available for advice and would review the patients as required. Out of hours specialist support was provided by the red cell haematology consultants, who worked a 1:4 on call rota.

A play specialist was available from Monday to Friday between 9am and 5pm.

For children and young people admitted to BH, arrangements were in place to access clinical support and advice from the specialist team at LNWUHT.

Day Care

Paediatric day care services for children on long-term transfusions were provided at NPH and EH. A play specialist was available from Monday to Friday between 9am and 5pm as required. Daily paediatric medical cover was in place, with access to specialist haemoglobinopathy advice and review as required.

Out-patient Care

Paediatric out-patient clinics were held weekly on the Rainbow Children's Unit at CMH, and monthly at EH. Both paediatric clinics were attended by the multi-disciplinary team, which comprised a consultant paediatrician, a clinical psychologist, a consultant haematologist, a clinical nurse specialist and a community specialist nurse.

In addition, paediatric outreach clinics were held every six months (April and October) at BH, which enabled the majority of children and young people to attend locally for their annual review. The outreach clinics were attended by the multi-disciplinary team, which comprised a consultant paediatrician, a clinical psychologist, a consultant haematologist, a clinical nurse specialist and a community specialist nurse. Young people transitioning to adult care were seen at the SHT out-patient clinics based at CMH.

Community-based Care

The Brent Sickle Cell and Thalassaemia Centre based at CMH was part of the LNWUHT haematology department, and managed the regional newborn screening programme (including for Luton and Bedford), community support services including genetic testing and counselling, health monitoring, health promotion for individuals including parental and patient education, and community support for patients and their families.

Progress since Last Visit

- The Trust had recruited an additional haemoglobinopathy clinical nurse specialist (1 WTE) for the acute paediatric service.
- Ferriscans were now undertaken at the Trust.
- As part of a CQUIN project, funding had been received to enable the recruitment of a network data manager.
- The team had developed an educational software programme (SickleBuddy App) for use by children and young people.
- The SHT had achieved 100% for the four targets of the National Sickle Cell Newborn Screening Programme Standards.

Views of Service Users and Carers

The visiting team met with a group of children and young people with sickle cell disease and thalassaemia and with their families during the visit. See their feedback about the services provided by the Trust on pages 8 to 10.

Good Practice

1. Reviewers were impressed with the outreach work delivered by both the SHT and the community team to raise awareness and provide information about haemoglobin disorders across the community, especially their work with the local councils and churches.
2. A good fail-safe process was in place for affected newborn babies to ensure that these babies commenced on prophylactic antibiotics as soon as possible. If babies were not brought for their clinic appointments, the community team were notified and would then liaise with the family.
3. A good discharge process from the ward was in place: the community team was notified, and would then make contact with the family to check on their progress and provide additional support.
4. The transition leaflet was very thorough in explaining the importance of transition. The leaflet covered each stage of the transition pathway and the different support young people may require in helping them prepare, and stressed the need for ongoing care once they reached 18 years of age.
5. Reviewers were impressed with the level of support the SHT provided for patients residing in the Bedford area and for the local team based at BH. Telephone conference calls were held on alternate months with the local team to discuss any patients, and eight outreach clinics were held, two of which were attended by the NPH consultant haematologists and consultant paediatrician.
6. The psychologist, with input from children and young people, had developed an educational software programme (SickleBuddy App) for use by children and young people to tell them more about their condition. The 'App', once piloted, had been made available on social media platforms nationally.

Immediate Risks: None were identified during the visit.

Concerns

1. **Consultant staffing**

   Reviewers were concerned that the service had insufficient paediatric consultant medical staff time available for the care of people with haemoglobin disorders in order to carry out regular reviews (annual reviews, and hydroxycarbamide and routine monitoring), provide support for paediatric day units and clinics across two sites and provide SHT support for 21 children and young people under the care of the local team at BH.

