# Health services for people with haemoglobin disorders

## Barts Health NHS Trust

## Children and Young People Services

Visit Date: 6th and 7th November 2019

Report Date: February 2020

8831

## Contents

# Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders at Barts Health NHS Trust that took place on 6th and 7th November 2019. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V4, 2018, which were developed by the UK Forum on Haemoglobin Disorders working with the Quality Review Service (QRS). The peer review visit was organised by QRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

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

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

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

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

- Barts Health NHS Trust
- East London NHS Foundation Trust
- North East London NHS Foundation Trust
- NHS England & NHS Improvement Specialised Commissioning – Haemoglobinopathies
- NHS City and Hackney Clinical Commissioning Group
- NHS Newham Clinical Commissioning Group
- NHS Tower Hamlets Clinical Commissioning Group
- NHS Waltham Forest 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 commissioners in relation to this report are NHS England & NHS Improvement Lead Commissioner for Haemoglobinopathies, NHS City and Hackney Clinical Commissioning Group, NHS Newham Clinical Commissioning Group, NHS Tower Hamlets Clinical Commissioning Group, and NHS Waltham Forest 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 Barts Health 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 and young people with haemoglobin disorders at Barts Health NHS Trust. Reviewers visited The Royal London Hospital (RLH), Newham University Hospital (NUH), and Whipps Cross University Hospital (WXH) and during the course of the visit viewed the emergency departments, paediatric day units, inpatient wards and outpatient departments on each site. Reviewers also met with patients and carers and with staff providing the services across the health economy.

Barts Health NHS Trust was established in April 2012, merging Barts and The London NHS Trust, Tower Hamlets Community Health Trust, Newham University Hospital NHS Trust and Whipps Cross University Hospital NHS Trust. The Trust provided services to a large, ethnically diverse and underprivileged population with complex health care needs.

At the time of the visit the haemoglobinopathy services at the Trust were part of the East London and Essex Haemoglobin Disorders Network, which was formed with Homerton University Hospital NHS Foundation Trust, Barking Havering and Redbridge University Hospitals NHS Trust, Basildon and Thurrock University Hospitals NHS Foundation Trust, Mid Essex Hospital Services NHS Trust, The Princess Alexandra Hospital NHS Trust, East Suffolk and North Essex NHS Foundation Trust, Southend University Hospital NHS Foundation Trust, the Sickle Cell and Thalassaemia Centres in Hackney and Newham, North East London NHS Foundation Trust, and the community service covering Essex.

All children resident in the London Boroughs of Hackney and Tower Hamlets attended the RLH and all patients (except patients with Hb SC disease) living in Essex were also seen at the RLH for their annual reviews. Patients with complex needs living in Barking, Havering and Redbridge had shared care arrangements in place with Barking, Havering and Redbridge University Hospitals NHS Trust and the specialist haemoglobinopathy team based at RLH; 394 patients were registered from this area on the National Haemoglobinopathy Register (NHR).

In October 2019, following a national procurement exercise conducted by NHS England (NHSE), Barts Health NHS Trust was formally designated as a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell Disease and Thalassaemia. The Trust was keen to support this development and was working with the team to implement the action plan agreed with NHSE. At the time of the visit discussions were ongoing with NHSE specialist commissioners to agree funding for additional support.

A number of issues in this report will require executive focus and support from the Trust in order for the paediatric teams to function as comprehensive Specialist Haemoglobinopathy Teams (SHTs) and Local Haemoglobinopathy Teams (LHTs). Some of the areas of concern had been identified at the last visit in 2016 and had not yet been addressed. Further support from the Trust executive will also be required in order for the SHT to fulfil its role as an HCC.

**Concern**

1. **Service Organisation**

   The Trust provided haemoglobinopathy services from three locations; RLH, WXH and NUH. Reviewers were concerned that, at all locations, staffing levels were less than the expected level for the number of patients being cared for by the teams. Different local management processes for decision-making had resulted in solutions being implemented without consideration of the impact on the other teams, and the reviewers were given conflicting information about how often local management teams across the sites met to review issues relating to the haemoglobinopathy services. Reviewers were concerned that, in a Trust providing this level of service, there appeared to be very limited capacity to manage variation in workload across the whole service, and they felt that this increased the service vulnerability.

**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 |
|---|---|---|---|---|
| Barts Health NHS Trust<br>The Royal London Hospital | SHT | 373 | 78 | 64 |
| Barts Health NHS Trust<br>Newham University Hospital | LHT | 180 | 24 | 25 |
| Barts Health NHS Trust<br>Whipps Cross University Hospital | LHT | 96 | 6 | 23 |

| Support Groups [1] | Tower Hamlets (RLH) | Hackney (RLH) | Waltham Forest (WXH) | Newham (NUH) |
|---|---|---|---|---|
| Sickle Cell Disease – Children and families | Y | Y | N | Y |
| Thalassaemia – Children and families | Y | Y | N | Y |

Return to Index

[1] A support group run at the RLH was open to any children, young people and their families who were under the care of the SHT.

## Specialist Team (Children and Young People Services): The Royal London Hospital, Barts Health NHS Trust

**General Comments and Achievements**

This was an experienced service with strong leadership evident throughout. It was clear to the reviewers that the team was highly committed and enthusiastic, although they were working under extreme pressures.

There were good working relationships with the community teams across the network, and these teams considered that engagement and involvement with the SHT was very positive. A monthly network-wide multi-disciplinary team (MDT) meeting was held with representation from the Trust and community teams.

The SHT had a strong commitment to training and education, with a regular programme for local teams across the network as well as from other sites across the UK.

Nurse-led hydroxycarbamide clinics were in place. A lead nurse role had been established to provide outreach support to the LHTs within the Trust.

| Specialist Haemoglobinopathy Team | Local Haemoglobinopathy Teams |
|---|---|
| Barts Health NHS Trust: Royal London Hospital | • Barts Health NHS Trust: Newham University Hospital<br>• Barts Health NHS Trust: Whipps Cross University Hospital<br>• Barking Havering and Redbridge University Hospitals NHS Trust *(in the process of applying to become an SHT)*<br>• Basildon and Thurrock University Hospitals NHS Foundation Trust<br>• East Suffolk and North Essex NHS Foundation Trust<br>• Homerton University Hospital NHS Foundation Trust<br>• Mid Essex Hospital Services NHS Trust: Broomfield Hospital<br>• Mid Essex Hospital Services NHS Foundation Trust: Chelmsford Hospital<br>• Southend University Hospital NHS Foundation Trust<br>• The Princess Alexandra Hospital NHS Trust, Harlow |

**Staffing**

| Staffing for a Paediatric Specialist Haemoglobinopathy Team (SHT) [2] | Number of patients | Actual WTE (at time of the visit) | NHSE recommended staffing WTE |
|---|---|---|---|
| Consultant haematologist/paediatrician with - >0.6 WTE per 150 patients dedicated to work with patients with haemoglobinopathies | 451 | 1 | 1.8 |
| At least 0.25 WTE allocated to haemoglobinopathies CPD in the Consultant haematologist/paediatrician job plan | 451 | 0.1 | - |
| Clinical psychologist for paediatric patients with >0.5 WTE per 150 patients dedicated to work with patients with haemoglobinopathies | 451 | 0.2 | 1.5 |

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

**Emergency Care**

Children with haemoglobin disorders with acute complications were seen initially in 'streaming' in the paediatric emergency department (PED) by a paediatric emergency medicine consultant, who could access the child's electronic health record (EHR). Two generic analgesia protocols were in place, one for children under 14 years of age, and one for children aged 14 years and older. Some children and young people with complex needs had an individualised emergency care plan. For acute sickle pain management, the first two doses of analgesia were given in the emergency department (ED) and then a further assessment was provided by the shared ED/paediatric medical team or paediatric haematology and oncology SHO and SpR (during normal working hours). If patients required admission, then they were transferred to an acute paediatric ward under the care of one of the four consultants covering paediatric haematology and oncology. Out of hours, the patient was reviewed by the paediatric medical teams with telephone advice from the on-call paediatric haematology consultant.

