Health Services for People with Haemoglobin Disorders

Whittington Health NHS Trust

Visit Date: 4th July 2019

Report Date: October 2019

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Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Whittington Health NHS Trust that took place on 4th July 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 Teams (SHT)
- Local Haemoglobinopathy Teams (LHT) or linked providers

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

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

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

- Whittington Health NHS Trust
- NHS England and NHS Improvement Specialised Commissioning – Haemoglobinopathies, Regional and National Teams

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 Regional Lead Commissioner for Haemoglobinopathies.

About the Quality Review Service

The Quality Review Service 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 Whittington 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 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 health services provided for children and young people with haemoglobin disorders at Whittington Health NHS Trust. During the course of the visit, reviewers visited the emergency department, paediatric ambulatory care facilities, day units, inpatient wards and the paediatric outpatient department, and met with patients and carers and with staff providing the services for the local health economy.

Whittington Health (WH) was an integrated care organisation (ICO) which provided hospital and community care to 500,000 people living in Islington and Haringey as well as other London boroughs including Barnet, Enfield, Camden and Hackney.

WH had, and continues to have, a national and international reputation in the clinical care of patients with haemoglobin disorders, especially thalassaemia and it also provided tertiary and quaternary care to patients from all over the country. Some paediatric patients had shared care arrangements in place for sickle cell care with other centres, such as Barts Health NHS Trust, St Mary's Hospital (Imperial College Healthcare NHS Trust) and King's College Hospital NHS Foundation Trust, and some children who required surgical procedures to be undertaken at Great Ormond Street Hospital for Children NHS Foundation Trust also had shared care arrangements.

CHILDREN AND YOUNG PEOPLE

Data submitted by Trust for 2018/19

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	Usually seen by the linked hospitals/local teams (except for annual reviews)	No. of children on long-term red cell transfusions
Whittington Health	SHT	131	34	0	20

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

Staffing

Staffing for the SHC Paediatric Haemoglobinopathy Service [1]	Number of patients	Actual WTE (at time of visit)
Consultant haematologist/paediatrician - >0.6 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	165	0.25
Is at least 0.25 WTE allocated to haemoglobinopathies CPD in the Paediatric Consultant Job	165	0.1
Trust employ a clinical psychologist for paediatric patients who has >0.5 WTE per 150 patients dedicated to work with patients with haemoglobinopathies ?	165	0.2wte

Specialist Haemoglobinopathy Team *(C*hildren and Young People Services): Whittington Health NHS Trust

General Comments and Achievements

This was an experienced team with strong medical and nursing leadership evident throughout. The multi-disciplinary team (MDT) as a whole were extremely proud of what they had achieved since the last visit in 2015, and it was clear to the reviewers that the MDT was highly committed and enthusiastic in their vision to provide a high quality service.

Over 160 children and young people were cared for by the team. A weekly joint 'red cell' MDT was held, attended by all four haematologists, both paediatricians, three clinical nurse specialists (CNS), a psychologist, a psychotherapist and trainee medical staff.

Emergency Care

All families affected by haemoglobin disorders had 'emergency cards' that entitled them to direct access to the paediatric department in an emergency. Families could phone a dedicated number on the children's ward, and the senior nurse on duty would then ask the family to attend the Children's Ambulatory Unit (CAU) or the outpatient clinic or would give telephone advice. Only children who were brought to the hospital via the ambulance service would be seen initially in the Emergency Department.

An emergency referral clinic led by a paediatric consultant was held in the CAU every weekday morning from 10am to 12 noon. During normal working hours, support and advice was also available by contacting the Paediatric Haemoglobinopathy Nurse Specialist.

Inpatient Care

Children and young people up to their 17th birthday were admitted directly to Ifor Ward. The ward had 19 beds, including four beds in an adolescent area and two high dependency beds that were used for children and young people who required admission for emergency exchange blood transfusions.

Day Care

Children and families with sickle cell disease and thalassaemia were seen in the ambulatory care facilities, which were split between the CAU for acutely unwell children and young people and the Roses Day Unit, which

[1] *Recommended Staffing: National NHS England compliance exercise for designation of SHTs 2019. Trust data submitted after the peer review visit for inclusion in the report.*

admitted children and young people for planned and elective care. Both units were staffed with nurses who could cannulate children, and there was access to support from duty medical staff for more challenging/difficult cannulations. The CAU was open seven days a week between 7.30am and 8.30pm, and the Roses Day Unit was open Monday to Friday between 7.30am and 7.30pm. Reviewers were impressed with the nurses in the CAU, who were very clear about the pathway and care of children and young people attending in an emergency.

