Health services for people with haemoglobin disorders

Queen Elizabeth Hospital, Lewisham and Greenwich NHS Trust

Visit Date: 9th October 2019

Report Date: February 2020

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Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Queen Elizabeth Hospital, Lewisham and Greenwich NHS Trust that took place on 9th October 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 Queen Elizabeth Hospital, Lewisham and Greenwich 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:

- Lewisham and Greenwich NHS Trust
- Oxleas NHS Foundation Trust
- NHS England Specialised Commissioning – Haemoglobinopathies
- NHS Bexley, Greenwich and Lewisham Clinical Commissioning Groups

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioner in relation to this report is the NHS England & NHS Improvement Lead Commissioner for Haemoglobinopathies, and NHS Bexley, Greenwich and Lewisham Clinical Commissioning Groups.

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 Queen Elizabeth Hospital, Lewisham and Greenwich NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. We are also grateful to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

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Review Visit Findings

Trust-wide

General comments

This review looked at the care of children, young people and adults with haemoglobin disorders. During the course of the visit, reviewers met with patients, parents and carers, and with staff providing the services, and visited the emergency department (ED), day units, the paediatric out-patients department, and wards.

The Lewisham and Greenwich NHS Trust was formed on 1st October 2013 following the dissolution of the South London Healthcare Trust. Queen Elizabeth Hospital (QEH) in Woolwich and University Hospital Lewisham (UHL) were merged to form the Lewisham and Greenwich NHS Trust. Queen Elizabeth Hospital served a local population of approximately 500,000.

The Trust worked in three boroughs, Lewisham, Greenwich and Bexley, and provided an integrated community service for the borough of Lewisham. Oxleas NHS Foundation Trust provided community services to Greenwich and Bexley, including haemoglobinopathy community services. A specialist haemoglobinopathy community service, commissioned by the boroughs of Lambeth, Southwark and Lewisham and provided by Guy's and St Thomas' NHS Foundation Trust, provided haemoglobinopathy counselling and community care to patients in Lewisham. At the time of the visit there was no equivalent service for Greenwich and Bexley patients, although Oxleas provided a limited paediatric haemoglobinopathy community service to Greenwich and Bexley residents. The Guy's and St Thomas' Hospital NHS Foundation Trust specialist haemoglobinopathy community service also provided antenatal counselling to Greenwich and Bexley residents attending the QEH Maternity Unit. Since the last visit in 2015 the laboratory services had been consolidated, with the main laboratory situated at the QEH site and a rapid response laboratory at the UHL site providing a full transfusion service and urgent haemoglobinopathy service.

The Trust had been formally recognised as a Specialist Haemoglobinopathy Team (SHT) for adults and children in April 2019 following the national procurement exercise conducted by NHS England (NHSE). Both teams were working towards expanding staffing and facilities further to meet the requirements of a comprehensive SHT, and an action plan had been submitted to NHSE. A business plan covering both adult and paediatric services to secure a Trust-based specialist psychology service, an increase in clinical nurse specialist (CNS) and consultant sessions, and access to benefits advice, had received provisional approval in early September, and was pending confirmation of commissioning arrangements.

The haemoglobinopathy services were part of the South East London Sickle Cell and Thalassaemia Network led by Guy's and St Thomas' Hospital NHS Foundation Trust and King's College Hospital NHS Foundation Trust (KCH).

At the time of the visit the QEH adult haemoglobinopathy team was reviewed as an SHT. The QEH paediatric service was reviewed as a local haemoglobinopathy team (LHT).

ADULTS

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long-term red cell transfusions
The Lewisham and Greenwich NHS Trust – Queen Elizabeth Hospital (QEH)	SHT	183[1]	6	3

[1] *From Trust presentation total of 403 registered on the NHR - 220 patients at UHL, 183 patients at QEH*

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
The Lewisham and Greenwich NHS Trust – Queen Elizabeth Hospital (QEH)	LHT	330	7	10

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Specialist Team (Adult Services): Queen Elizabeth Hospital, Lewisham and Greenwich NHS Trust

General Comments and Achievements

This was an enthusiastic team with strong leadership from the lead clinician for haemoglobin disorders for the Trust. There was evidence of collaborative working and good relationships with both the managerial team and the paediatric service. A patient support group had met for the first time in early October 2019.

Patients attending QEH who required access to an automated exchange programme were transferred to UHL. Out of hours, the apheresis service was not available, but patients were able to receive manual exchange transfusions at QEH and UHL. As the apheresis service was based at UHL, some day-time emergency automated exchange transfusions could be performed at UHL. Shared care arrangements were in place for patients with thalassaemia major, who would attend University College London Hospitals NHS Foundation Trust for annual reviews.