**Inpatient Care**

Paediatric patients requiring admission were transferred to an acute paediatric ward under the care of one of the four consultants covering paediatric haematology and oncology. The children were then prioritised for admission to a designated ward (7E). Out of hours, children with complications related to sickle cell were admitted under the care of the general paediatric team, who received specialist advice from the on-call paediatric haematologist (1:3 rota). Severely ill children and those requiring urgent exchange transfusions were managed on the paediatric intensive care unit and supervised by paediatric intensivists, assisted by the haematology team. There was no dedicated adolescent ward, but adolescent facilities were available on the ward. Two dedicated clinical nurse specialists (CNSs) for paediatric haematology saw patients on the ward and the day care unit, and supported nursing staff. The acute paediatric pain team was responsible for setting up and monitoring intravenous analgesia if required.

**Day Care**

The unit provided paediatric medical and surgical day care services, with designated beds for surgical and medical patients. For paediatric haematology, the services included simple top-up transfusion, automated exchange transfusion (ARCET) and venesection. The unit had capacity to transfuse six patients a day, four days a week. Out-of-hours transfusions could be delivered after school as the day unit was open until 9pm (except on Wednesdays). The ARCET service was run by the two nurse specialists and could support three ARCET procedures per week; it offered out-of-hours transfusions until 9pm Monday to Friday. Plans were in place to train additional staff to provide more procedures. Arrangements were in place for children to have a medical review during their transfusions. There was also support from the hospital school on site.

**Outpatients**

Paediatric haemoglobinopathy clinics were held twice weekly on a Wednesday morning and Thursday afternoon. Fortnightly Trans-Cranial Doppler (TCD) clinics were held alongside the haematology clinic, and there were also monthly non-imaging TCD clinics. Children with strokes, or those with a high risk of strokes, were managed in the paediatric haematology clinic with consultative access to paediatric neurology services. Regular reviews of neuro-images were undertaken with a paediatric neuro-radiologist.

One of the hospital-based haematology CNSs and the community CNS based in Hackney also attended the Wednesday clinic to provide multi-disciplinary input and to meet and support families. The hospital-based CNS administered vaccines such as pneumovax, followed up any patients who were 'not brought in', and arranged follow-up appointments. Two hospital-based CNSs ran a hydroxycarbamide monitoring clinic.

Ferriscans were available on site and T2* cardiac MRI scanning for iron overload monitoring was available through the Royal Brompton and Harefield NHS Foundation Trust.

**Community-based Care**

**Tower Hamlets Community Service**

The community service was based at the RLH and consisted of a CNS (1 wte) who provided support for children and their carers and adults resident in Tower Hamlets. The CNS also liaised with the antenatal screening service, provided genetic counselling and followed up all pregnant women (and their partners) who had a carrier status or haemoglobinopathy condition and were booked for obstetric care at the RLH; the CNS also undertook the first and subsequent home visits to newborn babies. The CNS provided training for RLH midwives and other health professionals when requested, and some training to schools when capacity allowed. The CNS attended the SHT MDT and referred newly diagnosed children to the team.

**The Hackney Sickle Cell and Thalassaemia Centre**

The community-based centre was part of the integrated service provided by Homerton University Hospital NHS Trust. Services were provided for Hackney-based patients who attended the RLH, with a designated paediatric CNS. The service provided a comprehensive service.

**Progress since Last Visit**

- Development of shared guidelines and policies to cover care across all of Barts Health NHS Trust and the East London and Essex Network.
- Development and delivery of structured MDT meetings and teleconferences to discuss paediatric patients within the network.
- Initiation of an ARCET service for paediatric patients at RLH.
- Provision of annual review for the most complex patients cared for by teams across Barts Health NHS Trust.
- Establishment of a paediatric haemoglobinopathy lead nurse role to support training, education, and service across the Trust sites.
- Recruitment of a network manager.
- Establishment of psychology education and support / mentoring groups for paediatric patients in collaboration with the Sickle Cell Society.
- Continued use of sickle cell and clinical databases networked across the Trust sites, used for clinical management, research and audit.
- Increased level of research activity.
- Integrated Children's Hospital website developed.
- Establishment of sonographer-led TCD clinic to support the clinician-led service, and to improve access and the development of cross cover arrangements across the sites.
- Development of internal quality assurance for TCD scanning.
- Supporting TCD scanning training for Basildon team.
- Pathway for GP management of children (Hackney CCG).
- Agreement to formalise elective transfusions for local Essex paediatric patients residing in the Basildon area.

**Views of Service Users and Carers**

The visiting team met with three families 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 families spoke highly of the consultants' team; they valued the reassurance and the education about their child's condition that were provided by the consultants when they attended appointments.
- All those who met with the visiting team held the specialist nursing team in high regard and felt reassured when they were around.
- All staff on the wards were extremely pleasant and always responsive.

- Some parents who met with the visiting team commented that there was sometimes a lack of communication between the MDT members, with messages not always being communicated or documented. This meant, for example, that they received different opinions and care decisions from different doctors.
- Parents commented they felt less confident when dealing with junior medical staff; they considered that junior staff did not always listen to their child, and they felt they needed to advocate on their child's behalf.
- When attending the ED and day unit there were often delays in getting medications prescribed. The parents took the view that this was because staff were waiting for a member of the hospital paediatric team to take action.
- Some families had experienced issues when attending for treatment and had encountered problems with the availability of staff to cannulate. One family commented that 18 attempts to cannulate had been made on one visit, while others commented that, although they had tried to advise staff about specific cannulation devices, junior medical staff 'would just keep going'. When the lead nurse and CNS were available there were not any issues.
- Parents were not aware of any community support, especially of any available help with the development of school care plans.
- Out-patient appointments were often cancelled, which meant that patients' follow-up appointments exceeded the usual timeframes for regular reviews. There were mixed experiences, with some families being given new appointments straightaway and others having to make enquiries.
- Those with complex needs commented that coordination between specialist services and the SHT could be better in terms of information sharing. They wondered whether the number of out-patient appointments could be coordinated to reduce the number of times they needed take their child out of school.
- When the day care unit was full, the step-down area was used; users and carers felt that this area was cramped and lacked privacy.
- When attending for a blood transfusion, patients were often on the unit for eight hours which they thought was longer than necessary.
- The discharge process was often rushed.
- The parents commented that they felt the lead consultants and CNSs were wonderful but very overworked.

**Good Practice**

1. Reviewers were impressed with the arrangements the SHT had in place to provide advice to the LHT and community services across the network. Teams could contact the SHT for telephone advice or by email, and staff who met with the reviewers all commented that the SHT were prompt in responding to their queries. Weekly virtual MDT meetings were held with the specialty doctor (who had taken over as the lead clinician for haemoglobinopathies) at Whipps Cross University Hospital, and all patients who attended out-patient clinics, and any in-patients, were discussed at these meetings and treatment decisions reviewed. The monthly network-wide MDT was universally popular and well attended by the teams across the network.

2. The most recent 'time to analgesia' audit showed that 70% of children and young people received analgesia within 30 minutes of arrival. Reviewers were particularly impressed that the audit results showed that the longest time that a child had waited for analgesia was 38 minutes.

3. The TCD ultrasound information for children, young people and their carers was very comprehensive. The information clearly explained how the results were categorised, what each category meant, and what the next steps would be.

4. The internal quality assurance process for TCD ultrasound was very robust.

5. Educational support for children and young people was very supportive: -

    a. The education staff could provide one-to-one support for children whilst they were in-patients. Arrangements were also in place to liaise with a child's school to ensure that any work followed the programme of work there, and schools were notified of attendance at the hospital so that this could be noted on their school attendance records.

b. School care plans were very detailed and were individualised for each child. The care plans included who to contact for general advice as well as what to do in an emergency.

6. Reviewers were impressed with the approach to pain management. In conjunction with the acute pain service, the team had developed an innovative approach of using oral morphine slow release tablets and intranasal diamorphine spray for the management of acute pain, which had greatly reduced the need for parenteral opiates. The acute pain team also ran a monthly 'drop in' education session for staff.

7. One of the lead consultants ran a bi-monthly Saturday TCD clinic in the Newham Community Service Centre, which reduced the need for children to attend for TCD ultrasounds during the school day.

8. Reviewers were impressed with the strong commitment to research into red cell disorders. Since the last visit in 2015, the team, with support from the research unit, 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.