Transfusion activity for the unit was 236 paediatric thalassaemia day case transfusion episodes and 62 paediatric sickle cell day case transfusion episodes (top-up and manual exchange) per annum. Planned automated red cell exchange transfusions were undertaken at the University College Hospital (UCLH) site.

Outpatient Care

A dedicated sickle cell outpatient clinic was held weekly on a Monday afternoon, and patients were seen jointly by the MDT (consultant paediatricians, CNS, clinical psychologist and family psychotherapist). Consultant haematologists were available for joint reviews and to give advice as needed.

A multi-disciplinary thalassaemia and sickle cell clinic was held every two months in the evening for children and young people with transfusional iron overload. Tertiary and new referrals of older children were usually seen by a consultant haematologist before being seen in the next available joint clinic.

A joint specialist endocrine clinic was held on site every three months, with a consultant paediatric endocrinologist and visiting specialist from Great Ormond Street Hospital for Children NHS Foundation Trust.

Weekly nurse-led clinics were in place for patients to monitor their drug therapy, and the advanced nurse practitioner (ANP) held a monthly Transcranial Doppler (TCD) clinic.

Annual workshops were held for young people in preparation for their transition to the adult service.

Community Based Care

Community care was provided by the community team, which was based at the Camden and Islington Sickle Cell and Thalassaemia Centre on Hornsey Street, Holloway. The community services became an integral part of Whittington Health NHS Trust when it became an Integrated Care Organisation (ICO) in 2011. An enhanced 'Hospital at Home' service was operational daily from 7.30am to 10.30pm, providing community children's nurse input. This team was also able to provide multiple doses of intravenous antibiotics and to assist with the family's monitoring of a child's condition.

Progress since the last visit

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

- Appointments to the multi-disciplinary team:
    - a deputy paediatric haemoglobinopathy nurse specialist (0.45wte) had been appointed to assist and provide some cover for the ANP;
    - a psychologist (0.5wte) had been appointed jointly for the adult and the paediatric services, with dedicated time (0.2wte) allocated for work with children, young people and families;
    - a fourth haematologist (1wte) had been appointed jointly with UCLH and spent 50% of their time at the Whittington Hospital site;
    - a consultant paediatrician had been replaced by a consultant paediatrician with an interest in haemoglobinopathy who had taken up the role of deputy lead clinician for the paediatric service; and
    - a genetic counsellor (1wte) had been appointed.

- Establishment of the apheresis programme for red cell exchange.
- Recruitment of local patients to clinical trials involving innovative therapies in association with UCLH.

Views of Service Users and Carers

The visiting team met with nine parents and one young person during the course of the visit. Overall, the carers were highly complimentary about the care their child received at the hospital, and they were particularly appreciative about the support from the haemoglobinopathy team. The visiting team also reviewed responses to 18 questionnaires from patients and families that had been collected by the team between 2016 and 2018, and these were also very complimentary about the service received. The comments by the user and carers covered the following matters:

- The users and carers considered that the team was 'amazing' and that all members of the team provided care for the whole family. Parents were particularly appreciative of the relationships they had with everyone involved with their child's care, commenting on the holistic approach and on the encouragement they received from the MDT to be fully involved in any decisions. All staff were extremely pleasant and always responsive. Several of the parents who met with the visiting team commented that 'nothing was too much trouble'.
- It was very helpful to receive texts about the support group, especially if the users and carers were unable to attend. There was proactive communication, and they were always kept up to date with changes and useful information.
- Parents commented that support was always available from members of the team if they raised issues relating to their child's education or school. Members of the team were quick to meet with children, their parents and school staff to ensure problems were quickly resolved.
- Some parents who met with the visiting team had been linked to the service over the generations. The parents commented about the unwavering commitment from the lead paediatrician over many years, and registered their appreciation of the ongoing and consistent support given to them and their family.
- All those who met with the visiting team held the specialist nursing team in high regard; in particular, they said that the ANP was 'wonderful'. The service was described as small but involved and cohesive with no silos, and nursing staff worked together for the benefit of the children.
- Parents did, however, express their concerns about the high workload of the ANP, and said that they had felt vulnerable when the previous CNS had left the service, although reviewers were encouraged to hear that these concerns had been allayed following the appointment to the vacant CNS post within the team.

