Health services for people with haemoglobin disorders

Oxford University Hospitals NHS Foundation Trust

Visit Date: 6th February 2020

Report Date: May 2020

8831

Contents

Introduction

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Oxford University Hospitals NHS Foundation Trust that took place on 6th February 2020. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V4, 2018 which were developed by the UK Forum on Haemoglobin Disorders working with the Quality Review Service (QRS). The peer review visit was organised by QRS on behalf of the UK Forum on Haemoglobin Disorders. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

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

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

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

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

- Oxford University Hospitals NHS Foundation Trust
- NHS England & NHS Improvement Specialised Commissioning – Haemoglobinopathies
- NHS Oxfordshire Clinical Commissioning Group

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

About the Quality Review Service

QRS is a collaborative venture between NHS organisations to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews (often through peer review visits), producing comparative information on the quality of services and providing development and learning for all involved.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more

confidence and competence in reviewing the quality of clinical services. More detail about the work of QRS is available at www.qualityreviewservicewm.nhs.uk

Acknowledgments

We would like to thank the staff of Oxford University Hospitals NHS Foundation 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 the time to come and meet the review team. Thanks are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

Return to Index

Review Visit Findings

Trust-wide

General comments

Oxford University Hospitals NHS Foundation Trust (OUH) was a Specialist Haemoglobinopathy Team (SHT) for children and young people residing in Oxfordshire (overall population approximately 750,000) and acted as the hub for major haemoglobinopathy referrals for tertiary care from the Thames Valley network (catchment population 2.2 million). The Trust was a large tertiary hospital that provided a vast range of specialised services.

The paediatric SHT was part of the Department of Paediatric Haematology at the Children's Hospital, a purpose built environment for children on the John Radcliffe Hospital site.

Formal designation of the service by NHS England (NHSE) as an SHT for Sickle Cell Disease and Thalassaemia had been agreed in June 2019, and as part of the national procurement exercise being conducted by NHSE during 2019, OUH had been designated as a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell Disease for the Thames Valley and Wessex regions.

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
Oxford University Hospitals NHS Foundation Trust – Oxford Children's Hospital	SHT	203 (network-wide)	17	16

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

Specialist Team (Children and Young People Services): Oxford University Hospitals NHS Foundation Trust

General Comments and Achievements

This service was led by the lead clinician and specialist haemoglobin disorders nurse who were clearly committed to providing a good service for children, young people and families within the Trust and to those being cared for by the local haemoglobinopathy teams across the network. It was evident to the reviewers that there were good relationships between the team and the adult SHT based at Churchill Hospital (CH).

Well-established links existed, with shared care arrangements between Oxford University Hospitals NHS Foundation Trust and other local hospitals across the network, and with outreach clinics in operation. Trans-Cranial Doppler (TCD) scans and annual reviews were held for children and young people with HBSS/BO at the Children's Hospital in Oxford for patients from Royal Berkshire NHS Foundation Trust (Reading), Frimley Health NHS Foundation Trust (Slough), Great Western Hospitals NHS Foundation Trust (Swindon), and Buckinghamshire Healthcare NHS Trust (Aylesbury). Every three months the SHT held outreach clinics at Milton Keynes, which had the largest number of children and young people with haemoglobin disorders (84+) within the network, so these patients could have their annual reviews and routine TCD ultrasound scans performed locally.

The SHT was overseen by the consultant paediatrician, who had a total of 3.5 programmed activities (PA) allocated for haemoglobinopathy work. An additional locum paediatric consultant had been appointed who had some haemoglobinopathy experience and who would provide additional cover for the lead clinician and take responsibility for the outreach care at Royal Berkshire NHS Foundation Trust in Reading.

Access to 24 hour automated red cell exchange, provided by NHS Blood and Transplant (NHSBT), was in place and the NHSBT team were able to undertake red cell exchange transfusions for children on the paediatric high dependency unit if necessary.

Monthly multi-disciplinary team (MDT) meetings were held with local referring hospitals via a telephone conference to discuss patient concerns and significant events. Monthly quality meetings were also held with the adult haemoglobinopathy team based at the CH, and 'red cell' meetings with the clinical laboratory and neonatal screening team were held every two months.