9. The bespoke Trust haemoglobinopathy database had evolved further since the last visit and continued to provide comprehensive information for the clinical teams. It was also possible for the database to be synchronised with other Trust information systems. The SHT had plans develop the database function further in order for the system to be web-based, which would enable the information to be available remotely and to be accessed by the LHTs.

10. The community team in Hackney held coffee mornings for parents with newly diagnosed children to meet and share ideas, which had also led to the carers developing a carers forum.

11. The SHT had actively taken part in the mentoring programme for 10 to 24 year olds which was funded by City and Hackney Clinical Commissioning Group and facilitated by the Sickle Cell Society. The aim of the project was to support emotional, social and physical wellbeing by fostering the development of skills and positive behaviours through mentor–mentee interaction.[3] The newsletter for parents and carers was well written and informative, providing updates and useful local and national information.

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

**Concerns**

1. **Consultant staffing**

   The service had insufficient consultant medical staff with time for the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care, clinics, and support and oversight to the LHTs across the network. At the time of the visit there were two consultant haematologists (2 wte) who rotated between the adult and paediatric haemoglobinopathy services, and who therefore provided 1 wte for each service; they were working a 1:3 on-call rota, as well as providing specialist advice and support across the East London and Essex Network. In October 2019 the service had been designated as a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell Disease and Thalassaemia, which would require an increase in the time available for leadership and support to other paediatric haemoglobinopathy services across the region.

2. **Specialist nursing support**

   Specialist nursing support time was insufficient (2 wte), given the number of patients being cared for with haemoglobin disorders (approximately 450), to provide clinical services, training and leadership across the network, and administration for the specialist haemoglobinopathy service. One CNS had been seconded to a lead nurse post to provide outreach support to LHTs across the Trust. Recruitment to the vacant CNS post was in progress but at

[3] *BSH2019-496 Peer to peer mentoring for patients with Sickle Cell Disease – interim analysis of results from a pilot programme in East London*

the time of the visit the lead nurse was covering the leadership and CNS roles for the SHT, which also included the provision of nurse-led hydroxycarbamide clinics.

3. **Access to psychology**

   Psychology staff with appropriate competences in the care of people with haemoglobin disorders was insufficient for the number of children, young people and families cared for by the SHT. Some support was available from the child and adolescent mental health service (0.2 wte), but the postholder was on maternity leave and there was no cover in place.

4. **Community support**

   A community service to provide support for patients and their carers within the Tower Hamlets area was limited. The community CNSs (1 wte) provided genetic counselling for antenatal clients and follow-up care for those children identified following new-born screening, as well as support for children, adults and families residing in the Tower Hamlets area. The CNS had no cover for absences. The Trust were aware of the issue, and reviewers were told that there were plans to increase the level of specialist nursing support in the community.

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

   A competence framework was not in place for nursing staff caring for people with haemoglobin disorders. A number of training sessions were delivered to staff, and ward and day unit nurses did have competences in transfusion skills.

   There was also no training plan in place to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.

6. **'Fail safe' arrangements**

   The 'fail safe' process to ensure that all newly diagnosed babies were notified to the SHT was not robust. Reviewers were told that the agreed process was that the community based CNSs were notified by the new-born screening service and undertook the initial visit. Notification to the SHT was via the MDT or by email from the community nurses. From discussion with the SHT at the time of the visit, reviewers were not assured that the network-wide process was robust and that all babies would be appropriately notified to the SHT, although following the visit the Trust confirmed that, since March 2019, they had been accessing the electronic National Newborn Outcome Screening System for referrals and tracking of transition to clinical care.

7. **National Haemoglobinopathy Register**

   Patients were registered on the NHR, but no other information, such as annual reviews, was submitted. Reviewers acknowledged that the Trust database was very comprehensive but considered that this information should be submitted to enable monitoring of NHR data trends.

8. **Service level agreements**

   Service level agreements with LHTs across the network (apart from Homerton) were not yet in place to formalise the shared care arrangements and level of advice provided by the SHT. Reviewers were concerned at the increasing demands on the SHT to provide care and advice which was not formally recognised. Formalising contractual arrangements would ensure that there was Trust oversight and that the service was supported to ensure that the service provision was correctly governed and managed.

9. **Organisational structure**

   Reviewers were made aware that, because of the autonomous nature of the organisation's hospitals, decisions were sometimes made about the LHTs at other hospitals within the Trust (for example, the decisions mentioned in the Whipps Cross University Hospital serious concerns section of the report) without consideration of the impact on the lead team at RLH. The review team were given conflicting information about how often the management teams at the different sites met to review issues relating to the haemoglobinopathy services.

**Further Consideration**

1. 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 made is fully understood by staff and implemented.
2. A validation process to ensure that all children and young people across the Trust had TCD ultrasound when indicated was not yet in place. Data seen by the reviewers covering the proportion of children who had been offered treatment following TCD screening appeared low for the number of children and young people cared for by the SHT. There was also no support for TCD data collection.
3. Some of the audits expected by the Quality Standards had not yet been undertaken (QS HN-705), and evidence of any resulting audit action plan was limited. Reviewers considered that it would be important to develop an audit programme to ensure that audits were completed and a clear process was in place for reviewing the implementation of any resulting action plans.
4. Training on the red cell apheresis machine had not taken place since 2017. Reviewers commented that there were usually opportunities to access training for staff as part of the annual service contract with the machine manufacturer.
5. Reviewers considered that there was insufficient data management and coordination support available for coordination of data across hospital sites and for submission to the NHR.
6. Reviewers were encouraged that there was willingness from the Trust to support the team to develop the HCC role, but highlighted the importance of building close links with specialised commissioners in order that the necessary assistance is provided to the team to develop these regional network structures.

Return to Index

## Local Team (Children and Young People Services): Newham University Hospital, Barts Health NHS Trust

**General Comments and Achievements**

This was a relatively new team who were clearly enthusiastic and worked well together. It was evident to the reviewers that there were good relationships between the team, paediatric services and hospital management. In the 12 months before the visit the locum haematologist had been appointed as lead for the LHT and was supported by a deputy on site and the SHT based at the RLH. A CNS (1 wte) had been seconded to work with the team and had plans to develop the training available to staff. A wide range of support was provided at the Newham Sickle Cell and Thalassaemia Centre, including TCD scanning and home visits for children and families residing in Newham.

Reviewers were impressed with the progress that had been made by the new team in a relatively short space of time.

| Local Haemoglobinopathy Teams | Specialist Haemoglobinopathy Centre |
|---|---|
| Barts Health NHS Trust: Newham University Hospital | Barts Health NHS Trust: The Royal London Hospital |

**Staffing**

| Staffing for a Paediatric Local Haemoglobinopathy Service (LHT) | Number of patients | Actual wte (at time of visit) |
|---|---|---|
| Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies | 204 | 0.3 |
| Clinical psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies | 204 | 0 |

**Emergency Care**

Children presenting with acute complications were first assessed in the children's ED following triage. Sickle cell or thalassaemia patients presenting to the ED with an open access 'passport' card were seen directly by paediatric doctors. Initial acute pain management was initiated by the ED or the attending team using the sickle pain protocol. All patients were reviewed by a member of the paediatric team in the ED prior to admission to Rainbow children's ward, and patients who were safe for discharge home from the ED were discussed with the paediatrics team before such decisions were taken. Other acute presentations of sickle cell or thalassaemia patients were discussed with the paediatric team. The paediatric consultant of the week provided clinical leadership for all children with chronic disease (including haemoglobinopathies) attending the ED. One of the paediatric consultants was also informed of all haemoglobinopathy-related attendances and admissions during routine hours, and the lead clinicians for the haemoglobin disorders service could be contacted where specialist support was indicated. Individualised care plans from clinic letters were accessible on the Trust IT system. The Newham community centre in East Ham was also notified of discharges from the ED and Rainbow Ward for home follow-up and family support. Children who were acutely unwell were admitted to the Rainbow Ward HDU for stabilisation and then transferred to the paediatric critical care unit (PCCU) at RLH following discussion with RLH haematology team and the PCCU.

**In-patient Care**

Any patients requiring in-patient care were admitted to the paediatric medical wards. Facilities for teenagers were available.