Specialist Haemoglobinopathy Team	Links with other Specialist Haemoglobinopathy Teams
The Lewisham and Greenwich NHS Trust - Queen Elizabeth Hospital (QEH)	• King's College Hospital NHS Foundation Trust • Guy's and St Thomas' NHS Foundation Trust

Staffing

QEH Staffing for the SHT Adult Haemoglobinopathy Service [2]	Number of patients	Actual wte (at time of the visit)	Staffing required as recommended by NHSE
Consultant haematologist with >0.6 wte per 150 patients dedicated to work with patients with haemoglobinopathies	183	0.275	0.73
At least 0.25 wte allocated to haemoglobinopathies CPD in the adult consultant job plan	183	No dedicated haemoglobinopathy CPD, formed part of general CPD allocation	-
Clinical psychologist for adult patients who has >0.5 wte per 200 patients dedicated to work with patients with haemoglobinopathies	183	0	0.46

Emergency Care

Patients with acute problems usually attended the Emergency Department (ED) at QEH. No arrangements were in place for direct admission to either wards or day care. Patients were admitted via the medical team, and the haematology team was notified within 12 hours of admission (or sooner if there were any concerns about the patient's condition).

A consultant haematologist cover was available at all times to provide general haematological advice, with additional cover from the specialist trainee doctors (ST3 and above) or specialty doctor some of the time. The QEH and UHL sites had separate on-call rotas, though there were plans to develop a joint on-call rota in the future.

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

In-patient Care

Patients at the QEH site were usually admitted from the ED to one of the acute medical wards (Ward 1 or 2), and then transferred to Ward 21 when a bed became available. Occasionally patients were admitted directly to Ward 21 from the ED or the haematology clinic.

Day Care

Transfusions were available on the medical diagnostic unit at QEH, which was operational from 8am to 6pm, or Ward 21. Day treatment beds were available for transfusion at weekends from 8am to 6pm.

Community-based Care

A specialist nurse-led community service was based at the South East London Sickle Cell and Thalassaemia Centre for patients residing in the borough of Lewisham. No equivalent service was in place for patients living in the Greenwich and Bexley areas. General community services were provided by Oxleas NHS Foundation Trust for patients residing in these boroughs.

Progress since Last Visit

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

a. Specialist Haemoglobinopathy Team (SHT) status had been granted (as of 1 April 2019) following a successful application and the full achievement of both Haemoglobinopathy CQUINS for 2017-2018 and 2018-2019. At the time of the visit, the team had provisional approval of an action plan and a business case to develop the SHT, including plans to develop a psychology service for children, young people and adults, the appointment of an additional adult consultant, the appointment of an apheresis / community CNS, additional paediatrics CNS time and the purchase of some benefits advice sessions.

b. Transition clinics for young people transitioning to the adult haemoglobinopathy services had been implemented at each hospital site.

c. The adult CNS team had been increased to 2.5 wte to work across both the QEH and UHL hospital sites.

d. The provision of an automated exchange transfusion programme based at the UHL site had been implemented; this was accessible to all patients.

e. A consultant haematologist had been appointed who had a specific interest in the care of young people transitioning to adult services and young adults with haemoglobin disorders.

f. A data manager had been appointed.

Views of Service Users and Carers

The visiting team met ten adult patients who had sickle cell or thalassaemia, all of whom received out-patient care from the visiting consultant. The visiting consultant stayed with the patients during the meeting with reviewers, which may have affected the services users' ability to be open with the visiting team about their views on the service. Reviewers drew the following conclusions from the meeting:

- Overall, the users and carers were highly complimentary about the care and support available from the visiting consultant and the QEH CNS team.
- The patients and carers complemented the CNS team and spoke highly of their commitment and compassion in caring for the patients: 'they go over and beyond'.
- The nursing staff on Ward 21 were described as "amazing".
- Patients would only see the visiting consultant and, if they could not contact the consultant on the consultant's mobile number, were unsure who else to contact for help and advice.

- All the service users who met with the visiting team commented that arrangements for receiving blood transfusions worked well.
- Patients considered that they were seen quickly when attending the ED, and that staff were helpful.
- Patients commented that their emergency care plans were not always accessed by staff, which meant that they were constantly repeating their medical histories.
- Service users commented that the lack of any community services meant that they were unsure where to go for additional local support and advice.
- The service users were not confident that staff in the admissions wards had sufficient understanding of haemoglobin disorders, commenting that patients often had to wait for appropriate analgesia and help with care. Access to patient controlled analgesia (PCA) was not possible for in-patients on either of the acute admission wards.
- Of particular concern was feedback from service users that when they were admitted to Ward 1 they felt as if they were always 'disturbing the nurses', and on occasions were being encouraged by a few nursing staff not to rely on 'pain killers' but to 'put their trust in their spiritual leader'.
- All those who met with the reviewers considered that the lack of access to psychology support was an issue, and that they would benefit from access to specialist psychological support.