All new patients were registered on the National Haemoglobinopathy Registry (NHR), and data were submitted to the NHSE dashboard.

Following the formal designation by NHSE of the service as an SHT, several joint appointments were planned: an additional Band 6 Nurse (0.4 WTE), a specialist haemoglobinopathy psychologist (0.4 WTE) for both the adult and paediatric SHTs, and a service co-ordinator.

As part of the development of the HCC, discussions were taking place as to how to support the Southampton Haemoglobinopathy Network (the SHT and its local referring teams).

Specialist Haemoglobinopathy Team	Local Haemoglobinopathy Teams
Oxford University Hospitals NHS Foundation Trust – Oxford Children's Hospital	• Milton Keynes University Hospital NHS Foundation Trust – Milton Keynes General Hospital (MK) • Royal Berkshire NHS Foundation Trust – Royal Berkshire Hospital (RB) • Frimley Health NHS Foundation Trust – Wexham Park and Frimley Park Hospitals (WP) • Buckinghamshire Healthcare NHS Trust – Stoke Mandeville and Wycombe Hospitals (SM) • Great Western Hospitals NHS Foundation Trust – Great Western Hospital (GW)

Staffing

Staffing for the Paediatric Specialist Haemoglobinopathy Service (SHT) [1]	Number of patients across the network	Actual WTE (at time of visit)	Staffing required as recommended by NHSE (WTE)
Consultant haematologist/paediatrician with >0.6 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	220	0.35	0.8
At least 0.25 WTE allocated to haemoglobinopathies CPD in the paediatric consultant job plan	220	-	-
Clinical psychologist for paediatric patients with >0.5 WTE per 150 patients dedicated to work with patients with haemoglobinopathies	220	0	0.67

Emergency Care

Children with haemoglobin disorders living in the local catchment area were admitted directly to Kamran Ward. Occasionally patients were admitted to adjacent paediatric wards if a bed on Kamran Ward was not available. Parents had open access to Kamran Ward at any time and were encouraged to phone in advance when they felt the need for urgent medical input. During office hours, urgent clinical assessments for such children were also possible on the adjacent Kamran Day Ward.

Any patients admitted to hospital during normal working hours were seen by the ward-based haematology / oncology team, and a consultant review was provided by the on-call consultant haematologist or oncologist. The clinical lead for haemoglobinopathy was also available for advice if needed. Outside normal working hours, patients were reviewed by the on-call junior doctor who was responsible for management of all admissions at the Children's Hospital and the on-call consultant haematologist or oncologist.

In-patient Care

Kamran Ward was the designated in-patient paediatric haematology / oncology ward. It had nine beds. If a bed was not available, a patient with a haemoglobin disorder requiring admission was admitted to one of the other four paediatric wards. Daily consultant ward rounds were undertaken in order to review all new overnight admissions. Access to patient-controlled analgesia (PCA) was possible on all wards, with support from the pain team during normal working hours and from the on-call anaesthetist at other times.

Day Care

Kamran Day Ward was a designated haematology / oncology day care ward open between the hours of 8am and 8pm, Monday to Friday. Patients could attend for their elective blood transfusions as well as urgent assessments prior to admission to the in-patient ward.

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

Out-patient Care

Weekly consultant-led haemoglobinopathy clinics took place every Tuesday and Thursday afternoon. Children and young people attending had access to phlebotomy and play therapists. Members of the paediatric team also attended the joint clinics at the Churchill Hospital with the adult haemoglobinopathy team if there was a teenage patient who required transition to the adult service.

Community-based Care

Community care for children and young people with haemoglobin disorders was provided by the community children's nursing team. The specialist haemoglobin disorder nurse undertook some outreach work and liaised with education providers for children and young people who needed school care plans.

Feedback from Local Haematology Teams

Reviewers spoke with representatives from five local haematology teams (MK, RB, WP, SM and GW). All those who spoke to the reviewers were highly appreciative of the advice and support provided by the SHT.