At the time of the visit, the lead paediatric consultant had only 0.45 WTE time allocated for work with the haemoglobinopathy service. Some cross cover was available from the clinician from the adult service, and patients who required admission were cared for by the general paediatric consultant rostered to attend the ward.

2. **Care in the Emergency Department at NPH**

Reviewers were concerned about the care provided for children and young people attending the ED, for the following reasons:

a. Patients reported long delays in being seen by reception staff on arrival, and then further delays waiting for an initial assessment of their condition.

b. Reviewers heard feedback from several service users about the poor attitudes of staff when the service users attended the ED.

c. Patients raised concerns at the lack of knowledge among ED staff about haemoglobin disorders and about the need for patients to receive timely analgesia.

d. Eight months of data from April to November 2019 showed that the number of patients who received analgesia within 30 minutes of arrival at the ED was low, ranging from 29% to 57% for the first five months and dropping considerably after that, with no patients receiving analgesia within 30 minutes of arrival for September and October and only 1% in November. The reasons for the change in compliance were not clear.

Reviewers considered that prompt action will be required to address staff attitudes and behaviour, and that there needed to be a plan to deliver a programme of training for ED staff to ensure that children and young people are seen quickly and appropriate analgesia given.

3. **Access to psychology**

One full-time psychologist 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 554 adults, children and young people) being cared for by the service. The psychologist also undertook all neuropsychology assessments, was the lead for transition across both services and had no cover for absences. The provision in place did not meet the national workforce recommendations of 1 WTE clinical psychologist for every 300 patients.

4. **Ward care**

Reviewers were concerned that staff on the paediatric wards to which children and young people with haemoglobin disorders were usually admitted did not have appropriate competences to care for patients with haemoglobin disorders. A competence framework was in place, but patients who met with the reviewing team expressed concerns about some staff because of their attitude towards them when they were in-patients, and their lack of knowledge about the condition. Reviewers were concerned that, unless staff training addressed these issues and a more robust process was implemented for assessing and carrying out ongoing monitoring of staff competences and attitudes, the patients' experience and care they received was unlikely to improve.

5. **Out of hours pathway for patients residing in the Bedford area**

Reviewers were concerned about the complicated pathway for children and young people residing in the Bedford area out of hours, and considered that this required a quick resolution across the new HCC. Reviewers were told that out of normal working hours the team at Bedford would contact the NPH for advice on admission. The NPH team would then speak to the team based at St Mary's Hospital, Paddington (Imperial College Healthcare NHS Trust) to discuss where it was best for the child to be admitted. The team at NPH would then contact the team at Bedford with the decision. Reviewers were

concerned that, for some children and young people, the pathway created unnecessary delays, particularly for those with a suspicion of a stroke (who would also require out of hour access to specialist imaging) who would always require admission to St Mary's Hospital in Paddington for out of hours care.

Further Consideration

1. Patients and families did not have access to a social worker for advice on benefits and social care. Staff were spending considerable time providing social care advice and support, which was having an impact on the time they had available for clinical work. A fact sheet had been developed for patients, but some of the patients and families who met with the reviewing team commented that they were not aware of the services available in their local area.
2. In the light of the comments received from patients and families, further work should be undertaken to ensure that the policy for the number of cannulation attempts that should be made, and for the care of patients with compromised venous access, is fully understood by all staff and implemented. If staff need to deviate from the cannulation policy, this should be clearly communicated to the child and their family.
3. Out of hours provision for routine transfusions or phlebotomy was not yet available. Patients and families who met with the reviewing team would value access to transfusions and phlebotomy outside school hours.
4. Reviewers were told of plans to implement an imaging TCD service at NPH by the vascular team who ran the Trust vascular laboratory and would have capacity to undertake a TCD service once training of clinical scientists had been completed. The TCD service would be provided at NPH, whereas the paediatric out-patient service was at CMH. Although there would be more access to advice from the day unit staff based at NPH, the number of times that children, young people and their families would need to attend the Trust for their various assessments and out-patient reviews would increase.
5. A service level agreement with BH to formalise the shared care arrangements and level of advice provided by the SHT was in the process of being renewed. Renewing contractual arrangements would ensure that there was ongoing Trust oversight, and the service would have support to ensure that the service provision was correctly governed and managed.
6. Some audits expected by the Quality Standards had not yet been undertaken (QS HN-705), and evidence of any resulting audit action plans was limited. Reviewers considered it would be important to develop an audit programme to ensure that audits were completed and there was a clear process for reviewing the practice implementation of any resulting action plans.
7. A data manager had been recruited as part of a CQUIN initiative, but reviewers were told that funding for data management support had not been secured after April 2020. The lack of data management support to the SHT would have an impact of clinical staff, as they would then be spending time on data administration.