**Day Care**

A six-bedded day care facility was available for children who required simple top-up transfusions. Nursing and clinical reviews were done to inform chelation dosing and treatment adherence, and for the management of drug toxicities. Because of a change in ward policy, open access reviews were undertaken in the ED, and sickle cell and thalassaemia patients were provided with a 'passport' card to enable quicker access for such reviews. There was no out-of-hours provision for routine transfusions, and transfusions were only available on Wednesdays.

**Out-patient Care**

A general haematology clinic (for patients with haemoglobinopathies and also for those who required hydroxycarbamide monitoring) was run every Wednesday afternoon and twice a month on a Thursday afternoon. An evening clinic was run at the Newham Sickle Cell and Thalassaemia Centre in East Ham twice a month. A joint multi-disciplinary transition clinic with an adult haematologist was held every four months.

**Community-based Care**

**The Newham Sickle Cell and Thalassaemia Centre**

Residents of the Newham area were supported by the Newham Sickle Cell and Thalassaemia Centre, which provided a comprehensive service. The service was provided by two CNSs who provided care for approximately 160 children, and the team were able to offer home visits for children and families residing in Newham.

A Saturday non-imaging TCD clinic, funded by the East London NHS Foundation Trust, was held monthly at the Centre by one of the lead consultant haematologists from the RLH.

**Progress since Last Visit**

- Appointment of CNS based at NUH (secondment for 12 months).
- Development of shared guidelines and policies to cover care across all of Barts Health and the East London and Essex Network.

**Views of Service Users and Carers**

The visiting team met with four children and young people and two 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 of the support from the haemoglobinopathy team. In addition:

- The parents commended the consultant for 'popping in' to see their children during their transfusions. They felt that the consultant was very engaged in their children's treatment.
- All those who met with the visiting team considered that the service provided had improved since the new team had been in place, and were appreciative of the reassurance and advice available, saying that the team were 'wonderful'.
- One family who had moved to another area had chosen to stay with the team at NUH as they considered the service they received was excellent.
- Users reported that, when attending the ED, the pathway worked well and their pain was effectively managed.
- Experiences around transition were reported as working well, and one young person commented that being able to meet representatives from the adult team as part of the transition process had helped them to be more confident about their transition to the adult service.
- The users liked the 'anonymous map' in the teenage room which they could use for feedback (see Good Practice section of the report).
- Comments were made that there had been issues in 'cross matching', with blood samples having to be repeated because of illegible labels on the sample bottles.

**Good Practice**

1. Reviewers were impressed with the environment for the children, young people and families attending the hospital. Development of the area had involved young people, their families and staff. The environment was welcoming and worked as a 'hub' with patients at the centre of care. The ED was adjacent to the main paediatric area, with all other services such as phlebotomy, out-patients, in-patient wards, day unit, and parents' and teenage rooms collocated.
2. The ED pathway worked well. Patients had 'passports' that enabled them to bypass the initial 'streaming' process so they were seen quickly. Staff who met with the reviewing team were knowledgeable about haemoglobin disorders, and a training programme for ED staff was in place.
3. A designated phlebotomist was assigned to attend the day unit when children and young people attended for blood investigations. Children and families were very appreciative of this process, as they saw a familiar person who had experience of taking blood samples from their children, especially if gaining venous access was complex. Parents commented that this had resulted in their children being far less anxious about having their bloods taken.
4. Work to reduce the number of children and young people who were 'not brought' for appointments had resulted in the percentage of appointments missed reducing from 27% to 11%. When appointment letters were returned as not being delivered, families were telephoned, and all parents were sent a text message 48 hours before their scheduled appointment. The community team were also notified when families missed appointments, and would work with families to provide support and to encourage families to keep review appointments.
5. Reviewers were impressed with the enthusiasm of the lead clinician, who had many ideas about involving children, young people and their families. Particularly impressive was the lead clinician's work to link with a number of charities to help provide ongoing support, especially short breaks for families with sickle cell disease.
6. The teenage room had an 'anonymous map' where young people could give feedback and write any other comments on which they would like advice, and staff would then add an anonymous reply.
7. Support from the community children's team was very good. The team provided a wide range of support to both the hospital team and the community, providing training for families and also undertaking blood investigations.

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

**Concerns**

1. **Clinical Nurse Specialist**

   Reviewers were concerned about whether the service had sufficient support from clinical nurse specialists with appropriate competences in the care of people with haemoglobin disorders to provide a comprehensive service (clinical, education, liaison with other services and audit) for the number of children and young people being cared for by the service. At the time of the visit the CNS post (1 wte) was temporary for 12 months, and the CNS seconded into the role did not have cover for absences, although reviewers were told at the feedback session that funding had been identified to support a substantive post.

2. **Access to psychology**

   Psychology staff with appropriate competences in the care of people with haemoglobin disorders were not available.

3. **Access to patient controlled analgesia (PCA)**

   Patients with acute pain admitted to NUH were not able to access PCA, and children and young people requiring PCA were transferred to the RLH. Reviewers were told that equipment was available but that the governance infrastructure was not in place to cover, for example, who would have oversight of the service, ongoing patient monitoring processes and staff training.

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

   A competence framework was not in place for nursing staff caring for people with haemoglobin disorders. A number of training sessions were delivered to staff, and ward and day unit nurses did have competences in transfusion skills.

   A training plan to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders was also not in place, although reviewers were told that the CNS had plans to implement a range of training sessions for staff.

**Further Consideration**

1. The local arrangement for notification of newly diagnosed children with haemoglobinopathy disorders was via the community service. Reviewers considered that developing more formal links with the neonatal screening service would make the 'fail-safe' arrangements more robust.
2. At the time of the visit the paediatric unit did not have a qualified teacher who was able to provide educational support to make sure that children received regular teaching either at the bedside or in the ward classroom.
3. Out-of-hours provision for routine transfusions was not yet available, and transfusions were only available on Wednesdays.
4. The team had a number of audits in progress and reviewers considered it would be important to develop an audit programme to ensure that audits were completed and that there was a clear process for reviewing the implementation of any resulting action plans.

Return to Index

## Local Team (Children and Young People Services): Whipps Cross University Hospital, Barts Health NHS Trust

**General Comments and Achievements**

The newly appointed lead for the service was enthusiastic and keen to develop the service with limited resources. There was good integration between the community CNS and the hospital-based team. The speciality doctor provided regular teaching to ED staff, junior doctors and GPs.

Good links were in place with the SHT based at the RLH to support the lead clinician, with the implementation of weekly virtual MDTs, and the lead at Whipps Cross regularly attended the network MDT meetings.

| Local Haemoglobinopathy Teams | Specialist Haemoglobinopathy Centre |
|---|---|
| Barts Health NHS Trust<br>Whipps Cross University Hospital | • Barts Health NHS Trust: The Royal London Hospital<br>• Homerton University Hospital NHS Foundation Trust (adults only) |

**Staffing**

| Staffing for a Paediatric Local Haemoglobinopathy Service (LHT) | Number of patients | Actual wte (at time of visit) |
|---|---|---|
| Consultant haematologist/paediatrician dedicated to work with patients with haemoglobinopathies | 102 | 0<br>(0.2 speciality doctor) |
| Clinical psychologist for paediatric patients dedicated to work with patients with haemoglobinopathies | 102 | 0 |

**Emergency Care**

Patients attending the ED were 'streamed' directly to be seen by an ED doctor and given a first dose of analgesia according to the paediatric pain protocol. Patients were then seen by the paediatric team in the ED. Individual patient information, including any personalised care plan, was available via a shared drive on the intranet. Patients who were acutely unwell were transferred to the RLH under the care of the paediatric haematology or PCCU team.

**In-patient Care**

Children and young people requiring admission were admitted to the paediatric ward (Acorn Ward) under the care of the general paediatric attending consultant who was resident until 10pm on weekdays. The lead clinician for the service was informed of all haemoglobinopathy-related attendances and admissions during routine hours, and advice was always available from the SHT at the RLH. A room was available for use by teenagers. The community-based CNS provided some in-reach support to families whose children were admitted to hospital.

**Day Care**

Day care facilities were available on the Acorn Medical Day Unit (MDU), which was led by two Band 7 paediatric nurses. Children requiring blood transfusions were able to attend on a Wednesday, with some additional capacity available on a Thursday. In the absence of the speciality doctor and the senior nurse, the paediatric team provided cover. There were out-of-hours facilities for transfusion.