Progress since Last Visit in 2015

- A specialist haemoglobin disorder nurse had been appointed in April 2018 using funding support from the Roald Dahl's Marvellous Children's Charity.
- Revised pathways for newborn screening and for the transition of young people to the adult SHT had been implemented.
- Submission of data to the NHR had increased.
- Processes had been strengthened to ensure that all children had TCD screening undertaken within national guidelines.
- The service had been designated as a specialist haemoglobinopathy team (SHT) in June 2019.
- A service coordinator, to coordinate MDT meetings, clinics and NHR data entry, had been recruited.
- The service had been designated as a haemoglobinopathy coordinating centre (HCC) for Sickle Cell Disease in October 2019 for the Thames Valley and Wessex regions.
- Monthly mortality and morbidity meetings had commenced in January 2019.
- Monthly joint quality meetings had been implemented with the adult SHT based at Churchill Hospital.
- Network protocols had been agreed and made available via the Network Site Specific Group (NSSG) Haemoglobinopathies website.

Views of Service Users and Carers

During the visit the visiting team met with three families caring for children and young people with sickle cell disease. Overall, the families were highly complimentary about the care they received at the hospital. In addition:

- They were particularly appreciative about the support from the lead clinician and CNS who were 'wonderful'.
- The parents commented that when their children had been born they had experienced issues with the knowledge and experience of staff, but that since the lead consultant and CNS had started in 2018 the service had been 'great'. One parent commented that if she had to quantify how she found the service, it would be '99% positive'.
- Carers reported that their children liked attending the hospital and were made comfortable, were well looked after and had fun. They considered that the staff at the hospital provided 'top quality care'. They had access to plenty of information.

- The CNS was their first point of contact. The CNS would respond quickly to their queries and liaise with medical staff on their behalf if necessary. The CNS was active in liaising with education providers to ensure that school care plans were developed and implemented.
- Carers felt they had enough knowledge to be able to manage their children at home. All the children represented at the meeting were on hydroxycarbamide, and the carers had a good understanding of the monitoring needed. They felt well educated on their children's conditions, had completed patient surveys and were aware of how to give feedback.
- If an urgent assessment was needed, the process worked well. Carers would call the ward, who would advise them to attend, and they were always seen quickly on arrival at the ward. If a bed was not available on Kamran Ward the staff would arrange admission to another ward where they were assessed by the team.
- Other examples of coordinated care were described by carers:
    - One parent was very impressed with the emergency care their child had received when they sustained a fracture unrelated to their sickle cell disease. They had attended the ED, were seen quickly and analgesia was given; the ED staff also notified the haematology team of the situation.
    - One parent commented on an experience when she had no car to bring her child to hospital and the taxi was delayed. She was worried that her child's condition was deteriorating and contacted the ward, who arranged for an ambulance transfer to hospital. The ambulance arrived within 10 minutes. The child received a speedy response on arrival at the hospital, and had been made comfortable by the time the assessing clinician attended to review them.
- All carers reported that their children had care plans and had had annual reviews performed.
- Those who met with the reviewers commented that the nurses had a good understanding of their children's condition and were reassuring and calming, often providing support and reassurance for their child when medical staff were performing cannulation and other investigations.
- A parent commended 'Dr Amrana' for the way she went above and beyond to help her patients, including follow-up calls, engaging with the child and providing extra support in critical situations. One parent described how the lead clinician had helped her communicate with the airline when her child became unwell before a holiday. The lead clinician contacted the airline to inform them of the situation on discharge and the patient's requirements for a safe trip.
- Care on the day unit was well organised and efficient. The parents praised the health care support worker who they considered was 'really great'.
- Information was given to parents to pass on to their GPs, though some commented that their GPs were not particularly knowledgeable about haemoglobin disorders. The parents were appreciative of the team's involvement in ensuring that their children were up to date with the required immunisations.
- Parents who spoke to the reviewing team were not aware of any options to obtain psychological support if needed.
- None of the parents had been successful with their Disability Living Allowance (DLA) applications.
- Only one parent seemed aware of the NHR card.
- Parents who spoke to the reviewing team were all clear about the transitioning process. One parent had met the CNS at Churchill Hospital, and one young person commented that discussions about transition would start when they attended for their next review appointment.
- Parents raised the issue of delays in receiving medication, both when being discharged from the wards and with the out-patient arrangements for the collection of hydroxycarbamide medication.

