WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

Our Lady's Children's Hospital, Crumlin

Visit Date: 21st May 2015 Report Date: September 2015

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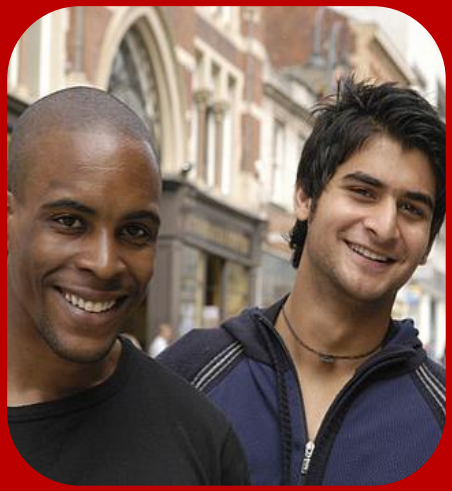

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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Our Lady's Children's Hospital, Crumlin (OLCHC), which took place on 21st May 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014 which were developed by the UK Forum on Haemoglobin Disorders working with the West Midland Quality Review Service (WMQRS). The peer review visit was organised by WMQRS on behalf of the UK Forum on Haemoglobin Disorders following a request by Our Lady's Children's Hospital, Crumlin to review the service in recognition of the hospital as the leading provider of specialist haemoglobinopathy services for children in Ireland. The Quality Standards refer to the following types of specialised service for people with haemoglobin disorders:

Specialist Haemoglobinopathy Centre (SHC)

Accredited Local Haemoglobinopathy Team (A-LHT): A Local Team to which the Specialist Centre has delegated the responsibility for carrying out annual reviews

Local Haemoglobinopathy Teams (LHT): These are sometimes also called 'Linked Providers'

The review team recognised the differences in the health service structure in Ireland, including the different provision of primary (including community services), secondary and tertiary care, and Standards which were not applicable to the Irish system have been noted and acknowledged. Financial systems were also different to those of the UK. OLCHC had an allocated yearly budget for all of its services including haemoglobin disorders, which at the time of the visit was not recognised as a national service and so did not have an individual budget. The team at OLCH wanted to benchmark against a quality system to ensure best practice in patient care.

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. Appendix 1 lists the visiting team and Appendix 2 gives details of compliance with each of the standards and the percentage of standards met.

This report describes services provided by Our Lady's Children's Hospital, Crumlin, Dublin. For the purpose of this review Our Lady's Children's Hospital, Crumlin was reviewed as a Specialist Haemoglobinopathy Centre.

Acknowledgements

We would like to thank the staff of Our Lady's Children's Hospital, Crumlin for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review.

About West Midlands Quality Review Service

WMQRS is a collaborative venture by NHS organisations in the West Midlands 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. A brief summary of the process and development of the Quality Standards for Health Services for People with Haemoglobin Disorders is available in Appendix 3 and more detail about the work of WMQRS is available on www.wmqrs.nhs.uk

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HAEMOGLOBIN DISORDERS SERVICES IN OUR LADY'S CHILDREN'S HOSPITAL, CRUMLIN

Our Lady's Children's Hospital Crumlin (OLCHC) is an acute paediatric teaching hospital and Ireland's largest paediatric hospital.

The centre for haemoglobin disorders sat within the department of haematology-oncology and shared many facilities, including out-patient clinics and a day ward. The centre had been located at the site since 2003 following the amalgamation of three small centres and the appointment of a consultant haematologist with a special interest in haemoglobin disorders and red cells. A clinical nurse specialist for children with haemoglobin disorders was also appointed with an additional nurse specialist appointed in 2007. The number of children and young people with haemoglobin disorders had increased significantly since the centre opened in 2003.

CHILDREN AND YOUNG PEOPLE

Hospital	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
Our Lady's Children's Hospital, Crumlin	374	15	81

Less than five adult patients with β Thalassaemia major received regular blood transfusions at OLCHC as the local adult centre, St James's Hospital, did not have the capacity to do so. A further 12 adult patients with sickle cell disease, two of whom remained on a chronic transfusion programme, were treated at the hospital as they were unable to transition to the adult service at St James's Hospital.