Good Practice

1. Reviewers were impressed with the range of information for patients and their families, which provided clear information and advice. The checklist allowing parents to assess their competence in administering chelation therapy was very good, as the self-assessment would help them to identify areas where they needed additional guidance and support, and the vaccination checklist from birth to 17 years of age was very comprehensive. The 'Red Cell' newsletter was also well written and informative, providing updates and useful local and national information.
2. The psychology service annual report was well written and comprehensive, with information about the service, including how to access help and the range of support available for patients and their families.
3. New patient notification letters to general practitioners (GP) were very well structured, with formatted headers, so that the patient's plan of care was clear to the GP. The letters included actions to be

progressed by the GP, and set out who, within the acute or primary health care teams, was responsible for each element of the patient's care plan.

4. The ambulatory paediatric care model pathway enabled many patients with acute complications to be treated as day patients.

5. Discharge letters sent to GPs following an inpatient admission were very good, with clear instructions about actions for the GP and details of ongoing treatment following discharge.

6. The Non-Transfusion Dependent Thalassaemia (nTDT) guidance was very detailed, and included a comprehensive review of chelation agents and clear guidance on the management of patients with increasing iron overload.

7. The involvement of young people in the development of the paediatric haemoglobinopathy service was well established, with a number of mechanisms to capture feedback, including a young people's forum. Young ambassadors also provided feedback for children's services as a whole; for example, they visited clinical areas and confirmed that their presence in the area was acknowledged by staff within 'fifteen steps' of walking into the clinical areas, in keeping with locally-established standards Additionally, the young ambassadors had stayed on the ward one night until the early hours of the morning to determine the level of noise on the ward.

8. The service had good links with both local and specialised commissioners, who were very engaged and supportive about the development of the service. Commissioners who met with the visiting team also praised the service provided by the community sickle cell and thalassaemia centre. The commissioners also mentioned that the community service had met all the agreed CCG contracting standards, and that they had received very good feedback from patients accessing the service.

9. The Trust information about making a complaint was very clear and detailed about each stage. It covered information about what service users could expect when making a complaint, and the rationale for each element of the complaints process. Reviewers were particularly impressed with the language used, which they considered was supportive rather than confrontational.

Immediate Risks: None

Concerns

1. **Access to psychology**

   Despite the progress in appointing some psychology support to the team, access to psychology was limited, with only 0.2wte time of a psychologist allocated for work with the paediatric service (approx. 200 children and young people). Reviewers considered that this was insufficient to provide a comprehensive psychology service for the number of children and young families being cared for by the service and did not meet the national workforce recommendations of 1wte for 300 patients.

2. **Transcranial Doppler ultrasound**

   The non-imaging TCD service was dependent on one ANP, with no cover to provide the service when the ANP was absent. Staff who met with the reviewing team were told that providing an imaging TCD service had been explored following the previous peer review visit. However, the development of an imaging TCD service was reliant on funding for staff and on equipment being available and had been deemed financially prohibitive. Reviewers were concerned at the ongoing vulnerability of the existing service, and wondered whether training additional personnel, such as clinical scientists, in non-imaging TCD may be a way forward.

3. **Thalassaemia guidance**

   Guidelines covering the acute management of fever and acute symptoms for patients with thalassaemia were not yet in place. Access to guidance was considered particularly important because of the low number of patients with thalassaemia admitted for acute care, and the need for these patients to receive a rapid assessment and urgent treatment.

Further Consideration

1. Reviewers expressed concern at the reliance on the ANP, who was pivotal to providing a wide range of services. Although additional support was available from the CNS, reviewers considered that this was only 0.45 wte time and therefore that the workload of the ANP should be kept under review.
2. Reviewers considered that the team's plans to develop the transition pathway further by seeking user views about the pathway and engaging young people earlier with the provision of additional workshops and the implementation of the 'Ready Steady Go®' transition model would improve the process for young people transitioning to the adult service.
3. As a specialist haemoglobinopathy service, the team had limited involvement in research. Reviewers considered that as the Trust was renowned for its expertise in haemoglobin disorders, it should have been supporting the team to engage in clinical trials and investigator-led projects. Reviewers were told that the nurse consultant for the children service had been successful in gaining funding from the National Institute for Health Research (NIHR), which may help support this function.

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Commissioning

Some issues in the provider section of this report will also require commissioner support to ensure they are addressed.

Good Practice: See Good Practice section of the report.

Further Consideration

1. Staff who met with the reviewing team commented about the inequity of service provision across the health economy; for example, the 'Hospital at Home' service was not available in all areas, which caused some issues for the acute service in terms of admission avoidance and early discharge. Commissioners who met with the visiting team were hopeful that the inconsistences in community provision would be addressed as part of the work being undertaken by the local Sustainability and Transformation Partnership (STP).