Good Practice

1. Reviewers were impressed with the range of information for patients and their families, which provided clear information and advice:

    a. Travel advice information was comprehensive. The information included vaccination advice before travelling and the suggestion that parents should take copies of their child's care plans and clinic letters in case they required medical assistance when away from home.

    b. The information written for children, young people and families covering the clinic plan for an annual review provided clear advice and information about the rationale for the review and what exactly would happen when they attended.

    c. The information covering priapism was sensitively written and was easy for children and young people to understand.

    d. The *Helpful guidelines for new carers* provided useful information about the different techniques that may be helpful to parents when administering oral medication to their baby.

2. The outreach support from the lead clinician and CNS was highly valued by the LHTs across the network. Representatives from the local teams praised the arrangements that were in place for obtaining specialist advice and support from the lead clinician and specialist nurse, as well as the advice available to them out of hours from the on-call haematology team. Those who were also linked to other specialist haemoglobinopathy services were particularly complimentary about the support and advice they received from the team at OUH.

3. The arrangements in place to communicate across the network were very good. The monthly network-wide MDT meetings were universally popular and were well attended by teams across the network. Patients and staff had easy access to patient information and guidelines via the network website, and much of the information available had been co-produced with the adult and paediatric SHTs.

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

Concerns

1. **Consultant staffing**

    Reviewers were concerned that the service had insufficient paediatric consultant medical staff time available for the care of people with haemoglobin disorders in order to carry out regular reviews (annual reviews, and hydroxycarbamide and routine monitoring) and to provide support to the local haemoglobin teams across the network. At the time of the visit, the lead consultant had only 0.35 WTE allocated for work with the haemoglobinopathy service, with no deputy in place or cover for absences. A locum consultant had been appointed to provide some cover, but had limited experience in caring for children and young people with haemoglobin disorders in the UK and would need some time to become accustomed to the Trust. Reviewers were told that the locum consultant would take responsibility for the LHT at the Royal Berkshire Hospital in Reading, but that there were no plans for the locum to support the lead clinician to provide specialist advice to the other LHT sites across the network. As the service had been designated as a Haemoglobinopathy Coordinating Centre (HCC) for Sickle Cell Disease, additional time would also be required from the lead clinician to provide leadership and support to other paediatric haemoglobinopathy services across the Thames Valley and Wessex regions.

2. **Specialist haemoglobin disorder nurse**

    The specialist haemoglobin disorder nurse had insufficient time (1 WTE) available for the number of patients being cared for with haemoglobin disorders (approximately 220 across the network) to perform clinical duties, training, leadership and administrative tasks for the specialist haemoglobinopathy service.

Some cover was available from the adult service for absence, but for 'sign posting' only, and from the paediatric specialist nurse (1 WTE) in Milton Keynes who managed the paediatric haemoglobinopathy caseload. The Trust was in the process of recruiting an additional clinical nurse specialist (0.4 WTE / 15hours) for the adult and paediatric SHTs, but reviewers considered that this would still not provide sufficient cover, as the majority of children and young people with haemoglobin disorders were cared for at other Trusts across the network. The work of the new HCC would also require additional time to be available to provide leadership and support to other paediatric haemoglobinopathy services across the Thames Valley and Wessex regions.

3. **Staff competences**

   From the evidence available at the time of the visit, only nine out of 26 ward staff had recorded competences for caring for children and young people with haemoglobin disorders. Day unit staff did have competences covering the delivery of blood transfusions but not cannulation skills, as most patients cared for were oncology patients who had indwelling devices. New staff received some formal teaching as part of their induction programme, but no rolling programme of competence assessment and ongoing monitoring was in place. A training programme for non-consultant career grade staff was not seen at the time of the visit.

4. **Access to psychology**

   Access to psychology services was very limited. Referrals could be made to the general psychology service, but patients would wait six weeks for an initial assessment, and the general psychology service did not have specific competences in caring for patients and families with haemoglobin disorders. Funding had been agreed to appoint a 0.4 WTE psychologist to support adults, children and young people as part of the 'all life' model of care, with the view that the postholder would undertake a scoping exercise to assess the level of psychology support available in the LHTs. From discussions with representatives from the LHTs, the waiting list at Reading to see a psychologist was one year, children and young people at Wexham Park had some access to psychology services, and the other three LHTS had no access to a psychologist for children and young people. Reviewers were concerned that, even if the service was successful with the appointment, the time available would still not be enough for the numbers of people cared for by both the adult and the paediatric SHTs.