Good Practice

1. The pathway for patients attending in an emergency to the ED was very efficient. The department was led well by the ED consultants and team. Patients were assessed quickly and a patient group direction (PGD) was in place for giving opiate analgesia. Patients reported that they only had to wait ten minutes for their initial triage assessment.
2. The written information available for patients was very comprehensive. Information was of a good quality and professionally printed by the Trust.

Immediate Risks: No immediate risks were identified during the course of the visit.

Concerns

1. **Consultant staffing**

   Reviewers were concerned about whether the haemoglobinopathy service had sufficient consultant medical staff at QEH to provide staffing for regular reviews, emergency care and clinics as well as time for leadership and governance. At the time of the visit there was a locum consultant haematologist who was the deputy lead clinician, and a visiting consultant from King's College Hospital NHS Foundation Trust (KCH). The visiting consultant, who had previously worked at the Trust, provided an outreach clinic at QEH one day a month. Cover was available from the overall Trust lead for the haemoglobin disorders service and other haematologists based at QEH. Interviews for the substantive consultant haematologist vacancy, to which the locum consultant had been invited, were due to take place the week after the review visit.

2. **Acute admissions wards**

   Reviewers were concerned about the care provided on the acute admission wards (Wards 1 and 2) for the following reasons:

   a. Reviewers heard feedback from a number of service users about attitudes to care and timely access to appropriate analgesia when they were admitted to Ward 1 (see views of service users on pages 10 and 11). Reviewers considered that prompt action will be required to address staff attitudes and behaviour, and that there should be a plan to deliver a programme of training for ward staff covering the needs of patients with haemoglobin disorders.

   b. Staff who met with the reviewers commented that they were not always notified that patients had been seen in the ED or admitted to the acute admissions wards over the weekend. Reviewers were told that patients

admitted to the acute admissions wards were often discharged without being notified to, or reviewed by, a senior haematology decision-maker.

3. **Patient expectations**

From discussions with staff and service users during the course of the visit, reviewers were concerned at what appeared to be the over-reliance on the visiting consultant to provide ongoing care and emergency advice to a large number of patients. Reviewers were told that when the consultant had left the Trust in 2017, seventy patients, most with complex needs, also moved and were seen by the visiting consultant at KCH. At other times the patients would call the consultant's mobile phone for advice and ongoing monitoring. Whilst the arrangements were understood, as the patients were initially concerned about consistency in care, reviewers considered that these arrangements were not sustainable or appropriate, particularly as the patients accessed the QEH ED and preferred not to be seen by any other haemoglobinopathy consultants, although emergency care was provided by the QEH team. Reviewers also considered that providing this level of service created an imbalance within the QEH team. This raised unreasonable patient expectations for other consultant staff to provide similar access (see also Concern 5 about records management) and could affect the ability of the service to develop as an SHT.

4. **Ward nurse competences**

No evidence was available to assure reviewers that staff on the wards to which people with haemoglobin disorders were usually admitted (acute admissions unit and the haematology / oncology ward) had appropriate competences to care for patients with haemoglobin disorders.

5. **Records management**

Reviewers were concerned at the Trust governance arrangements in place to ensure that data were being appropriately managed and accessible to all staff to make clinical decisions. Reviewers were made aware that a number of different databases, electronic records and paper records for out-patients' notes, and a standalone database, were being used to record patient information. Reviewers were particularly concerned that the visiting consultant was having to update some patient information on a standalone Excel spreadsheet which was then sent to the ED and the leads in the service on a monthly basis to keep them informed of any changes in the patients' clinical management, including the latest diagnostic results. This could mean that records were out of date with the latest treatment decisions.

6. **Generic pain protocol**

The generic management of pain protocol did not contain sufficient detail about the management of pain. For example, the protocol referred to the World Health Organisation (WHO) analgesia ladder but did not include reference to the agreed Trust specification on the use of opiates. The criteria for the use of either intravenous or subcutaneous analgesia were also not clear enough to enable staff to reach a decision on the most appropriate route of analgesia for the patient.

7. **Clinical nurse specialist**

The CNS team had insufficient time available for the number of patients being cared for with haemoglobin disorders (approximately 430 patients being cared for across both hospital sites) to provide a comprehensive apheresis service, nurse-led clinics, specialist nursing advice and leadership for the service. At the time of the visit the CNS team consisted of one Band 8a CNS working across both hospital sites, 1 wte Band 7 CNS for the haemoglobinopathy service at QEH and a 0.5 wte Band 7 CNS for the service at UHL.

8. **Access to psychology**

Access to psychology staff with appropriate competences in the care of people with haemoglobin disorders and neuropsychology was not available.

9. **Community support**

   A community service to provide support for patients and their carers within Greenwich and Bexley boroughs was not commissioned. Reviewers were told that initial discussions had been held with local commissioners to discuss the issue.