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APPENDIX 1 Membership of Visiting Team

Visiting Team		
Dr Subarna Chakravorty	Consultant Paediatric Haematologist	King's College Hospital NHS Foundation Trust
Pauline Garnett	Haemoglobinopathy Genetic Counsellor	Bradford Teaching Hospitals NHS Foundation Trust
Sajid Hussain	Service user	
Hazel Marriott	Sickle Cell and Thalassaemia Nurse Specialist	Nottingham University Hospitals NHS Trust
Cherryl Westfield	Carer	
Dr Sarah Wilkinson	Consultant Paediatrician	Lewisham and Greenwich NHS Trust

QRS Team		
Sarah Broomhead	Assistant Director	Quality Review Service

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APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

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

Service	Number of applicable QS	Number of QS met	% met
Specialist Haemoglobinopathy Team (Children and Young People Services): Whittington Health NHS Trust	51	44	86

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Specialist Services for People with Haemoglobin Disorders

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

Ref	Standard	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	A wealth of information was available to children and families. The checklist for parents to assess their competence in administering chelation therapy was very good, as the self-assessment would help them to identify areas where they needed additional guidance and support. The vaccination checklist from birth to 17 was also very comprehensive. The information in the generic booklet was not specific about the possible need for long-term blood transfusions for patients with sickle cell disease. Reviewers considered that providing additional information about the long-term requirement for blood transfusions, using the format in the leaflet on chelation, would be very helpful.
HN-103	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	Y	

Ref	Standard	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	
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	Y	
HN-106	**School Care Plan (Children's Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school e. Specific health or education need (if any)	Y	

Ref	Standard	Met?	Comments
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	The environment was very spacious, ergonomic, calm and child-friendly.
HN-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services b. A named coordinator for the transfer of care c. A preparation period prior to transfer d. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards	Y	A good process was in place, with regular workshops held for young people and families about transition. As part of the transition pathway, young people also had the opportunity to attend alternate children's and adults' outpatient clinics.
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	
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	

Ref	Standard	Met?	Comments
HN-202	**Lead Nurse** A lead nurse should be available with: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. Competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) The lead nurse should have appropriate time for their leadership role and cover for absences should be available.	Y	
HN-203	**Medical Staffing and Competences** The service should have sufficient medical staff with appropriate competences in the care of people with haemoglobin disorders, including: **All services:** a. Haematology or paediatric medical staffing for clinics and regular reviews b. 24/7 consultant and junior staffing for emergency care **SHCs only:** c. A consultant specialising in the care of people with haemoglobin disorders on call and available to see patients during normal working hours d. If doctors in training are part of achieving 'a' or 'b' then they should have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y	Paediatric trainee medical staff attended a half-day training course on haemoglobinopathies as part of their weekly programme of protected learning whilst working with the Trust.

Ref	Standard	Met?	Comments
HN-204	**Nurse Staffing and Competences** The service should have sufficient nursing staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Clinical nurse specialist/s with responsibility for the acute service b. Clinical nurse specialist/s with responsibility for the community service c. Ward-based nursing staff d. Day unit (or equivalent) nursing staff e. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y	The ANP and CNS held monthly ward training sessions, and an annual haemoglobin disorders study day was held. Ward nurses and consultant staff were also in the process of training to undertake manual exchange transfusions.
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	Insufficient psychologist time was available for the children's service. The psychologist (0.5wte) covered both the adult and the children services, with only 0.2wte time allocated for work with all children with haemoglobin disorders. *British Psychology Society Special Interest Group for Psychologists working in Sickle cell and Thalassaemia (2017) suggested workforce recommendation of 1 wte: 300 pts.*
HN-206	**Training Plan** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders.	N	A training plan covering all staff was not yet in place. Staff had completed mandatory training.

Ref	Standard	Met?	Comments
HN-207	**Trans-Cranial Doppler Ultrasound Competences (Children's Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	Y	
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	A data manager had commenced in post.
HN-301	**Support Services** Timely access to the following services should be available. In Specialist Centres staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) as required. a. Social worker/ benefits adviser b. Leg ulcer service c. Play specialist (children's services only) d. Chronic pain team (adult services only) e. Dietetics f. Physiotherapy (in-patient and community-based) g. Occupational therapy h. Mental health services (adult and CAMHS) i. DNA studies j. Polysomnography	Y	
HN-302	**Emergency Department – Staff Competences** Medical and nursing staff working in the Emergency Department/s should have competences in urgent care of people with haemoglobin disorders.	Y	The reviewers were impressed with the nurses in the clinical assessment unit, who were very clear about the care of children and young people attending in an emergency. An audit of compliance with the NICE clinical guideline on the management of acute pain had been undertaken.