Further Consideration

1. The CNS had a number of ideas to improve the care of children and young people with haemoglobin disorders, such as the development of a nurse-led transition programme and information for young people on developing life skills. As the specialist haemoglobin disorder nurse was a single-handed practitioner, reviewers suggested that it may be helpful to explore links with other paediatric services who transition young people, to share expertise and documentation.
2. Some of the guidelines covering chronic complications were adult-based, and although the number of children with these complications would be smaller, reviewers considered that the guidance should be reviewed to ensure that it was applicable to children and young people.
3. No internal quality assurance process for TCD ultrasound was in place.
4. At the time of the visit, staff were spending time on data collection and data submissions to the NHR, which reviewers considered was not a good use of clinical time. Reviewers were made aware that this issue may be resolved with the recent appointment of the service coordinator.
5. In the light of the comments made by families during the visit (see page 11), the processes in place to access timely medications on discharge and following out-patient consultation would benefit from review.

6. Comments received from the representative of the LHT based at GH identified some issues with the criteria for the transfer, by the critically ill and injured child retrieval service, of patients who were seriously unwell. Reviewers considered that, as part of the HCC development, it may be helpful to review the arrangements in place for the retrieval of acutely unwell children and young people with haemoglobin disorders across the region.

7. No service level agreement with Milton Keynes University Hospital NHS Foundation Trust was in place for undertaking the annual reviews for patients. The team at OUH did undertake the annual reviews for patients with HbSS, but the arrangements were not clear about the process for reviewing children and young people with complex HbSC disease. Formal contractual arrangements would ensure that there was Trust oversight, and the service would have support to ensure that the service provision was correctly governed and managed.

8. The network covered a large geographical area. The distance that the specialist nurse from OUH had to travel between the centres limited the time available to support the LHTs. Reviewers were aware of some additional specialist nursing time (7.5hrs) planned to support the service, and this may resolve this issue, but they considered that this arrangement should be kept under review to ensure sufficient support to the LHTs is available.

Return to Index

Commissioning

Reviewers met with the NHS England Regional Specialist Commissioner for Thames Valley and Wessex. Several of the issue in this report will require active involvement of the Trust and commissioners in order to ensure that progress is made. Particularly important would be working with other commissioners across the network to ensure that specialist care and advice is sufficient for the increasing numbers of children and young people residing in other areas, particularly Milton Keynes.

Return to Index

APPENDIX 1 Membership of Visiting Team

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

Visiting Team		
Mary Hinton	Sickle Cell and Thalassaemia CNS (Adults and Paediatrics)	University Hospital Southampton NHS Foundation Trust
Amy Leach	Paediatric Haemoglobinopathy Nurse Specialist	University Hospitals Coventry and Warwickshire NHS Trust
Roanna Maharaj	Patient Representative	UK Thalassaemia Society
Maureen Scarlett	Community Nurse Specialist Haemoglobinopathies	Cambridgeshire Community Services NHS Trust
Dr Alison Thomas	Consultant Paediatric Haematologist	St George's University Hospitals NHS Foundation Trust
Vanessa Wills	Patient Representative	

QRS Team		
Sarah Broomhead	Assistant Director	Quality Review Service

Return to Index

APPENDIX 2 Compliance with the Quality Standards

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

Table 1 - Percentage of Quality Standards met

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

Service	Number of applicable QS	Number of QS met	% met
Specialist Haemoglobinopathy Team	51	36	71
Total	**51**	**36**	**71**

Return to Index

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	However, some of the parents who met the visiting team commented that they did not know how to appeal if their application for benefits was not accepted. The service booklet when reviewed would benefit from more detail about accessing the phlebotomy service, and how to access psychology support and social services and benefits advice.

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	N	Written information for patients with thalassaemia did not cover transfusion and iron chelation (e) or the self-administration of medicines (i). The written information that was available was provided by a pharmaceutical company. Information for patients with sickle cell disease covered everything except the self-administration of medicines.
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	A new care plan was in the process of being implemented. Reviewers did see some notes which included both care plan templates completed for the same annual review period. The clinic letters were detailed, but the reviewers considered that it would be helpful for patients with thalassaemia if the letter made it clear that the information covered their annual review.