**Out-patient Care**

Paediatric clinics were held in the paediatric out-patients. A dedicated haemoglobinopathy clinic was held each week on various days of the week and led by the speciality doctor with support from the community CNS.

There was a twice-yearly transition clinic attended by representatives of the paediatric haemoglobinopathy and adult haematology teams.

**Community-based Care**

**Waltham Forest service**

The service was commissioned by the North East London NHS Foundation Trust (NELFT) and was provided by a CNS (1 wte) with some cover from the CNS's line manager. The service provided counselling and antenatal screening, diagnosis and follow-up care for affected babies, children and adults. The CNS had limited capacity to provide education and training but would do so on request. At the time of the visit the CNS was supporting the hospital service, attended the weekly clinics, and visited children when admitted for day or in-patient care.

At the time of the visit, support groups were not in place.

**Changes since Last Visit**

- Implementation of shared guidelines and policies to cover care across all of Barts Health and the East London and Essex Network.
- The lead paediatric haemoglobinopathy consultant had left the organisation in May 2019, and the speciality doctor had been appointed as the lead for the service in July 2019.

**Views of Service Users and Carers**

The visiting team met with seven children and their parents during the course of the visit:

- Access to diagnostic tests was very good.
- Support from the community nurse, including when attending clinics and on the day unit, was appreciated.
- All staff on the wards were extremely pleasant and always responsive.
- Parents and children who met the visiting team had mixed views about the support available for school care plans. Some parents expressed the need for more support.
- The parents had mixed views about waiting times in the ED department. Some parents would talk to staff about bypassing the 'streaming' process, whereas others were not clear if they could do this, and spoke about their child being very unwell and waiting to be seen. All the parents asked if a process could be implemented whereby they could be fast-tracked so that they could be seen more quickly in the ED.
- Children did not always feel that they had privacy when admitted to the ward.
- A number of parents commented that in the last few months their child's out-patient appointments had been cancelled and rearranged.
- During revision and exam times, young people would really value more flexibility in appointments so that they did not have to miss revision sessions at school.
- Parents were not aware of any support groups in place and would value help to develop a group.
- Some in the group talked about arrangements that had been in place a number of years ago which they had valued, such as communication with the LHT for help and advice, and support plans from 'birth to school'. The view from parents was that this level of support was no longer available.

**Good Practice**

1. The information on the hospital 'shared drive' was very comprehensive, and provided staff with up to date information on clinic reviews and care plans for all patients with haemoglobin disorders. A system to alert the ED and other paediatric services was in place for patients with complex needs.
2. The education provision by the hospital school for children who were in-patients was very impressive. Staff would liaise with the child's school to ensure support was appropriately targeted.
3. Support from the community CNS was very good. The CNS would 'reach in' to the hospital service, attending clinics and visiting children when they attended the day unit for their blood transfusions.

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

**Serious Concern**

1. Reviewers were seriously concerned that there were insufficient staff with specialist expertise in the care of people with haemoglobin disorders at Whipps Cross University Hospital, for the following reasons:

    a. A lead speciality doctor (who had previously been the deputy) had been appointed as lead for the LHT when the lead consultant for the service had left in May 2019. The speciality doctor was highly motivated and enthusiastic, but had only 0.2 wte (2 PAs) for their work with the haemoglobinopathy service to provide staffing for clinics, regular reviews and emergency care. There was no cover for absences for the lead clinician, especially outside normal working hours, and the speciality doctor was also part of the general paediatric and neonatal on-call rota. Staff who met with the reviewers commented that, in the absence of the lead clinician, the SHT would be contacted for advice.

    At the time of the visit the SHT based at the RLH were providing clinical support and advice to the lead at the hospital and had implemented virtual MDT meetings which were held on a weekly basis. At the MDT meetings, all patients who had attended out-patient clinics and all in-patients were discussed and treatment decisions reviewed.

    b. A hospital-based CNS was not in place, which had resulted in the community CNS 'reaching-in' to provide support for children and young people and families attending the clinic and when admitted for blood transfusions.

    Reviewers were seriously concerned that the staffing in place at the time of the review provided insufficient specialist expertise for the number of patients with haemoglobin disorders and was unsustainable. Had there not been the level of in-reach support measures put in place from the SHT and the community CNS, reviewers considered that there would have been an immediate risk to clinical safety and clinical outcomes.

**Concerns**

1. **Access to analgesia**

    The most recent service audit of compliance with the NICE clinical guideline on the management of acute pain showed that only 32% of patients had received analgesia within 30 minutes of arrival in the ED. Reviewers were told that the delays in receiving analgesia were due to the streaming process which delayed children and young people in being triaged quickly to the paediatric ED. A meeting was being held on the day of the visit with representatives from the clinical commissioning group who commissioned the 'streaming service', to discuss this issue.

2. **Access to psychology**

    Psychology staff with appropriate competences in the care of people with haemoglobin disorders were not available.

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

   A competence framework was not in place for staff on those wards to which people with haemoglobin disorders were usually admitted.

   A training plan to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders was also not in place, although the lead clinician did provide a range of training for ED, ward, and day unit staff. The two nurses on the day unit did have competences in cannulation and transfusion skills.

4. **Community CNS Support**

   Due to the lack of specialist nursing support, the community CNS (1 wte) was spending time supporting the hospital service, which reviewers considered was detracting from the time available for work with children, young people and their families in the community.

**Further Consideration**

1. Support for data management and management of the haemoglobin disorder database was not available and clinical staff were spending time on administrative duties; this was not a good use of their time.
2. The local arrangements for notification of newly diagnosed babies with haemoglobinopathy disorders was via the community service. Reviewers considered that developing more formal links with the neonatal screening service would make the 'fail-safe' arrangements more robust.
3. The users and carers who met with the visiting team were enthusiastic about having the opportunity to meet other families, and would value more information about where to access further advice and support, and help with starting a support group.
4. Access to blood transfusions was still limited. The service had 23 children and young people who were on long-term blood transfusions who had to be accommodated on Wednesdays with some availability on Thursdays. All blood transfusions had to be commenced by 3pm as the unit was only operational until 6pm on Wednesdays and 7pm on Thursdays.
5. Community-based transition clinics were held two to three times per year; however, the discussions with parents showed that parents were not clear on the arrangements in place following changes to the lead team.

Return to Index

## Commissioning

The review team had discussions with local commissioner representatives from Tower Hamlets, City & Hackney, and Newham, and the regional NHSE specialist commissioner.

Several of the issues in this report will require active involvement of the Trust and commissioners in order to ensure that progress is made.

Return to Index

# APPENDIX 1 Membership of Visiting Team

| Clinical Lead | | |
|---|---|---|
| Dr Mark Velangi | Consultant Paediatric Haematologist | Birmingham Women's and Children's NHS Foundation Trust |

| Visiting Team | | |
|---|---|---|
| Mary Adeturinmo | Patient Representative | |
| Edith Aimiuwu | Paediatric Haemoglobinopathy Clinical Nurse Specialist | Whittington Health NHS Trust |
| Dr Jeremy Anderson | Sickle Cell Team Psychologist | Imperial College Healthcare NHS Trust |
| Roanna Maharaj | Patient Representative | UK Thalassaemia Society |
| June Okochi | Patient Representative | Sickle Cell Society |
| Giselle Padmore-Payne | Senior Clinical Nurse Specialist for Haemoglobinopathies | King's College Hospital NHS Foundation Trust |
| Louise Smith | Sickle Cell CNS | Alder Hey Children's NHS Foundation Trust |
| Ralph Brown | Quality Lead for Clinical Haematology and Paediatric Haematology | Imperial College Healthcare NHS Trust |
| Dr Sheana Wijemanne | Consultant Paediatrician | London North West University Healthcare NHS Trust |

| QRS | | |
|---|---|---|
| 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 |
|---|---|---|---|
| Barts Health NHS Trust: The Royal London Hospital – SHT | 50 | 37 | 74 |
| Barts Health NHS Trust: Newham University Hospital – LHT | 39 | 28 | 72 |
| Barts Health NHS Trust: Whipps Cross University Hospital – LHT | 41 | 26 | 63 |
| **Total** | **130** | **91** | **70** |