Return to Index

Commissioning

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

Further consideration

1. Formal contract management of community services was not in place. After discussions with local commissioners, reviewers supported the plans of local commissioners to define key performance indicators which would enable the development of community services and ensure that the service provision was correctly governed and managed.

Return to Index

APPENDIX 1 Membership of Visiting Team

Clinical Leads		
Dr Rachel Kesse-Adu	Consultant (Haematology and Sickle Cell Disease)	Guy's and St Thomas' NHS Foundation Trust
Dr Subarna Chakravorty	Consultant Paediatric Haematologist	King's College Hospital NHS Foundation Trust

Visiting Team		
Waheeda Abbas	Haemoglobinopathy Specialist Midwife / Counsellor	Manchester University NHS Foundation Trust
Dr Magbor Akanni	Haematology Consultant	Milton Keynes University Hospital NHS Foundation Trust
Verna Davis	Service Manager	Manchester University NHS Foundation Trust
Roanna Maharaj	Patient Representative	UK Thalassaemia Society
Debbie Omodele	Children's Haemoglobinopathy Nurse Specialist	Barking, Havering and Redbridge University Hospitals NHS Trust
Dede-Kossi Osakonor	Highly Specialist Psychologist	Homerton University Hospital NHS Foundation Trust
Giselle Padmore-Payne	Senior Clinical Nurse Specialist for Haemoglobinopathies	King's College Hospital NHS Foundation Trust
Dr Farrukh Shah	Consultant Haematologist	Whittington Health NHS Trust
Siobhan Westfield	Patient Representative	
Vanessa Wills	Patient Representative	

QRS Team		
Sarah Broomhead	Assistant Director	Quality Review Service

Return to Index

APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

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

Service	Number of applicable QS	Number of QS met	% met
Adults (SHT)	42	34	81
Children and Young People (SHT)	50	41	82
Total	**92**	**75**	**82**

Return to Index

Specialist Services for People with Haemoglobin Disorders

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-101	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint vi. Get involved in improving services (QS HN-199)	Y	However, some of the patients who met with the reviewers at the time of the visit were not aware of all the information that was available to them.	Y	However, some of the patients and families who met with the reviewers at the time of the visit were not aware of all the information that was available to them.

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-102	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition (SC or T), how it might affect them and treatment available b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	Some information was available in the Centre for those with sickle cell disease, but there was limited information covering thalassaemia. Service users commented that they had not seen any information. Reviewers were also told that the website was no longer accessible, but a new website was in the process of being developed. Once this work was completed it would provide an additional information resource for patients.	N	The information for children, young people and families with thalassaemia was limited and appeared to be only from a pharmaceutical company (Novartis) about exchange transfusions. Some written information was available covering sickle cell disease. Reviewers were told that the website was no longer accessible, but a new website was in the process of being developed. Once this work was completed it would provide an additional information resource for patients and families.