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	N	The information sent to the primary healthcare team did not appear to cover contraception and sexual health guidance for young people with haemoglobin disorders.
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	
HN-195	**Transition to Adult Services** Young people approaching the time when their care will transfer to adult services should be offered: a. The opportunity to discuss the transfer of care at a joint meeting with paediatric and adult services b. A named coordinator for the transfer of care c. A preparation period prior to transfer d. Written information about the transfer of care including arrangements for monitoring during the time immediately afterwards	Y	The team were also working on improving the transition process and had begun implementing the Ready Steady Go transition programme.
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.	N	The service had insufficient consultant medical staff with appropriate competences in the care of children and young people with haemoglobin disorders to cover clinics and regular reviews in the absence of the lead clinician. Limited training was provided for new junior medical staff on the care of people with haemoglobin disorders who were admitted to outlying wards.

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.	N	The CNS covered the Trust, community and liaison with other LHTs, and there was no cover for absences. The Trust had plans to appoint an additional 15 hours of Band 6 nurse time, but this would be shared between the adult and paediatric services. Only nine out of 26 ward staff had recorded competences for the care of children and young people with haemoglobin disorders. Evidence that staff had achieved competences was not seen at the time of the visit, although reviewers were told that all ward and day unit staff did have competences in delivering blood transfusions but not in cannulation skills as the majority of oncology patients had indwelling devices. All new staff completed an induction programme workbook, but once the workbook had been completed there was no rolling programme of competence assessment and ongoing monitoring in place for staff. In practice, junior medical staff were called to cannulate children and young people with haemoglobin disorders.

Ref	Standard	Met?	Comments
HN-205	**Psychology Staffing and Competences** The service should have sufficient psychology staff with appropriate competences in the care of people with haemoglobin disorders, including: a. An appropriate number of regular clinical session/s for work with people with haemoglobin disorders and for liaison with other services about their care b. Time for input to the service's multi-disciplinary discussions and governance activities c. Provision of, or arrangements for liaison with and referral to, neuro-psychology Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	N	There was insufficient psychology time for the number of patients and families cared for by the service. At the time of the visit only 0.4WTE psychology time was available for adults, children and young people and their families.
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	No training plan to show how all staff were developing and maintaining appropriate competences was in place. There was no evidence that any training was provided for non-consultant career grades. A log of delivered training was kept, although it was not clear what level of training was provided and which staff attended.
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.	N	Data support was not available and clinical staff were spending time on data administration. A network coordinator had been appointed and was due to commence in post within the next few months.

Ref	Standard	Met?	Comments
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	Some families who met with the visiting team were not sure how to access a social worker or benefits adviser.
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 majority of patients were admitted directly to the day unit or the ward. Patients did have electronic care plans that could be accessed easily in the ED or the wards.
HN-303	**Specialist On-site Support** Access to the following specialist staff and services should be easily available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Erythrocytapheresis c. Acute pain team including specialist monitoring of patients with complex analgesia needs d. High dependency care, including non-invasive ventilation e. Level 2 and 3 critical care	Y	

Ref	Standard	Met?	Comments
HN-304	**Specialist Services - Network** Access to the following specialist staff and services with an appropriate level of specialist expertise in the care of people with haemoglobin disorders should be available: a. Pulmonary hypertension team (adults) b. Consultant obstetrician with an interest in care of people with haemoglobin disorders and specialist high risk anaesthetics (adults) c. Respiratory physician with interest in acute/chronic sickle lung disease and obstructive sleep apnoea (adults & children) d. Fertility, including pre-implantation genetic diagnosis and sperm storage (adults) e. Consultant cardiologist with interest in sickle cardiomyopathy, iron overload related heart disease (adults) f. Consultant endocrinologist with interest in thalassaemia related endocrinopathy and osteoporosis (adults) g. Consultant paediatric endocrinologist with interest in growth problems related to haemoglobinopathies and thalassaemia related endocrinopathy (children) h. Hepatobiliary team with an interest in sickle hepatopathy, viral liver disease, iron overload-related liver disease (adults & children) i. Consultant neurologist and neurosurgeon with an interest in sickle vasculopathy (adults & children) j. Hyperacute stroke service (adults) k. Consultant ophthalmologist with an expertise in sickle retinopathy and chelation related eye disease (adults & children) l. Consultant nephrologist with expertise in sickle nephropathy (adults & children) m. Consultant urologist with expertise in managing priapism and erectile dysfunction (adults & children) n. Orthopaedic service with expertise in managing sickle and thalassaemia related bone disease (adults & children) o. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) p. Bone marrow transplantation services (children only) q. Physiotherapy services (in patient and community based) r. Interventional and neuroradiology for neurovascular complications	Y	
HN-305	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	Y	