Return to Index

## Specialist Services for People with Haemoglobin Disorders

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-101 | **Haemoglobin Disorder Service Information**<br><br>Written information should be offered to patients and, where appropriate, their carers covering at least:<br>a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services<br>b. Clinic times and how to change an appointment<br>c. Ward usually admitted to and its visiting times<br>d. Staff of the service<br>e. Community services and their contact numbers<br>f. Relevant national organisations and local support groups<br>g. Where to go in an emergency<br>h. How to:<br>i. Contact the service for help and advice, including out of hours<br>ii. Access social services<br>iii. Access benefits and immigration advice<br>iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent)<br>v. Give feedback on the service, including how to make a complaint<br>vi. Get involved in improving services (QS HN-199) | Y | | Y | | Y | |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-102 | **Information about Haemoglobin Disorders**<br><br>Written information should be offered to patients and, where appropriate, their carers covering at least:<br>a. A description of their condition (SC or T), how it might affect them and treatment available<br>b. Problems, symptoms and signs for which emergency advice should be sought<br>c. How to manage pain at home (SC only)<br>d. Splenic palpation and Trans-Cranial Doppler scanning (children only)<br>e. Transfusion and iron chelation<br>f. Possible complications, including priapism and complications during pregnancy<br>g. Health promotion, including:<br>i. Travel advice<br>ii. Vaccination advice<br>h. National Haemoglobinopathy Registry, its purpose and benefits<br>i. Self-administration of medications and infusions | Y | | Y | | N | Written information covering Trans-Cranial Doppler scanning was not seen at the time of the visit. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-103 | **Care Plan**<br><br>All patients should be offered:<br>a. An individual care plan or written summary of their annual review including:<br>i. Information about their condition<br>ii. Plan for management in the Emergency Department<br>iii. Planned acute and long-term management of their condition, including medication<br>iv. Named contact for queries and advice<br>b. A permanent record of consultations at which changes to their care are discussed<br>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable). | Y | | Y | | Y | |
| HN-104 | **Information for Primary Health Care Team**<br><br>Written information should be sent to the patient's primary health care team covering available local services and:<br>a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC)<br>b. Side effects of medication, including chelator agents [SC and T]<br>c. Guidance for GPs on:<br>i. Hydroxycarbamide and iron chelation therapy (if being prescribed by GPs)<br>ii. Immunisations<br>iii. Contraception and sexual health<br>d. Indications and arrangements for seeking advice from the specialist service | Y | | Y | | Y | |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-105 | **Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)**<br><br>Written information should be offered to patients and their carers covering:<br>a. Reason for the scan and information about the procedure<br>b. Details of where and when the scan will take place and how to change an appointment<br>c. Any side effects<br>d. Informing staff if the child is unwell or has been unwell in the last week<br>e. How, when and by whom results will be communicated | Y | | N/A | This QS is not applicable to LHTs. In practice a TCD clinic was run monthly by the lead clinician from the RLH at the Newham Sickle Cell and Thalassaemia Centre. | N | This QS is not applicable to LHTs who did not perform TCDs, but TCDs were performed by this LHT and written information was not available as defined in the QS. |
| HN-106 | **School Care Plan (Children's Services Only)**<br><br>A School Care Plan should be agreed for each child or young person covering, at least:<br>a. School attended<br>b. Medication, including arrangements for giving / supervising medication by school staff<br>c. What to do in an emergency whilst in school<br>d. Arrangements for liaison with the school<br>e. Specific health or education need (if any) | Y | | Y | | Y | |
| HN-194 | **Environment**<br><br>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 | | Y | | Y | However, the out-patient waiting area for families was very cramped. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-195 | **Transition to Adult Services**<br><br>Young people approaching the time when their care will transfer to adult services should be offered:<br>a. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services<br>b. A named coordinator for the transfer of care<br>c. A preparation period prior to transfer<br>d. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards | Y | | N/A | This QS is not applicable to LHTs. Transition clinics were held at NUH every four months with representatives from the paediatric and adult teams. | N/A | This QS is not applicable to LHTs. Transition clinics were held at WXH twice a year with representatives from the paediatric and adult teams. |
| HN-199 | **Involving Patients and Carers**<br><br>The service's involvement of patients and carers should include:<br>a. Mechanisms for receiving feedback from patients and carers<br>b. An annual patient survey (or equivalent)<br>c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service<br>d. Examples of changes made as a result of feedback and involvement of patients and carers | Y | | Y | | N | Reviewers did not see any examples of changes made as a result of feedback. There were no support groups in operation in the local area for children, young people and their families. See also comments from parents in the main report. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-201 | **Lead Consultant**<br><br>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 | | N | The lead consultant only had three PAs allocated to the haemoglobinopathy service (clinical and administration). | N | The service was led by a non-consultant grade clinician. The lead clinician only had two PAs allocated to the haemoglobinopathy service (clinical and administration) and there was no cover for absences. |
| HN-202 | **Lead Nurse**<br><br>A lead nurse should be available with:<br>a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders<br>b. Responsibility for liaison with other services within the network<br>c. Competences in caring for people with haemoglobin disorders<br>d. Competences in the care of children and young people (children's services only)<br>The lead nurse should have appropriate time for their leadership role and cover for absences should be available. | N | The lead nurse post was new and at the time of the visit the lead nurse had only 1 wte for the haemoglobinopathy service (clinical, administration, training and leadership across the network) and was covering the vacant CNS post. The community CNS (1 wte) had insufficient time for the number of patients cared for by the service, and there was no cover for absences. | N | Insufficient specialist nursing time (1 wte) was available for the number of patients cared for by the service (approximately 204), and there was no cover for absences. At the time of the visit the CNS post was temporary and the postholder had been seconded to the role for 12 months (although reviewers were told at feedback that the Trust had secured long-term funding for the post). | N | A lead nurse with responsibilities as defined by the QS was not in place. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-203 | **Medical Staffing and Competences**<br>The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>**All services:**<br>a. Haematology or paediatric medical staffing for clinics and regular reviews<br>b. 24/7 consultant and junior staffing for emergency care<br>**SHCs only:**<br>c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours<br>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<br>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 | Staffing levels were insufficient for the number of patients cared for by the SHT and its role in the network.<br>As a result of the changes in leadership in the LHTs (NUH, WXH and Queen's Hospital in Romford), the SHT was providing additional peer support through regular MDT meetings. | Y | | N | The lead clinician did not have cover for absences and therefore the weekly clinic had to be rearranged when they were absent. If children were admitted acutely unwell the paediatricians would contact the SHT for advice. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-204 | **Nurse Staffing and Competences**<br>The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>a. Clinical nurse specialist/s with responsibility for the acute service<br>b. Clinical nurse specialist/s with responsibility for the community service<br>c. Ward-based nursing staff<br>d. Day unit (or equivalent) nursing staff<br>e. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion<br>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 | Insufficient CNS capacity was in place for the acute and community services (see main report). A training programme was in place, but there was no evidence that staff had completed competences in the care of people with haemoglobin disorders, as a competency framework was not in place. | N | The CNS was seconded to the post, but had plans to develop a training programme. A competence framework and training plan was not in place although staff did attend the RLH for training. Staff had blood transfusion skills but not cannulation skills, as cannulations were usually undertaken by medical staff. | N | There was no CNS for the acute service. Some support was available from the community CNS. A competence framework was not in place and there was no evidence that ward-based nursing staff had competences in the care of people with haemoglobin disorders. Day unit staff did have cannulation and transfusion skills. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-205 | **Psychology Staffing and Competences**<br>The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>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<br>b. Time for input to the service's multi-disciplinary discussions and governance activities<br>c. Provision of, or arrangements for liaison with and referral to, neuro-psychology<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available. | N | No specific psychology support for people with haemoglobin disorders was available. Some support was available from the child and adolescent mental health service (0.2 wte), but the postholder was on maternity leave and there was no cover in place.<br>Access to neuro-psychology was in place.<br>(British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggests 1 wte for 300 patients). | N | No specific psychology support for people with haemoglobin disorders was available.<br>(British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggests 1 wte for 300 patients). | N | No specific psychology support for people with haemoglobin disorders was available.<br>(British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggests 1 wte for 300 patients). |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-206 | **Training Plan**<br>A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders. | N | A number of study days were held, but no training plan was in place to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders. | N | A number of study days were held, but no training plan was in place to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders. | N | A number of study days were held, but no training plan was in place to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.The lead clinician delivered training for junior medical staff and local GPs. |