Emergency Care

All patients who required emergency care and who lived in the immediate area were advised to attend the Emergency Department (ED). ED staff had electronic access to the sickle cell disease and thalassaemia protocols and a sickle cell disease care bundle. Patients who lived too far away to attend were directed to go to their local ED for treatment. If a patient was unsure whether or not to attend the ED they were advised to contact the OLCHC team via the hospital switchboard.

Patients who arrived at EDs in other hospitals in Dublin were triaged, admitted and treated using a shared care / supportive care guideline which incorporated the OLCHC protocols**.** Following discussion between the admitting consultant and staff at OLCHC, the patient was transferred if necessary. Any children who required intensive care management were transferred and admitted using the ICU protocols from OLCHC.

A generic pain management protocol for sickle cell disease utilised intravenous administration of morphine for significant pain and was under review. Data from a recent local trial were being reviewed and implementation of recommendations being considered.

ED staff worked closely with the attending paediatric teams and had access to the haematology registrar on call in addition to the paediatric haematology consultants.

In-Patient Care

Patients were admitted to either St Michael's Ward or St Peter's Ward. St Michael's Ward was a 22 bedded medical ward for children aged over one year with a range of conditions including haemoglobin disorders and, specifically, sickle cell disease. The ward was staffed by 19 whole time equivalent staff nurses, supported by a clinical nurse facilitator and three clinical nurse managers.

St Peter's Ward was a mixed medical and surgical ward for children up to one year old. It contained 23 cots in individual cubicles. The ward had 37.5 whole time equivalent staff nurses supported by two nurse managers and a clinical facilitator for the ward.

A well-equipped teenage room, a play room for younger children and access to hospital schooling were provided. Parent accommodation was available on site and families were accommodated in two nearby houses.

Day Unit Care

The day unit was situated on the haematology oncology day ward. Nine beds and four couches were available and the facility was open from 8am until 7pm, Monday to Friday. Evening transfusions were also available. A weekend service had been implemented in 2006 but had been discontinued due to lack of take-up from patients and staffing issues. Patients could also be admitted to the medical day unit. A range of play facilities was available for patients as well as a play specialist and a visiting school teacher.

Children who lived close to the hospital attended the day before their transfusion for blood tests and blood was collected for them at 8am the following morning. A phlebotomist was available for routine pre transfusion testing and cannulation but the role was shared with other wards. Other staff included 1.5 whole time equivalent clinical nurse managers, 6.5 whole time equivalent nurses and a nurse educator.

Out-Patient Care

The out-patient facilities were contained in a new, purpose-built facility. Clinics were attended by the lead consultant, a junior doctor and usually both haemoglobinopathy nurse specialists. No cover was available for the consultant and therefore most clinics were rescheduled if the consultant was not available. The exception to this was the weekly hydroxyurea clinic. Out-patient clinics were shared with the haematology and oncology teams. There were four clinics per week, each lasting three hours.

Trans-Cranial Doppler (TCD) screening was carried out in conjunction with the general sickle cell disease clinic on Wednesdays and the hydroxyurea clinics on Thursdays. Screening could also be carried out at other times by prior arrangement.

A formal transition arrangement with the new adult haemoglobinopathy centre at St James's Hospital had been established shortly before the review. In anticipation of future need the service was continuing to develop the paediatric part of a transition service for children from the age of 12 years old.

Shared Care

A 'shared care' system was in place with other hospitals in Ireland to cater for patients who lived a considerable distance from OLCHC. Hospitals within the system used guidelines developed by OLCHC and had access to specialist clinical advice from the hospital.

Views of Service Users and Carers

The visiting team met a small number of patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They received responses to 232 questionnaires (from 248 sent).