10. **Executive support for specialist team development**

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

Further Consideration

1. From the evidence seen at the time of the visit, multi-disciplinary team (MDT) meetings were not well attended by staff from the QEH team. The number of QEH patients who were discussed within these meetings also appeared lower than would be expected for the number of patients being cared for by the team. Reviewing the arrangements for multi-disciplinary discussion may be helpful to understand the issues around attendance and the MDT process.
2. Access to evening and out of hours automated red cell exchange was not routinely possible at the Trust. The care of QEH patients requiring automated exchange transfusion programmes was transferred to UHL.
3. Transition clinics were being held bi-monthly, but a formal process for transition was not yet established.

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Specialist Team (Children and Young People Services): Queen Elizabeth Hospital, Lewisham and Greenwich NHS Trust

General Comments and Achievements

This was an experienced team who had good collaborative working relationships with the managerial team, adult service and the SHT based at KCH. It was clear to the reviewers that the team was highly committed and enthusiastic.

The paediatric service at Queen Elizabeth Hospital served 120,000 children from two London boroughs, Bexley and Greenwich. Children's community services for Bexley and Greenwich were provided by Oxleas NHS Foundation Trust.

The service continued to have an expanding population of haemoglobinopathy patients, with approximately thirty new patients accessing the service each year, including approximately nine new babies identified as having sickle cell disease from the local catchment area.

Cover for the lead paediatrician was provided by a general paediatrician with a special interest in haemoglobin disorders who had joined the service in 2018. A consultant haematologist had also been appointed, who had a special interest in the care of young people transitioning to adult services and young adults with haemoglobin disorders.

Monthly joint clinics were attended by a sonographer and a consultant haematologist from King's College Hospital NHS Foundation Trust. Multi-disciplinary meetings were held before the joint clinic.

There were 70 patients on hydroxycarbamide. A nurse-led hydroxycarbamide clinic had been established. The clinic was held alongside a clinic attended by one of the consultant paediatricians with a special interest in sickle cell disease, who was available for advice and support.

All patients were consented for registration on the National Haemoglobinopathy Registry[3] (NHR), and some part-time administrative support for the service was in place.

At the time of the visit the service was reviewed as a LHT however, the Trust had been successful in its application to become an adult and paediatric SHT, and at the time of the visit the paediatric service was in the process of transitioning from being an LHT to an SHT.

Local Haemoglobinopathy Team	Links to Specialist Haemoglobinopathy Teams
The Lewisham and Greenwich NHS Trust – Queen Elizabeth Hospital (QEH)	• King's College Hospital NHS Foundation Trust • Guy's and St Thomas' NHS Foundation Trust

Staffing

The table below details the expected staffing required for a SHT

Staffing for an SHT Paediatric Haemoglobinopathy Service [4]	Number of patients	Actual wte (at time of visit)	Staffing required as recommended by NHSE
Consultant haematologist / paediatrician with >0.6 wte per 150 patients dedicated to work with patients with haemoglobinopathies	337	0.25	1.35

[3] *The National Haemoglobinopathy Registry (NHR) is a database of patients with red cell disorders (mainly Sickle Cell Disease and Thalassaemia Major) living in the UK.*

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

Staffing for an SHT Paediatric Haemoglobinopathy Service [4]	Number of patients	Actual wte (at time of visit)	Staffing required as recommended by NHSE
At least 0.25 wte allocated to haemoglobinopathies CPD in the paediatric consultant job plan	337	As part of general consultant CPD	-
Clinical psychologist for paediatric patients with >0.5 wte per 150 patients dedicated to work with patients with haemoglobinopathies	337	0	1.12

Emergency Care

Children and young people attended the Emergency Department for triage, and, if required, were given analgesia before being fast-tracked for admission to the Happy Hippo Day Unit for further assessment by the paediatric team. If the patient's condition was unstable or they were in need of resuscitation, they would remain in the ED and the paediatric team were contacted to attend. The ED had a dedicated bay for paediatric resuscitation, and one bay for patients requiring high dependency care.

Inpatient Care

Safari and Tiger Wards were the children's in-patient wards and were able to provide in-patient care for between 20 and 24 children.

Safari Ward was an 18-bedded general paediatric ward providing in-patient care for children from birth until 16 years. In some circumstances, children older than 16 were admitted to the ward. There were 13 cubicles including two high dependency cubicles. Four cubicles had en suite facilities. In addition there was a five-bedded open ward. Parents were encouraged to stay at all times, and beds, washing and refreshment facilities were provided. There was a large playroom, a school room and a garden area.

Tiger Ward was a six-bedded in-patient unit consisting of six cubicles of which four had en suite facilities. Four of the beds were designated for Level 2 paediatric oncology shared care (POSCU), whilst the remaining two beds were used by other patients including patients with haemoglobin disorders.

Day Care

Happy Hippo Day Unit was open between the hours of 9.30am and 10pm seven days a week (and if staffing permitted, it would stay open until midnight). The unit was an assessment and observation unit for children presenting as emergencies. There were three assessment areas; one with four trolley places, one with two places and a single-bedded room. In addition to assessment and observation, the unit was used as an area to review recently discharged patients, or for out-patients. Children and young people requiring the administration of antibiotics or other infusions and those undergoing specialist investigations were also managed on the unit.