Ref	Standard	Met?	Comments
HN-401	**Facilities and Equipment** Facilities and equipment should be appropriate for the usual number and case mix of patients. Equipment should be appropriately maintained.	Y	
HN-501	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y	
HN-502	**Monitoring Protocols** Protocols should be in use covering the monitoring expected at: a. First out-patient appointment (SHC only) b. Routine monitoring c. Annual review (SHC & any LHTs to which annual reviews are delegated) Protocols should cover both clinical practice and information for patients and families.	Y	
HN-503	**Clinical Guidelines: LHT Management and Referral** Guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	N/A	

Ref	Standard	Met?	Comments
HN-504	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for: i. emergency and regular transfusion ii. use of simple or exchange transfusion iii. offering access to automated exchange transfusion to patients on long-term transfusions b. Protocol for carrying out a manual and automated exchange transfusion c. Investigations and vaccinations prior to first transfusion d. Recommended number of cannulation attempts	Y	
HN-505	**Chelation Therapy** Guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y	

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	Y	
HN-507	**Specialist Management Guidelines** Guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y	
HN-508	**Clinical Guidelines: Chronic complications** Guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y	Paediatric guidelines were in place for orthopaedic problems, endocrinopathies, growth delay and enuresis. All other guidelines covering chronic complications were adult–based, and although the number of children with these complications would be fewer, reviewers considered that the guidelines should be reviewed to ensure that they were applicable to children and young people.
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	
HN-599	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y	

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

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)	N	A written agreement with Milton Keynes University Hospital NHS Foundation Trust was not in place for undertaking the annual reviews for patients with HBSC. The team at OUH did undertake the annual reviews for patients with HBSS, but the criteria for reviewing those children and young people with complex HBSC disease were not clear.
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	There was no access to elective phlebotomy or out-patients outside the normal working day. Children and young people could attend for their transfusion at any time before 8pm and arrangements were in place for them to receive transfusions on a Saturday once a month.
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 SLAs were in place with any of the community teams or for the SHT work at the LHTs. As part of the development of the HCC the team were planning to agree formal arrangements.

Ref	Standard	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	The policy included all aspects of the QS but in practice no internal quality assurance process was in place (h)
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	The team did attend the network meetings. A combined adult and paediatric meeting was held once a year and a paediatric only network meeting every June.
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	Representatives from the neonatal screening service attended the red cell meetings which were held every two months

Ref	Standard	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.	N	The majority of patients were registered on the NHR. The percentage of patients who had an annual review entered varied. Oxford 62%, Royal Berkshire 75%, Buckinghamshire 14.3%, Great Western 54.5%. Milton Keynes submitted their own data and none of these patients had their annual review entered on the NHR. There was no evidence to show that any adverse events or patients lost to follow-up had been included.
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	N	Data covering the number of admissions and length of stay for inpatients were seen but not the other data as required by the QS.

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	
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	An audit programme had been agreed but not yet completed as defined by the QS.

Ref	Standard	Met?	Comments
HN-706	**Network Audits** The service should participate in agreed network-wide audits.	Y	The most recent time to analgesia audit from 2019 showed that 9 out of 11 patients had received analgesia within 30 minutes of arrival (81%)
HN-707	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	
HN-708	**Trans-Cranial Doppler Quality Assurance (Children's Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-207) b. Results of internal quality assurance systems (QS HN-606) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established)	N	A system for internal quality assurance was not in place (b). (c) was not applicable as a National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound had not been established
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	
HN-799	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	All guidelines were held on the network site and were easily available to staff.

Return to Index