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	N	A local decision had been made that patients would not routinely have individualised plans for their management in the ED (a ii). Some patients with complex needs did have individualised care plans and these were flagged on the Trust information systems. For other patients, a generic care plan for analgesia was in use.	N	A local decision had been made that patients would not routinely have individualised plans for their management in the ED (a ii). Some patients with complex needs did have individualised care plans and these were flagged on the Trust information systems. For other patients, a generic care plan for analgesia was in use.
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		Y	

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-105	**Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	N/A		Y	
HN-106	**School Care Plan (Children's Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school e. Specific health or education need (if any)	N/A		Y	
HN-194	**Environment** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	However, see comments from patients in the main report about the environment in the ED.	Y	Following feedback from families the pathway for patients aged over 16 years had been revised. Young people aged 16 - 18 years of age could be seen in either the paediatric or the adult ED and, if necessary, admitted to an adult ward.

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services b. A named coordinator for the transfer of care c. A preparation period prior to transfer d. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards	Y	The psychologist was the lead for transition.	Y	The psychologist was the lead for transition. However, not all the young people who met with the reviewing team and who were of an appropriate age had commenced on the transition pathway.
HN-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	Y		Y	
HN-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have an appropriate number of session/s identified for this role within their job plan and cover for absences should be available.	Y	The lead clinician had 3 PAs allocated for leading the service and clinical work across two sites (Northwick Park Hospital and Ealing Hospital). Cover for absences was provided by the recently appointed haematologist who had 0.3PA time allocated for the care of people with haemoglobin disorders.	N	The lead clinician was covering three hospital sites as well as performing outreach work at Bedford Hospital. Cover for the lead clinician was from the adult consultant haematologist.

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y		Y	
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. The team had 0.7 WTE for the care of 369 patients. The NHSE recommended ratio is 0.6 WTE / 150 patients.	N	The service had insufficient consultant medical staff with appropriate competences in the care of children and young people with haemoglobin disorders to cover clinics and regular reviews.

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-204	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y		Y	

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-205	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multi-disciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuro-psychology Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	There was insufficient psychology time for the number of people cared for by the service. Only 1 WTE psychologist was available, and the psychologist had no cover for absences, provided a neuropsychology service and was also the lead for transition (British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggests 1 WTE for 300 patients).	N	There was insufficient psychology time for the number of children and families cared for by the service. Only 1 WTE psychologist was available, and the psychologist had no cover for absences, provided a neuropsychology service and was also the lead for transition (British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggests 1 WTE for 300 patients).
HN-206	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.	Y	The sickle cell training pathway (previously called the sickle cell bundle) had been revised and included family stories.	Y	
HN-207	**Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A		Y	One practitioner provided a non-imaging TCD service.

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y		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	N	Timely access to a social worker/ benefits adviser was not available. Staff were spending time providing advice and support, and reviewers considered that this had an impact on the clinical time available. Although the service had developed a fact sheet which included some information, some patients and carers who met with the reviewing team commented that they were unclear how to access social worker and benefits support. All other aspects of the QS were met.	N	Timely access to a social worker/ benefits adviser was not available. Staff were spending time providing advice and support, and reviewers considered that this had an impact on the clinical time available. Although the service had developed a fact sheet which included some information, some carers who met with the reviewing team commented that they were unclear how to access social worker and benefits support. All other aspects of the QS were met.

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department/s should have competences in urgent care of people with haemoglobin disorders.	N	Eight months of data showed that the percentage of patients in each month receiving analgesia within 30 minutes of arrival ranged from 4-17%. Many patients who met with the reviewing team also commented about experiencing long delays before receiving any analgesia when attending the ED.	N	Eight months of data showed that the percentage of patients in each month receiving analgesia within 30 minutes of arrival ranged from 0-57%. The data indicated that from September to November 2019 the percentage of patients receiving analgesia within 30 minutes of arrival had dropped considerably to 0-1%. Families reported that they had to queue to be seen and that a wait of as much as two hours for analgesia was not unusual.
HN-303	**Specialist On-site Support** Access to the following specialist staff and services should be easily available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Erythrocytapheresis c. Acute pain team including specialist monitoring of patients with complex analgesia needs d. High dependency care, including non-invasive ventilation e. Level 2 and 3 critical care	Y		Y	Patients requiring a manual exchange transfusion (a) were transferred to St Mary's Hospital Paddington.