Outpatient Care

Dolphin Unit was dedicated paediatric out-patient department open five days a week. Paediatric phlebotomy services for children up to ten years of age were also available on the unit for part of the day (by appointment).

Weekly haemoglobinopathy clinics were held and a monthly joint sickle cell clinic attended by a sonographer and consultant haematologist from King's College Hospital. At this clinic Trans-Cranial Doppler (TCD) scans were performed.

Community-based Care

Children's community nursing services for the London boroughs of Bexley and Greenwich were provided by Oxleas NHS Foundation Trust. The service was provided by a single community-based CNS who also had general community nursing duties. The CNS provided support and guidance to families in the community and liaised with schools to ensure that health care plans were in place. The CNS was the contact for new-born referrals and would undertake the first new-born visit. When available, the CNS would attend the monthly joint sickle cell clinic.

Antenatal counselling was available at the Wooden Spoon Centre, provided by Guy's & St Thomas' NHS Foundation Trust.

Progress since Last Visit

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

- A nurse-led clinic for patients on hydroxycarbamide had been established.
- A second paediatric consultant with a specialist interest in sickle cell disease had been appointed.
- Nurse-controlled analgesia on ward for patients admitted with painful crises had been implemented.
- Funding had been granted for the appointment of a Trust-wide specialist nurse to support any young people transitioning to adult services.
- Closer links had been developed with haematology laboratory staff especially for blood transfusions.
- Funding for a psychologist and two CNSs (one adult, one paediatric) had been provisionally agreed.

Views of Service Users and Carers

During the course of the visit the visiting team met with five families representing five children aged between 9 and 14 years, and drew the following conclusions from these meetings:

- Overall, the users and carers were highly complimentary about the care and support available from the lead clinician and CNSs.
- Arrangements for communicating with medical and nursing staff were working well.
- The establishment of the nurse-led hydroxycarbamide clinic meant that the families felt that they understood more about the side effects of the therapy, and they valued the time they had with the CNS to discuss any other issues.
- Parents commented that support was always available from the CNS if they raised issues relating to their child's education or school; however, they commented that schools did not always follow the advice in the school care plans.
- The pathway of care when attending the ED was working well. The parents commented that all staff, from those who they met in the reception areas to ED staff, were helpful: the patients were seen quickly and, if required, received appropriate and timely analgesia.
- Parents commented that they had confidence in the team and would tend to return for care if they had moved to other areas.
- Blood transfusions after school were available, although there were often delays in starting transfusions because only two staff were available to cannulate children and young people, and the blood for transfusion was not always ready. Parents also commented that only one set of vital observations was taken during the procedure, which they considered was not sufficient to identify any problems.
- Parents commented that some staff were not as confident as others in caring for children and young people with haemoglobin disorders.
- The time for which children and young people had to wait for analgesia to be administered had improved.

Good Practice

1. The pathway for children and young people attending in an emergency had greatly improved, and parents commented that they were seen within 15 minutes of arrival.
2. The written information available for patients was very comprehensive. Information was of a good quality and professionally printed by the Trust.
3. A nurse-led hydroxycarbamide clinic had been established to provide monitoring, education and support for patient and carers.

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

Concerns

1. **Consultant staffing**

   Reviewers were concerned that the service had insufficient consultant medical staff with time available for the care of people with haemoglobin disorders to provide staffing for regular reviews, emergency care and clinics. At the time of the visit, the service was 0.8 wte short on consultant time, and the business case to develop the service to become a comprehensive SHT did not include any additional consultant time for the paediatric service. Reviewers considered that the lack of consultant time would make it difficult for further service developments to occur and for the national standards for a paediatric SHT to be met.

2. **Clinical nurse specialists**

   At the time of the visit the CNS team had insufficient time available for the number of patients being cared for with haemoglobin disorders (337 patients) to provide a comprehensive service, nurse-led clinics, specialist nursing advice and leadership for the service. At the time of the visit, the CNS team consisted of one CNS working across both hospital sites (who was only available on alternate days at QEH), and 1 wte children's community nurse who also had general community nursing duties. Reviewers were made aware that a business case for an additional CNS had received provisional approval from commissioners.

3. **Access to psychology**

   Access to psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders and their families and neuropsychology was not available.

4. **Competences and training plan**

   No evidence was available to assure reviewers that staff on the wards and day unit to which people with haemoglobin disorders were usually admitted had appropriate competences to care for patients with haemoglobin disorders. Reviewers were told that some staff could perform cannulation of children and young people.

   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 yet in place.