| HN-207 | **Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)**<br>Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available. | Y | | N/A | This QS is not applicable to LHTs. | Y | This QS is not applicable to LHTs but TCDs were performed on site and evidence was available to show compliance with this QS. |
| HN-299 | **Administrative, Clerical and Data Collection Support**<br>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service. | Y | | Y | | N | The service did not have support for data collection. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-301 | **Support Services**<br><br>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.<br>a. Social worker/ benefits adviser<br>b. Leg ulcer service<br>c. Play specialist (children's services only)<br>d. Chronic pain team (adult services only)<br>e. Dietetics<br>f. Physiotherapy (in-patient and community-based)<br>g. Occupational therapy<br>h. Mental health services (adult and CAMHS)<br>i. DNA studies<br>j. Polysomnography | Y | (d) is not applicable to children's services. | Y | (d) is not applicable to children's services. | N | Reviewers were told that access to (a) and (h) was not always timely. (d) is not applicable to children's services. |
| HN-302 | **Emergency Department – Staff Competences**<br><br>Medical and nursing staff working in the Emergency Department/s should have competences in urgent care of people with haemoglobin disorders. | Y | See Good Practice section of the report. | N | An audit of time to analgesia had not yet been completed. Staff who met with the reviewing team were clear about the process, and patients confirmed that they did receive analgesia quickly. | Y | However, the most recent pain audit identified issues with the initial 'streaming' process, which created delays in children being sent to the PED. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-303 | **Specialist On-site Support**<br>Access to the following specialist staff and services should be easily available on the same hospital site as the specialist team:<br>a. Manual exchange transfusion (24/7)<br>b. Erythrocytapheresis<br>c. Acute pain team including specialist monitoring of patients with complex analgesia needs<br>d. High dependency care, including non-invasive ventilation<br>e. Level 2 and 3 critical care | Y | | N/A | This QS is not applicable to LHTs. | N/A | This QS is not applicable to LHTs. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-304 | **Specialist Services - Network**<br><br>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:<br>a. Pulmonary hypertension team (adults)<br>b. Consultant obstetrician with an interest in care of people with haemoglobin disorders and specialist high risk anaesthetics (adults)<br>c. Respiratory physician with interest in acute/chronic sickle lung disease and obstructive sleep apnoea (adults & children)<br>d. Fertility, including pre-implantation genetic diagnosis and sperm storage (adults)<br>e. Consultant cardiologist with interest in sickle cardiomyopathy, iron overload related heart disease (adults)<br>f. Consultant endocrinologist with interest in thalassaemia related endocrinopathy and osteoporosis (adults)<br>g. Consultant paediatric endocrinologist with interest in growth problems related to haemoglobinopathies and thalassaemia related endocrinopathy (children)<br>h. Hepatobiliary team with an interest in sickle hepatopathy, viral liver disease, iron overload-related liver disease (adults & children)<br>i. Consultant neurologist and neurosurgeon with an interest in sickle vasculopathy (adults & children)<br>j. Hyperacute stroke service (adults)<br>k. Consultant ophthalmologist with an expertise in sickle retinopathy and chelation related eye disease (adults & children)<br>l. Consultant nephrologist with expertise in sickle nephropathy (adults & children)<br>m. Consultant urologist with expertise in managing priapism and erectile dysfunction (adults & children)<br>n. Orthopaedic service with expertise in managing sickle and thalassaemia related bone disease (adults & children)<br>o. Specialist imaging, including<br>i. MRI tissue iron quantification of the heart and liver<br>ii. Trans-Cranial Doppler ultrasonography (children)<br>p. Bone marrow transplantation services (children only)<br>q. Physiotherapy services (in patient and community based)<br>r. Interventional and neuroradiology for neurovascular complications | Y | | N/A | This QS is not applicable to LHTs. | N/A | This QS is not applicable to LHTs. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-305 | **Laboratory Services**<br><br>UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available. | Y | | Y | | Y | |
| HN-401 | **Facilities and Equipment**<br><br>Facilities and equipment should be appropriate for the usual number and case mix of patients. Equipment should be appropriately maintained. | Y | | Y | | Y | |
| HN-501 | **Transition Guidelines**<br><br>Guidelines on transition to adult care should be in use covering at least:<br>a. Age guidelines for timing of the transfer<br>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<br>c. Allocation of a named coordinator for the transfer of care<br>d. A preparation period and education programme relating to transfer to adult care<br>e. Communication of clinical information from paediatric to adult services<br>f. Arrangements for monitoring during the time immediately after transfer to adult care<br>g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams | Y | | Y | This QS is not applicable to LHTs. Transition clinics were held at NUH every four months with representatives from the paediatric and adult teams. | Y | This QS is not applicable to LHTs. Transition clinics were held at WXH twice a year with representatives from the paediatric and adult teams. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-502 | **Monitoring Protocols**<br><br>Protocols should be in use covering the monitoring expected at:<br>a. First out-patient appointment (SHC only)<br>b. Routine monitoring<br>c. Annual review (SHC & any LHTs to which annual reviews are delegated)<br>Protocols should cover both clinical practice and information for patients and families. | Y | | Y | | Y | |
| HN-503 | **Clinical Guidelines: LHT Management and Referral**<br><br>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 | | Y | Shared care guidance between the SHT and LHTs across the network had been agreed. | Y | Shared care guidance between the SHT and LHTs across the network had been agreed. |
| HN-504 | **Transfusion Guidelines**<br><br>Transfusion guidelines should be in use covering:<br>a. Indications for:<br>i. emergency and regular transfusion<br>ii. use of simple or exchange transfusion<br>iii. offering access to automated exchange transfusion to patients on long-term transfusions<br>b. Protocol for carrying out a manual and automated exchange transfusion<br>c. Investigations and vaccinations prior to first transfusion<br>d. Recommended number of cannulation attempts | Y | | Y | | Y | |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-505 | **Chelation Therapy**<br>Guidelines on chelation therapy should be in use covering:<br>a. Indications for chelation therapy<br>b. Choice of chelation drug/s, dosage and dosage adjustment<br>c. Monitoring of haemoglobin levels prior to transfusion<br>d. Management and monitoring of iron overload, including management of chelator side effects<br>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2<br>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.<br>g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible. | Y | | Y | | Y | |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-506 | **Clinical Guidelines: Acute Complications**<br><br>Guidelines on the management of acute complications should be in use covering at least:<br>**For patients with sickle cell disease:**<br>a. Acute pain<br>b. Fever, infection and overwhelming sepsis<br>c. Acute chest syndrome<br>d. Abdominal pain and jaundice<br>e. Acute anaemia<br>f. Stroke and other acute neurological events<br>g. Priapism<br>h. Acute renal failure<br>i. Haematuria<br>j. Acute changes in vision<br>k. Acute splenic sequestration (children only)<br>**For patients with thalassaemia:**<br>l. Fever, infection and overwhelming sepsis<br>m. Cardiac, hepatic or endocrine decompensation | Y | | Y | | Y | |
| HN-507 | **Specialist Management Guidelines**<br><br>Guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:<br>a. During anaesthesia and surgery<br>b. Who are pregnant<br>c. Receiving hydroxycarbamide therapy | Y | | Y | | Y | |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-508 | **Clinical Guidelines: Chronic complications**<br><br>Guidelines on the management of chronic complications should be in use covering at least:<br>a. Renal disease<br>b. Orthopaedic problems<br>c. Retinopathy<br>d. Cardiological complications / pulmonary hypertension<br>e. Chronic respiratory disease<br>f. Endocrinopathies<br>g. Neurological complications<br>h. Chronic pain<br>i. Liver disease<br>j. Growth delay / delayed puberty (children only)<br>k. Enuresis (children only) | Y | | Y | | Y | |
| HN-509 | **Referral for Consideration of Bone Marrow Transplantation (Children's Services Only)**<br><br>Guidelines for referral for consideration of bone marrow transplantation should be in use. | Y | | N/A | This QS is not applicable to LHTs. | N/A | This QS is not applicable to LHTs. |