Common themes raised by patients and carers were:

- Many patients and carers were highly complimentary of the staff and care they received. Some parents had relocated to Dublin in order to access the care offered at the hospital.
- Some patients and carers were disappointed by the long waits on the day of the scheduled transfusion, particularly for the transfusion to be initiated. Additionally some patients noted that transfusions had been rescheduled because of capacity issues.
- Delays in full transition to adult services.
- Availability of Ferriscan within the hospital was appreciated

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REVIEW VISIT FINDINGS

SPECIALIST TEAM: OUR LADY'S CHILDREN'S HOSPITAL, CRUMLIN

General Comments and Achievements

Overall an excellent service was provided for patients by a highly dedicated team. Despite limited resources the team was striving to meet the challenges of their patients and had developed a well-functioning service in a relatively short time frame.

The team was pro-active in their management with a high proportion of patients with sickle cell disease treated with sickle modifying interventions (transfusions or hydroxycarbamide).

The hospital management team was engaged and committed to the delivery of a high quality service for patients with haemoglobin disorders through their support for the haemoglobinopathy programme.

The team delivered care that was much appreciated by patients and their carers. The service worked on a shared care model with other centres in the Republic of Ireland and liaison with centres in Northern Ireland took place as necessary. Protocols had been rolled out across other centres in the Republic of Ireland. Much effort had gone into raising awareness of haemoglobin disorders including a national campaign and travelling educational 'road shows'.

Facilities for patients and carers were good and included accommodation for parents on site and for families in nearby houses.

Good Practice

1 A very good patient 'passport' was in use, which also acted as a hand-held record. The 'passport' was clear, comprehensive, professionally printed and was helping patients to self-manage their condition.

2 The transition education package was of a high standard.

3 Patient information for patients with sickle cell disease was clear, well-produced and easily accessible.

4 There had been several local training initiatives targeted at all health professionals, including study days on sickle cell disease, a 'Road Show' around the Republic of Ireland and regular teaching on the wards and in the Emergency Department. Articles for the local press had been written in order to raise awareness among the general public.

5 An annual review of all reported haemoglobinopathy incidents was undertaken and good clinical governance and reporting arrangements were in place.

Immediate Risks: No immediate risks were identified

Concerns

1 Staffing of the service was not sufficient for the number of patients:

   a. The lead consultant had additional responsibilities identified within her job plan, including Director of the Blood Transfusion Service and Director of Laboratories and, although highly dedicated to the haemoglobinopathy service, reviewers were concerned this was unsustainable in the long term. The demands of the service would justify consideration of the need for an additional consultant to support the lead consultant.

   b. Both the lead nurse and the two haemoglobinopathy nurses regularly worked beyond their contracted hours to meet the demands of the service. The service may benefit from reviewing what nurse specialist capacity was required for the workload.

c. The psychologist with an interest in haemoglobinopathies had insufficient time to support the service. Twenty hours per week were shared between patients and families with coagulation disorders and those with haemoglobin disorders. Cover for absences was not available.

d. One social worker provided support across several specialties so social work support was insufficient to support patients with haemoglobin disorders.

2 Guidelines on shared care with other hospitals did not cover 'escalation' of problems, including indications for contacting Our Lady's Children's Hospital for advice or for referring patients.

3 Our Lady's Children's Hospital was not able fully to implement transition arrangements as no specialist adult service was available at the time of the review, although a locum had started in post in St James's Hospital shortly before the review. This resulted in the paediatric service caring for patients aged 20 years and over.

4 Patients reported delays of up to two hours for a transfusion. There were a number of reasons for this delay including the need for a doctor to prescribe the volume of blood, assess the child and gain consent for the transfusion from the patient or carer on each occasion, as well as delays in initiating cannulation.

Further Considerations

1 Reviewers were told that attempts had been made to engage with GPs about the management of haemoglobin disorders however further work defining the role of the general practitioner in managing the care of patients with haemoglobin disorders may be helpful.

2 It was not clear if all correspondence was copied to patients, their GPs and other relevant health professionals. The patient 'passport' was also not always completed, including entering results. Additional support from clinical staff for this may be appreciated by patients and families.

3 The Hospital may wish to consider implementing nurse-led clinics where appropriate, such as nurse-led phlebotomy, cannulation, transfusion and monitoring. This could free up time for the lead consultant to give to other aspects of patient care.