5. **Clinical guidelines and protocols**

   Reviewers raised the following concerns about the availability of guidance and protocols:

   a. Guidance covering chelation therapy was not in place.

   b. Guidelines covering the management of patients with non-transfusion thalassaemia (nTDT) were not yet in place.

   c. The prescription of blood transfusions for patients with thalassaemia were based on the patients' investigation results, but the Trust blood transfusion guidance did not include clear indications for staff to make a decision

on this basis. Staff who met with the reviewers commented that they would often have to ring the team at KCH for advice as to whether to transfuse a child or young person.

d. The pain protocol lacked the instructions and specifications of adjunct, as required (PRN) medications, such as naloxone, antihistamines and laxatives, when morphine was prescribed for pain.

Reviewers also heard from one parent who raised concerns about the management of their child's pain when admitted to the Trust. The parent did not consider that all staff were confident about adapting the Trust protocol when a child was registering a higher score, and therefore that the level of analgesia given was not always sufficient.

6. **Chelation transfusion case notes**

The case notes held in the day unit for patients on regular transfusions had a laminated sheet attached which included out of date doses for chelation medication and should be removed. The general spreadsheet, with up to date information on transfusions for all patients, did include up to date medication doses, and reviewers were assured that neither the unit nor the pharmacy staff would in practice refer to the laminated sheet.

7. **Executive support for specialist team development**

Reviewers noted the ongoing work with commissioners to develop the service and to enable the team to function as a designated specialist haemoglobinopathy team, but commented that, in order for the team to progress, ongoing Trust executive support would also be needed to ensure that the action plan was fully implemented.

Further Consideration

1. Reviewers considered that undertaking an audit of the waiting times for cannulation would be helpful to understand the extent of the issues raised by parents around the delays being experienced.
2. The service was considering the development of a TCD service at the Trust. Reviewers considered that this initiative would be a sensible development providing that the service was appropriately commissioned.
3. Transition clinics were being held monthly or bi-monthly, but a formal process for transition was not yet established.
4. MDT meetings to discuss and review patient care with the KCH SHT were comprehensive and well attended. Reviewers considered that it would be important to build on the existing MDT processes as the Trust paediatric services started to function as a specialist haemoglobinopathy team.

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Commissioning

The service had good links with both local and specialised commissioners.

This report contains a number of issues which would need to be addressed in order for both the adult and the paediatric teams to function as comprehensive Specialist Haemoglobinopathy Teams (SHTs). Reviewers were made aware of a plan to address these issues in full provided commissioners fully engage with this process.

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APPENDIX 1 Membership of Visiting Team

Clinical Leads		
Dr Emma Drasar	Consultant Haematologist	Whittington Health NHS Trust
Dr Mark Velangi	Consultant Paediatric Haematologist	Birmingham Women's and Children's NHS Foundation Trust

Visiting Team		
Edith Aimiuwu	Paediatric Haemoglobinopathy Clinical Nurse Specialist	Whittington Health NHS Trust
Annette Blackmore	Non-Malignant Haematology CNS	Cardiff and Vale UHB – Child Health
Dr Farzana Bashir	Paediatric Speciality Doctor	Barts Health NHS Trust
Dr Mercy Ibidapo	Consultant Haematologist	London North West University Healthcare NHS Trust
Natasha Lewis	Lead Nurse Sickle Cell & Thalassaemia	Homerton University Hospital NHS Foundation Trust
Dr Jenna Love	Clinical Psychologist	St George's University Hospitals NHS Foundation Trust
Dr Asad Luqmani	Consultant Haematologist	Imperial College Healthcare NHS Trust Hammersmith Hospital
June Okochi	Patient Representative	Sickle Cell Society
Aldine Thomas	Clinical Nurse Specialist Haemoglobinopathies	Barts Health NHS Trust
Joan Walters	Senior Practitioner / Lecturer (Children and Young People / Haemoglobinopathies)	King's College Hospital NHS Foundation Trust

QRS		
Sarah Broomhead	Assistant Director	Quality Review Service

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APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

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

Service	Number of applicable QS	Number of QS met	% met
Adults (SHT)	42	29	69
Children and Young People (LHT)	40	20	50
Total	**82**	**49**	**60**

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Specialist Services for People with Haemoglobin Disorders

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

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-102	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of their condition (SC or T), how it might affect them and treatment available b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Travel advice ii. Vaccination advice h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	Y		N	Information available at the time of the visit did not cover how to manage pain at home or splenic palpation.
HN-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	N	None of the records seen included a plan for management in the ED. None of the patients who met with the reviewers had received any written information about their condition or been given a copy of their care/treatment plan.	N	The clinical letters seen at the time of the visit did not include all the information defined in the NHR annual review proforma. School care plans followed a generic template and would benefit from being individualised. Work was in progress to ensure that children had documented emergency care plans.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-104	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and: a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on: i. Hydroxycarbamide and iron chelation therapy (if being prescribed by GPs) ii. Immunisations iii. Contraception and sexual health d. Indications and arrangements for seeking advice from the specialist service	Y	Information for the primary health care team was documented in the electronic notes seen but not in the paper copies made available to the reviewers. Letters covering immunisations were given to the patients to give to their GP rather than being sent to the GP directly.	N	Information did not cover contraception and sexual health. Letters to the primary health care team could be more explicit about indications and arrangements for seeking advice from the specialist service. Written information seen by the reviewers covered all other aspects of the QS.
HN-105	**Information about Trans-Cranial Doppler Ultrasound (Children's Services Only)** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Any side effects d. Informing staff if the child is unwell or has been unwell in the last week e. How, when and by whom results will be communicated	N/A		Y	