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

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

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-502	**Monitoring Protocols** Protocols should be in use covering the monitoring expected at: a. First out-patient appointment (SHC only) b. Routine monitoring c. Annual review (SHC & any LHTs to which annual reviews are delegated) Protocols should cover both clinical practice and information for patients and families.	Y		Y	
HN-503	**Clinical Guidelines: LHT Management and Referral** Guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A		N/A	
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, two different network protocols for carrying out manual and automated exchange transfusions were in use, with slightly different criteria.	Y	

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

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

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-508	**Clinical Guidelines: Chronic complications** Guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y	Network guidelines had been adapted for use locally.	Y	Network guidelines had been adapted for use locally.
HN-509	**Referral for Consideration of Bone Marrow Transplantation (Children's Services Only)** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N/A		Y	
HN-510	**Non-Transfusion Dependent Thalassaemia (nTDT)** Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y		Y	
HN-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y		Y	

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a SHC (Children's SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Arrangements for liaison with community paediatricians and with schools (children's services only) e. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated (children's services only) f. Follow up of patients who do not attend g. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. h. Accessing specialist advice (QS HN-304) i. Two-way communication of patient information between SHC and LHTs j. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	Y		Y	

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-602	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and representatives of support services (QS HN-301).	Y		Y	
HN-603	**Delegation of Annual Reviews** If annual reviews are undertaken by LHT/s on behalf of the SHC, a written agreement should be in place covering: a. Monitoring protocols (QS HN-502) b. LHT management and referral guidelines (QS HN-503) c. National Haemoglobinopathy Registry data collection (QS HN-701)	N/A	All annual reviews were undertaken by the SHT.	N/A	All annual reviews were undertaken by the SHT.
HN-604	**Out of Hours Elective Care** Arrangements should be in place for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Out of hours elective care was not possible. Patients who met with the reviewing team would value access to elective care out of hours.	N	Out of hours elective care was not possible. Families who met with the reviewing team would value access to elective care out of hours.
HN-605	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A		Y	

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-606	**Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)** A Standard Operating Procedure for Trans-Cranial Doppler ultrasound should be in use covering at least: a. Trans-Cranial Doppler modality used b. Identification of ultrasound equipment and maintenance arrangements c. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-207) d. Arrangements for ensuring staff performing Trans-Cranial Doppler ultrasound have and maintain competences for this procedure, including action to be taken if a member of staff performs less than 40 scans per year e. Arrangements for recording and storing images and ensuring availability of images for subsequent review f. Reporting format g. Arrangements for documentation and communication of results h. Internal systems to assure quality, accuracy and verification of results	N/A		Y	
HN-607	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	
HN-608	**Neonatal Screening Programme Review Meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (QS HN-703), identify issues of mutual concern and agree action.	N/A		Y	

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

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

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. Availability of extended red cell phenotype in all patients and the proportion of patients who have developed antibodies b. Whether all eligible patients on long term transfusion have been offered automated exchange transfusion c. Waiting times for elective: i. Phlebotomy ii. Cannulation iii. Setting up of the blood transfusion (for pre-ordered blood)	N	An audit programme covering 'a' and 'b' had not been undertaken. The day unit had completed an audit covering 'c'.	N	An audit programme covering the requirements of the QS was not in place.
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	Y		Y	
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		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		Y	One practitioner performed all non-imaging TCD ultrasounds. Data indicated that 89% of children and young people had an annual TCD ultrasound performed.

Ref	Standard	Adults (SHT)		Children and Young People (SHT)	
		Met?	Comments	Met?	Comments
HN-798	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility c. Annual review of trends in National Haemoglobinopathy Registry data, activity data, Quality Dashboard, other quality data and other audits (QSs HN-701 to HN-705)	Y		Y	
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

Return to Index