4 Reviewers suggested that there may be potential to increase self-management opportunities and reduce dependency on the hospital team.

5 The hospital may wish to consider the development of an Irish Haemoglobinopathy Registry to record patient data, annual reviews and adverse events.

6 Further work to establish joint specialist clinics should be considered.

7 Consideration should be given to obtaining designation as a National service with appropriate funding.

Other Concerns

The following concerns were identified by the review team but were not the responsibility of Our Lady's Children's Hospital:

1 **Screening Programme**

OLCHC had advocated that a national neonatal screening programme for Haemoglobin disorders be established. Although local arrangements with various maternity hospitals were in place, a formal antenatal and new-born screening programme was not yet in place. Also, pathways for haemoglobin disorders screening, including 'fail safe' and follow up arrangements were not yet in place. Reviewers suggested that a formal standardised National screening programme should be considered.

2 **Adult Services**

Our Lady's Children's Hospital was not able to implement transition arrangements as no fully functioning adult specialist haemoglobinopathy service was available at the time of the review. This resulted in the

paediatric service caring for patients aged 20 years and over, particularly those requiring red cell transfusions. In addition to the lack of a service for young people transitioning from the paediatric services, reviewers were made aware of 40 to 50 adult patients for whom specialist care was not available. A locum consultant had, however, started in post in St James's Hospital shortly before the review.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead

Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust

Visiting Team

Dr Penelope Cream	Clinical Psychologist	St George's University Hospitals NHS Foundation Trust
Dr Moira Dick	Consultant Paediatrician	Kings College Hospital NHS Foundation Trust
Louise George	Haematology Nurse Specialist	Sheffield Children's NHS Foundation Trust
Hazel Marriott	Sickle Cell and Thalassaemia Nurse Specialist	Nottingham University Hospitals NHS Trust
Dr Chris Sotirelis	Trustee Advisor	UK Thalassaemia Society

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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 varied 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

Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for Children and Young People with Haemoglobin Disorders	49	35	71

Pathway and Service Letters

HN-	Specialist services for People with Haemoglobin Disorders
HY-	Haemoglobin Disorders: Network
HZ-	Haemoglobin Disorders: Commissioning

Topic Sections

Each section covers the following topics:

-100	Information and Support for Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment
-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

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Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-101 All	**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 and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199)	Y	
HN-102 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual and treatment 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. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	N	Information for 'b' was only available for sickle cell disease. Health maintenance guides were good but only applicable to patients with sickle cell disease.

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-103 All	**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 hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service	Y	Information for points 'b', 'c' and 'e' was limited.
HN-104 All	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	N	Clinic letters were not routinely copied to GPs and other appropriate health professionals.
HN-105 All	**School Care Plan (Paediatric 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	N	A consent form for exchange of information was available but no formal school care plan was in place.

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-106 SHC (A-LHT)	**Transition to Adult Services** Young people transferring to the care of adult services should be offered written information covering at least: a. Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer b. A joint meeting between children's and adult services to plan the transfer c. A named coordinator for the transfer of care d. A preparation period prior to transfer e. Arrangements for monitoring during the time immediately after transfer	N	Available information did not include a named coordinator for transition. Arrangements for monitoring during the time immediately after transfer were not clear. Other documentation and provision of evidence was good.
HN-107 SHC	**Information about Trans-Cranial Doppler Ultrasound** 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. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated	N	Available information did not include arrangements for 'e'.
HN-199 All	**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	N	Arrangements for 'c' and 'd' were not yet in place. A comprehensive survey had been carried out.
HN-201 All	**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 session/s identified for this role within their job plan.	Y	The lead consultant had a range of commitments outside of the haemoglobin disorders programme and reviewers were unclear how much time was available in the job plan to fulfil all aspects of the role.

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y	
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: 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. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	N	A highly competent lead nurse was available but did not have sufficient time to fulfil all aspects of this Quality Standard.
HN-204 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in 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	There was no cover available for either junior medical staff or the psychologist for the service. Hospital-specific competences were in place for nursing staff and roles and responsibilities were well-defined.