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-106	**School Care Plan (Children's Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school e. Specific health or education need (if any)	N/A		Y	
HN-194	**Environment** The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	However, reviewers commented that patients who needed regular transfusions were admitted to a range of different areas, as Ward 21 only had two cubicles.	Y	See also main report about patient feedback when attending for transfusions.
HN-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services b. A named coordinator for the transfer of care c. A preparation period prior to transfer d. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards	N	A formal process to ensure that children were transitioned to the adult service was not yet in place. The Trust had appointed a transition CNS to develop a programme for young people.	N	A formal process to ensure that children were transitioned to the adult service was not yet in place. The Trust had appointed a transition CNS to develop a programme for young people.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-199	**Involving Patients and Carers** The service's involvement of patients and carers should include: a. Mechanisms for receiving feedback from patients and carers b. An annual patient survey (or equivalent) c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service d. Examples of changes made as a result of feedback and involvement of patients and carers	Y		N	Processes were in place for involving service users and carers, but reviewers did not see any evidence of changes made as a result of feedback.
HN-201	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have an appropriate number of session/s identified for this role within their job plan and cover for absences should be available.	Y		Y	
HN-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y		Y	

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-203	**Medical Staffing and Competences** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including: **All services:** a. Haematology or paediatric medical staffing for clinics and regular reviews b. 24/7 consultant and junior staffing for emergency care **SHCs only:** c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours d. If doctors in training are part of achieving 'a' or 'b' then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	Consultant staffing was not sufficient for the number of patients cared for by the service. See main report.	N	Consultant staffing was not sufficient for the number of patients cared for by the service. See main report.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-204	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	No evidence was available to assure reviewers that staff on the wards to which people with haemoglobin disorders were usually admitted (the acute admissions unit and the haematology / oncology ward) had appropriate competences to care for patients with haemoglobin disorders. A community service was not in place.	N	No evidence was available to assure reviewers that staff on the wards and day unit to which people with haemoglobin disorders were usually admitted had appropriate competences to care for patients with haemoglobin disorders. Reviewers were told that some staff could perform cannulation of children and young people.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-205	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multi-disciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuro-psychology Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	Access to psychology staff with appropriate competences in the care of people with haemoglobin disorders and their families and neuropsychology was not available.	N	Access to psychology staff with appropriate competences in the care of children and young people with haemoglobin disorders and their families and neuropsychology was not available.
HN-206	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.	Y		N	A training plan to ensure that all staff were developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders was not yet in place. Study days were held.
HN-207	**Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A		N/A	The TCD service was provided on site from a practitioner from King's College Hospital NHS Foundation Trust.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-299	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	However, reviewers were told that the visiting consultant who provided a clinic each month did not have any administrative support.	Y	
HN-301	**Support Services** Timely access to the following services should be available. In Specialist Centres staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) as required. a. Social worker/ benefits adviser b. Leg ulcer service c. Play specialist (children's services only) d. Chronic pain team (adult services only) e. Dietetics f. Physiotherapy (in-patient and community-based) g. Occupational therapy h. Mental health services (adult and CAMHS) i. DNA studies j. Polysomnography	N	Access to a social worker and benefits advice was not available to patients residing in Greenwich and Bexley boroughs.	N	Access to a social worker and benefits advice was not available to families residing in Greenwich and Bexley boroughs.
HN-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department/s should have competences in urgent care of people with haemoglobin disorders.	N	A programme of training for ED staff was planned.	N	A programme of training for ED staff was planned.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-303	**Specialist On-site Support** Access to the following specialist staff and services should be easily available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Erythrocytapheresis c. Acute pain team including specialist monitoring of patients with complex analgesia needs d. High dependency care, including non-invasive ventilation e. Level 2 and 3 critical care	Y	Patients requiring red cell exchange were transferred to UHL.	N/A	This QS is not applicable for an LHT. Patients were transferred to the SHT at King's College Hospital. In order for the service to be compliant with the SHT criteria, access to manual exchange will need to be available on site.