| HN-510 | **Non-Transfusion Dependent Thalassaemia (nTDT)**<br><br>Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering:<br>a. Indications for transfusion<br>b. Monitoring iron loading<br>c. Indications for splenectomy | Y | | Y | | Y | |
| HN-599 | **Clinical Guideline Availability**<br><br>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 | | Y | |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-601 | **Service Organisation**<br><br>A service organisation policy should be in use covering arrangements for:<br>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)<br>b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission<br>c. Patient discussion at multi-disciplinary team meetings (QS HN-602)<br>d. Arrangements for liaison with community paediatricians and with schools (children's services only)<br>e. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated (children's services only)<br>f. Follow up of patients who do not attend<br>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.<br>h. Accessing specialist advice (QS HN-304)<br>i. Two-way communication of patient information between SHC and LHTs<br>j. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together | N | Reviewers were not assured that appropriate 'fail-safe' arrangements were in place for ensuring all newly identified babies were seen by the SHT and that children and young people had a TCD when indicated. | N | Reviewers were not assured that appropriate 'fail-safe' arrangements were in place for ensuring all newly identified babies were seen by the SHT, and that children and young people had a TCD when indicated. | N | Reviewers were not assured that appropriate 'fail-safe' arrangements were in place for ensuring all newly identified babies were seen by the SHT, and that children and young people had a TCD when indicated. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-602 | **Multi-Disciplinary Meetings**<br><br>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 | | Y | |
| HN-603 | **Delegation of Annual Reviews**<br><br>If annual reviews are undertaken by LHT/s on behalf of the SHC, a written agreement should be in place covering:<br>a. Monitoring protocols (QS HN-502)<br>b. LHT management and referral guidelines (QS HN-503)<br>c. National Haemoglobinopathy Registry data collection (QS HN-701) | N/A | | Y | Shared care guidance between the SHT and LHTs across the network had been agreed. | Y | Shared care guidance between the SHT and LHTs across the network had been agreed. |
| HN-604 | **Out of Hours Elective Care**<br><br>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 | | N | There was no out-of-hours provision for routine transfusions, and transfusions were only available on Wednesdays. | N | Access to out-of-hours routine transfusions was limited, and transfusions were only available on Wednesdays until 6pm with some capacity on Thursdays until 7pm. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-605 | **Service Level Agreement with Community Services**<br>A service level agreement for support from community services should be in place covering, at least:<br>a. Role of community service in the care of patients with haemoglobin disorders<br>b. Two-way exchange of information between hospital and community services. | N | A service level agreement was in place with Homerton University Hospital but not with other community services linked with the SHT. The community service for Tower Hamlets was part of Barts Health, and the team was embedded within the SHT. | N | No service level agreements were in place with local community services. | N | No service level agreements were in place with local community services. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-606 | **Trans-Cranial Doppler Ultrasound Standard Operating Procedure (Children's Services Only)**<br><br>A Standard Operating Procedure for Trans-Cranial Doppler ultrasound should be in use covering at least:<br>a. Trans-Cranial Doppler modality used<br>b. Identification of ultrasound equipment and maintenance arrangements<br>c. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-207)<br>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<br>e. Arrangements for recording and storing images and ensuring availability of images for subsequent review<br>f. Reporting format<br>g. Arrangements for documentation and communication of results<br>h. Internal systems to assure quality, accuracy and verification of results | Y | | N/A | This QS is not applicable to LHTs. | N/A | This QS is not applicable to LHTs. |
| HN-607 | **Network Review and Learning Meetings**<br><br>At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798). | Y | | Y | | Y | |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-608 | **Neonatal Screening Programme Review Meetings**<br>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 | Annual meetings with representatives of the neonatal screening programme were not held. | N/A | This QS is not applicable to LHTs, but the LHT was notified of newly diagnosed babies by the community team. Reviewers considered that developing links with the neonatal screening programme would make the 'fail-safe' arrangements more robust. | N/A | This QS is not applicable to LHTs, but the LHT was notified of newly diagnosed babies by the community team. Reviewers considered that developing links with the neonatal screening programme would make the 'fail-safe' arrangements more robust. |
| HN-701 | **National Haemoglobinopathy Registry**<br>Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies and patients lost to follow up. | N | Patients were consented and registered on the NHR, but the other data defined by the QS were not entered. | N/A | This QS is not applicable to LHTs, but patients were consented and registered on the NHR. | N/A | This QS is not applicable to LHTs, but patients were consented and registered on the NHR. |
| HN-702 | **Activity Data**<br>The service should monitor on an annual basis:<br>a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances<br>b. Length of in-patient stays<br>c. Re-admission rate<br>d. 'Did not attend' rate for out-patient appointments | N | Readmission was reported as being rare so the rates were not specifically collected. Data covering all other aspects of the QS were collected. | Y | | Y | |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-703 | **Quality Dashboard**<br>The service should monitor Quality Dashboard data including the number and percentage of:<br>a. Adverse events reported on the NHR for which a mortality or serious case review has taken place<br>b. Children who have had Trans-Cranial Doppler screening undertaken within national guidelines<br>c. Patients given pain relief within half an hour of presentation with sickle crisis<br>d. Patients with possible sickle disorders identified by neonatal screening who have been entered on a care pathway<br>e. Eligible children beginning penicillin at or before three months of age<br>f. Patients registered on the National Haemoglobinopathy Registry who had an annual review undertaken within the last year<br>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<br>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) | N | Monitoring of the quality dashboard data was not in place for (e), (f), (g) and (h). All other aspects of the QS were met. | N/A | This QS is not applicable to LHTs. | N/A | This QS is not applicable to LHTs. |
| HN-704 | **Other Quality Data**<br>The service should monitor on an annual basis:<br>a. Proportion of children who have been offered treatment following Trans-Cranial Doppler Screening | Y | However, data appeared low for the number of patients cared for by the SHT. See main report around the validation process. | N/A | This QS is not applicable to LHTs. | N/A | This QS is not applicable to LHTs. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-705 | **Other Audits**<br>Clinical audits covering the following areas should have been undertaken within the last two years:<br>a. Availability of extended red cell phenotype in all patients and the proportion of patients who have developed antibodies<br>b. Whether all eligible patients on long term transfusion have been offered automated exchange transfusion<br>c. Waiting times for elective:<br>i. Phlebotomy<br>ii. Cannulation<br>iii. Setting up of the blood transfusion (for pre-ordered blood) | N | Clinical audits covering (a) and (c) had not been undertaken in the last two years. For (b), numbers of children and young people on automated exchange transfusion were available but it was not clear from the evidence whether this included all patients on long term transfusions who would be eligible. | N | A range of audits had been commenced but not yet completed. | N | An audit programme covering the requirements of the QS was not in place. |
| HN-706 | **Network Audits**<br>The service should participate in agreed network-wide audits. | Y | | N | The service had not taken part in the agreed network audits. | Y | |
| HN-707 | **Research**<br>The SHC should actively participate in research relating to the care of patients with haemoglobin disorders. | Y | | N/A | This QS is not applicable to LHTs, but the LHT was referring eligible patients to the SHT for inclusion in clinical and investigator-led studies. | N/A | This QS is not applicable to LHTs, but the LHT was referring eligible patients to the SHT for inclusion in clinical and investigator-led studies. |

| Ref | Standard | The Royal London Hospital (RLH) SHT | | Newham University Hospital (NUH) | | Whipps Cross University Hospital (WXH) | |
|---|---|---|---|---|---|---|---|
| | | Met? | Comments | Met? | Comments | Met? | Comments |
| HN-708 | **Trans-Cranial Doppler Quality Assurance (Children's Services Only)**<br>The service should monitor and review at least annually:<br>a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-207)<br>b. Results of internal quality assurance systems (QS HN-606)<br>c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) | Y | The internal TCD quality assurance process was very good. See main report.<br>(c) was not applicable, as a national quality assurance process was not established. | N/A | This QS is not applicable to LHTs. | N/A | This QS is not applicable to LHTs. |
| HN-798 | **Review and Learning**<br>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:<br>a. Review of any patient with a serious adverse event or who died<br>b. Review of any patients requiring admission to a critical care facility<br>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) | N | Annual review of trends in NHR data was not possible as data for all aspects were not submitted. All other aspects of the QS were met. | Y | | Y | |
| HN-799 | **Document Control**<br>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | | Y | | Y | |

Return to Index