Ref	Standard	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	

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

Ref	Standard	Met?	Comments
HN-305	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	
HN-401	**Facilities and Equipment** Facilities and equipment should be appropriate for the usual number and case mix of patients. Equipment should be appropriately maintained.	Y	
HN-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y	The guidelines would benefit from clarification in respect of the arrangements for communication with local referring teams ('g'). In practice, staff were very clear about the process.
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	
HN-503	**Clinical Guidelines: LHT Management and Referral** Guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A	

Ref	Standard	Met?	Comments
HN-504	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. emergency and regular transfusion ii. use of simple or exchange transfusion iii. offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for carrying out a manual and automated exchange transfusion c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts	Y	The Trust did not provide automated exchange transfusions (a iii), so this aspect of the QS was not applicable.
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	Prescribing was not undertaken through shared care arrangements, so 'f' was not applicable.

Ref	Standard	Met?	Comments
HN-506	**Clinical Guidelines: Acute Complications** Guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	N	Guidance covering the care of acutely unwell patients with thalassaemia was not in place. The guidance seen could be clearer about acute renal failure. Some guidance was also included in the chelation therapy guidelines, for example on the care of a patient with a fever.
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	The preoperative surgery guidelines would benefit from review to amend the haemoglobin level per litre to 100 grams/litre rather than 60 grams/litre.
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)	N	Guidance on chronic respiratory disease only covered sleep studies and not other aspects such as hypoxia and abnormal pulmonary function tests.
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.	Y	

Ref	Standard	Met?	Comments
HN-510	**Non-Transfusion Dependent Thalassaemia (nTDT)** Network-agreed clinical guidelines for the management of Non-Transfusion Dependent Thalassaemia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y	The guidance was very detailed and included a comprehensive review of the chelation agents that could be offered and the management of increasing iron overload.
HN-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y	

Ref	Standard	Met?	Comments
HN-601	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a SHC (Children's SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 14 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Arrangements for liaison with community paediatricians and with schools (children's services only) e. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated (children's services only) f. Follow up of patients who do not attend g. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. h. Accessing specialist advice (QS HN-304) i. Two-way communication of patient information between SHC and LHTs j. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	N	Written arrangements for 'fail safe' ('a') were not seen at the time of the visit. Staff who met with the reviewing team were clear about arrangements. 'i' and 'j' were not applicable.
HN-602	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings to discuss and review patient care should be held regularly, involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, psychology staff and representatives of support services (QS HN-301).	Y	

Ref	Standard	Met?	Comments
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)	Y	Annual reviews were all undertaken by the SHT.
HN-604	**Out of Hours Elective Care** Arrangements should be in place for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	The day unit was open until 7.30pm, and at that time children could be transferred to the ward for ongoing care.
HN-605	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	Y	Service level agreements were in place for University College London and the Royal Free London NHS Foundation Trust. The team were also in the process of making an agreement with Luton and Dunstable University Hospital.
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	Y	

Ref	Standard	Met?	Comments
HN-607	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y	
HN-608	**Neonatal Screening Programme Review Meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (QS HN-703), identify issues of mutual concern and agree action.	Y	Meetings were held on a quarterly basis.
HN-701	**National Haemoglobinopathy Registry** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates, serious adverse events, pregnancies and patients lost to follow up.	Y	
HN-702	**Activity Data** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y	

Ref	Standard	Met?	Comments
HN-703	**Quality Dashboard** The service should monitor Quality Dashboard data including the number and percentage of: a. Adverse events reported on the NHR for which a mortality or serious case review has taken place b. Children who have had Trans-Cranial Doppler screening undertaken within national guidelines c. Patients given pain relief within half an hour of presentation with sickle crisis d. Patients with possible sickle disorders identified by neonatal screening who have been entered on a care pathway e. Eligible children beginning penicillin at or before three months of age f. Patients registered on the National Haemoglobinopathy Registry who had an annual review undertaken within the last year g. Patients on long-term transfusion who received cardiac MRI, and the proportion of those receiving a cardiac MRI who achieved a figure of less than 20ms h. Eligible patients with sickle cell disease who received an MRI for liver iron, and the proportion of those who received an MRI for liver iron who achieved more than 7 mg/gm/DW (sickle cell and thalassaemia separately)	Y	The team had just submitted data for quarter four to the national Quality Dashboard.
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	Y	
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 ‘b’ and ‘c’ had not yet been undertaken.

Ref	Standard	Met?	Comments
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	Y	
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	See also the further consideration section of the report about developing research involvement.
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)	Y	
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)	N	Arrangements were in place for all except a review of trends in the data submitted, as the team had only submitted once to the Quality Dashboard.
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

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