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

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

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-502	**Monitoring Protocols** Protocols should be in use covering the monitoring expected at: a. First out-patient appointment (SHC only) b. Routine monitoring c. Annual review (SHC & any LHTs to which annual reviews are delegated) Protocols should cover both clinical practice and information for patients and families.	Y	See also main report about electronic and paper patient records.	Y	
HN-503	**Clinical Guidelines: LHT Management and Referral** Guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A		N	Guidance was not in place covering arrangements or criteria for referral to the SHT, particularly criteria for who should be seen in the specialist clinic run by the visiting consultant from KCH.
HN-504	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. emergency and regular transfusion ii. use of simple or exchange transfusion iii. offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for carrying out a manual and automated exchange transfusion c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts	Y		N	Transfusion guidelines did not include guidance for patients with thalassaemia. Transfusion guidance was in place for patients with sickle cell disease.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-505	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y		N	Guidelines were not yet in place covering the requirements of this QS.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-506	**Clinical Guidelines: Acute Complications** Guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	Patient controlled analgesia was only available on the surgical ward. The guidance would benefit from review to update the dates of the appendices in line with the main body of the policy.	N	Clinical guidelines did not cover (h), (i), (j) and (k).
HN-507	**Specialist Management Guidelines** Guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y		Y	

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-508	**Clinical Guidelines: Chronic complications** Guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y		Y	
HN-509	**Referral for Consideration of Bone Marrow Transplantation (Children's Services Only)** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N/A		N/A	This QS is not applicable to an LHT.
HN-510	**Non-Transfusion Dependent Thalassaemia (nTDT)** Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y		N	Clinical guidelines for the management of non-transfusion dependent thalassaemia were not yet in place.
HN-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y		Y	

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

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-602	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and representatives of support services (QS HN-301).	N	See main report about MDT engagement by the QEH service.	Y	
HN-603	**Delegation of Annual Reviews** If annual reviews are undertaken by LHT/s on behalf of the SHC, a written agreement should be in place covering: a. Monitoring protocols (QS HN-502) b. LHT management and referral guidelines (QS HN-503) c. National Haemoglobinopathy Registry data collection (QS HN-701)	N/A		N/A	
HN-604	**Out of Hours Elective Care** Arrangements should be in place for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Two beds were available on Ward 21, although access to evening and out of hours transfusions had not been routinely possible since the service had moved to be based on the haematology / oncology unit.	Y	
HN-605	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N	No community service for adults with haemoglobin disorders was in place.	N	A service level agreement was not yet in place with the community Trust, who provided some specialist nursing support to patients with haemoglobin disorders in the community.

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

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

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-703	**Quality Dashboard** The service should monitor Quality Dashboard data including the number and percentage of: a. Adverse events reported on the NHR for which a mortality or serious case review has taken place b. Children who have had Trans-Cranial Doppler screening undertaken within national guidelines c. Patients given pain relief within half an hour of presentation with sickle crisis d. Patients with possible sickle disorders identified by neonatal screening who have been entered on a care pathway e. Eligible children beginning penicillin at or before three months of age f. Patients registered on the National Haemoglobinopathy Registry who had an annual review undertaken within the last year g. Patients on long-term transfusion who received cardiac MRI, and the proportion of those receiving a cardiac MRI who achieved a figure of less than 20ms h. Eligible patients with sickle cell disease who received an MRI for liver iron, and the proportion of those who received an MRI for liver iron who achieved more than 7 mg/gm/DW (sickle cell and thalassaemia separately)	N	The pain audit did not cover patients at QEH.	N/A	
HN-704	**Other Quality Data** The service should monitor on an annual basis: a. Proportion of children who have been offered treatment following Trans-Cranial Doppler Screening	N/A		N/A	This QS is not applicable to an LHT. TCD was provided by the team from KCH.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-705	**Other Audits** Clinical audits covering the following areas should have been undertaken within the last two years: a. Availability of extended red cell phenotype in all patients and the proportion of patients who have developed antibodies b. Whether all eligible patients on long term transfusion have been offered automated exchange transfusion c. Waiting times for elective: i. Phlebotomy ii. Cannulation iii. Setting up of the blood transfusion (for pre-ordered blood)	N	Audits covering waiting times for elective care had not yet been undertaken at QEH.	N	A pain audit had been completed, but no other audits as defined in the QS.
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	Y		Y	
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y		N/A	This QS is not applicable to an LHT.
HN-708	**Trans-Cranial Doppler Quality Assurance (Children's Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-207) b. Results of internal quality assurance systems (QS HN-606) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)	N/A		N/A	This QS is not applicable to an LHT.

Ref	Standard	Adults (SHT)		Children and Young People (LHT)	
		Met?	Comments	Met?	Comments
HN-798	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility c. Annual review of trends in National Haemoglobinopathy Registry data, activity data, Quality Dashboard, other quality data and other audits (QSs HN-701 to HN-705)	Y	However, in the notes of the mortality and morbidity meetings issues had been raised about attendance and the number of patients being discussed from the QEH service.	N	Evidence was not available to show compliance with this QS, and not all staff who spoke to reviewers were clear about the process.
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

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