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-205 All	**Competences and Training** 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 (QS HN-204).	Y	An extensive training programme was in place.
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y	
HN-207 All	**Training for Emergency Department Staff** The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	Y	
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y	
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	
HN-210 SHC	**Trans-Cranial Doppler Ultrasound Competences (Paediatric 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 All	**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	At the time of the review the support available was insufficient but two new appointments had been made.

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these 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) if required.	N	Social worker and psychologist time was insufficient for the needs of the service.
HN-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	Y	

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	Y	Patients requiring bone marrow transplants were referred to the UK.
HN-304 All	**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 All	**Facilities Available** 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	Facilities were of a high standard.
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-501 SHC A-LHT	**Transition Guidelines** Network-agreed guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	N	See main report in relation to the availability of a specialist centre for adults. There was no named coordinator for transition. Arrangements were not in place with local teams.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	Y	
HN-503 LHT	**Clinical Guidelines: LHT Management and Referral** Network-agreed 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	Shared care guidelines were in place but did not include information about escalation to a specialist service.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Offering access to exchange transfusion to patients on long-term transfusions c. Protocol for carrying out an exchange transfusion d. Hospital transfusion policy e. Investigations and vaccinations prior to first transfusion f. Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. g. Areas where transfusions will usually be given h. Recommended number of cannulation attempts	Y	Information on vaccination prior to transfusion could be clearer.

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-505 All	**Chelation Therapy** Network-agreed clinical 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	Point 'f' was not applicable to the service.
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed clinical 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	Comprehensive guidelines were available.
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical 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	

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed clinical 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	
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y	Patients were referred to the UK.
HN-510 All	**Thalassaemia Intermedia** Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y	
HN-511 All	**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	Quality Standard	Met? Y/N	Reviewer Comments
HN-512 SHC	**Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)** Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least: a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)	Y	

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-601 All	**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 specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. 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. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	N	The screening programme was not fully developed and 'fail safe' arrangement were not yet in place. Community paediatricians ('e') were not routinely available (though the different structure for community services in Ireland was acknowledged). Arrangements for 'j' were unclear.
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	Y	
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N/A	Community services were not available due to the difference in the healthcare structure in Ireland. Services within the community can strengthen the ability of patients to manage their own condition and so consideration should be given to how this could be achieved within the Irish healthcare system

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS **Error! eference source not found.**).	Y	
HN-605 SHC	**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 (HN-704), identify issues of mutual concern and agree action.	N	Robust screening data were not available.
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	N/A	See main report.
HN-702 All	**Annual Data Collection - Activity** 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	Quality Standard	Met? Y/N	Reviewer Comments
HN-703 SHC	**Annual Data Collection – Network Patient Data** The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia: a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network services during the course of the year: i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: i. Date seen in clinic ii. Date offered and prescribed penicillin d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year e. Number of network patients on long-term transfusion f. Number of network patients on chelation therapy g. Number of network patients on hydroxycarbamide h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients j. Number of network patients whose care was transferred to another service during the year k. Number of network patients who died during the year l. Number of network patients lost to follow up during the year	Y	

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	N	No audit data were seen for 'd', 'f' or 'j'.
HN-705 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	Y	Audits were not yet undertaken on an annual basis.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	

Ref	Quality Standard	Met? Y/N	Reviewer Comments
HN-707 SHC	**Trans-Cranial Doppler Quality Assurance (Paediatric 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-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required	Y	
HN-798 All	**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	Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

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APPENDIX 3 WHAT ARE WMQRS QUALITY STANDARDS?

1 The WMQRS and UK Forum Quality Standards for Health Services for People with Haemoglobin Disorders and quality review process were finalised following consultation with a wide range of stakeholders. More information about WMQRS and its approach is available on www.wmqrs.nhs.uk. Anyone with queries about the Quality Standards or the review process should contact WMQRS from the website in the first instance.

2 The aim of Haemoglobin Disorders Peer Review programme is to help organisations to improve the quality of clinical services in a developmental and supportive way. This process does not set out to be an inspection or performance management tool.

3 We hope that through the Haemoglobin Disorders Quality Standards and peer review programme:

a. Patients and carers will know more about the services they can expect.

b. Commissioners will be supported in assessing and meeting the need of their population, improving health and reducing health inequalities, and will have better service specifications.

c. Service providers and commissioners will work together to improve service quality.

d. Service providers and commissioners will have external assurance of the quality of local services.

e. Reviewers will learn from taking part in review visits.

f. Good practice will be shared.

g. Service providers and commissioners will have better information to give to the Care Quality Commission and Monitor.

As part of the Clinical Commissioning Groups' (CCG) assurance processes, participation in this process will help CCGS to demonstrate that they have appropriate arrangements for quality assurance and quality improvement.

4 The benefit that services gain from this process depends hugely on the way in which they approach it. Teams which link the review process with their ongoing work to improve service quality and who see the review visit as useful external quality assurance will find the whole process more constructive.

5 The Quality Standards for Services were originally developed separately for children and adults' services to support implementation of the 'Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK' (2005, 2nd edition 2008), 'Sickle Cell Diseases in Childhood: Standards and Guidelines for Clinical Care' (2006) and 'Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK' (2008). They have now been combined into a single set of Quality Standards for use in both children's and adult services.

6 Quality Standards, suitable for use in quality reviews, are fundamental to the clinical review processes used by WMQRS. They are also useful for services to monitor their own progress toward implementation of best practice guidance. Quality Standards are usually measures of structure and process quality (rather than outcomes) but include a) processes of collecting and using data on outcomes and b) processes for collecting information on patient and carer experience and for involving patients and carers in improving the service and care pathway. Quality Standards follow the patient and usually include a pathway summary. They reflect the latest national guidance and help to answer the question "If I walk into a service, how I will know that best-practice guidance has been implemented?" Where evidence-based guidance is not available, Quality Standards are based on a consensus of professional and service users' and carers' views.

REFERENCE SOURCES

Guidance Documents

	Year	Publisher	Title
1	2014	Department of Health	Introducing Fundamental Standards: Consultations on proposals to change CQC registration regulations
2	2013	NHS England	2013/14 NHS Standard Contract for Specialised Services for Haemoglobinopathy Care
3	2013	European Network for Rare and Congenital Anaemias (ENERCA), Thalassaemia International Federation and International Organisation for Migration (IOM)	Haemoglobinopathies on the Move: Is Europe ready? Health and Migration Policy Perspectives
4	2013	NHS Litigation Authority	NHS Risk Management Standards 2013-14 for NHS Trusts providing Acute, Community or Mental Health & Learning Disability Services and Non-NHS Providers of NHS Care
5	2012	NHS Sickle Cell and Thalassaemia Screening Programme	NHS Sickle Cell and Thalassaemia Screening Programme: Handbook for Laboratories
6	2011	NHS Sickle Cell & Thalassaemia Screening Programme	NHS Sickle Cell and Thalassaemia Screening Programme; Standards for the Linked Antenatal and Newborn Screening Programme – Summary of Changes
7	2011	Royal College of Nursing	Caring for people with sickle cell disease and thalassaemia syndromes – A framework for nursing staff
8	2011	Department of Health	Quality Services for Young People Friendly Health Services
9	2011	NHS Sickle Cell & Thalassaemia Screening Programme	Standards for the linked Antenatal and Newborn Screening Programme
10	2010	NHS Sickle Cell and Thalassaemia Screening Programme	Sickle Cell Disease In Childhood Standards and Guidelines for Clinical Care, 2nd Edition
11	2009	NHS Sickle Cell & Thalassaemia Screening Programme	Trans-Cranial Doppler Scanning for Children with Sickle Cell Disease
12	2008	Sickle Cell Society	Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (Sickle Cell Society)
13	2008	United Kingdom Thalassaemia Society	Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK
14	2008	NCEPOD	A sickle crisis? A report of the National Confidential Enquiry in Patient Outcome and Death report

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