WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

NHS Greater Glasgow and Clyde

Visit Date: 12th January 2016 Report Date: May 2016

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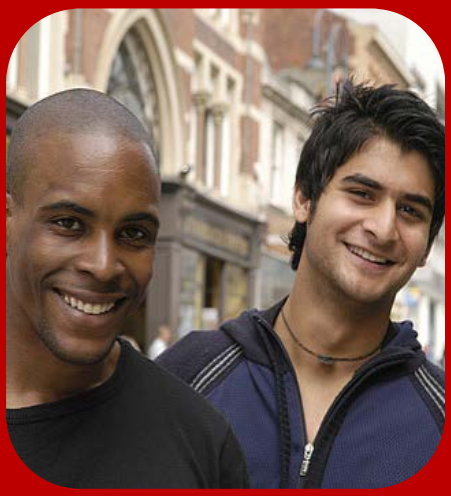

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Version Number	Date	Change from Previous Version
V1	12.05.16	N/A
V1.1	24.11.16	Minor amendment on page 39. Correction of error in QS ref no HN-706 and HN-707

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in NHS Greater Glasgow and Clyde, which took place on 12th January 2016. 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. 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 aim of the Standards and the review programme is to help providers 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 (or equivalent).

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 the following organisations:

- NHS Greater Glasgow and Clyde

Most of the issues identified by quality reviews can be resolved by organisations' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms.

Acknowledgements

We would like to thank the staff of NHS Greater Glasgow and Clyde 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. The NHS Sickle Cell and Thalassaemia Screening Programme funded this peer review programme.

About West Midlands Quality Review Service

WMQRS is a collaborative venture between 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. More detail about the work of WMQRS is available on www.wmqrs.nhs.uk

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HAEMOGLOBIN DISORDERS SERVICES IN SCOTLAND

The Scottish Government agrees national objectives and priorities for the NHS in Scotland, signed delivery plans with each NHS Board and the Special NHS Board, monitors performance and supports NHS Boards to ensure achievement of these key objectives.

NHS Boards in Scotland are 'all-purpose' organisations. They plan, commission and deliver NHS services and have overall responsibility for the health of their populations. This includes hospital and community health services as well as services provided by GPs.

The Quality Standards relating to the commissioning of services for patients with haemoglobin disorders were therefore not applicable in Scotland. Funding for haemoglobinopathy services was provided as part of the medical paediatrics department's haematology-oncology divisional funding.

Adults

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long term red cell transfusions
NHS Greater Glasgow & Clyde - Glasgow Royal Infirmary	SHC – shared services	24	<5	6
NHS Greater Glasgow & Clyde - Queen Elizabeth University Hospital		5	<5	0

Children and Young People

Trust	Reviewed as:	No. children with sickle cell disease	No. children with thalassaemia	No. children on long term red cell transfusions
NHS Greater Glasgow & Clyde: Royal Hospital for Children Glasgow	SHC	52	13	11
Dumfries Royal Infirmary	LHT	0	<5	0
Ninewells, Dundee	LHT	<5	0	0

ADULT SERVICES – GLASGOW ROYAL INFIRMARY (GRI) AND QUEEN ELIZABETH UNIVERSITY HOSPITAL (QEUH)

Emergency Care

GRI: During working hours, patients were encouraged to phone haemophilia nurses who liaised with the GRI haematologist registrar or consultant and arranged haemophilia day unit review by a haematologist or, for more severe symptoms, advised admission via the medical-receiving team. Outside normal working hours admissions were via the medical-receiving area or the Emergency Department (ED). Patients were admitted to the care of the consultant physician but were reviewed at least daily by the haematology consultant or trainee who coordinated all sickle cell disease-related care.

QEUH: For minor issues the patients were triaged through the haematology day unit and for more serious complaints they were advised to present to the ED. Patients were admitted directly to the haematology ward if a bed was available. More commonly, they were admitted into a medical ward and reviewed regularly by the haematology team.

In-Patient Care

GRI: The GRI site did not have designated haematology beds. Patients with sickle cell disease were seen and assessed in the Acute Medical Assessment Unit in Jubilee Building adjacent to the ED and then transferred to one of the acute medical-receiving wards. The top floor of the Jubilee Building had three large acute medical wards with 68 beds and one high dependency unit (HDU) with six beds. Patients with chest crisis were admitted to HDU, whilst patients with painful crises were admitted to the general medical assessment unit. Intensive care was available on-site. Between 24 and 48 hours after admission patients were transferred to one of the general medical wards usually to Ward 4 or 5. The haematology team had significant involvement with all patients with sickle cell disease during in-patient stays as it was an uncommon reason for admission. The admission rate was approximately one patient per month.

QEUH: Similarly, patients were admitted via the acute receiving unit into a medical bed with haematology input. Although QEH had haematology wards these were used mainly for oncology patients. Good medical HDU and ITU facilities were provided on-site.

Day Care

GRI: Transfusions and non-clinic reviews were performed in the haemophilia unit**.** This unit was designed for the care of haemophilia patients but the facility was well suited to supporting patients with haemoglobinopathies. Patients could be seen in the haemophilia unit for urgent out-patient assessment but would not routinely receive acute care in the day unit facility.

QEUH: Patients were assessed in the haematology out-patient clinic at Victoria Hospital part of NHS Greater Glasgow and Clyde. Regular transfusions were also carried out there if required. The day case facility at Victoria Hospital was not visited by the peer review team but it had a large haematology and oncology unit with ten nursing staff, a large main patient area and a number of single rooms.

Out-Patient Care

A haemoglobinopathy clinic was held monthly by the consultant with the haemophilia nurses at the GRI in the haemophilia unit. A haematology registrar attended this clinic as an educational opportunity but was not routinely required for service provision. Patients could be seen outside clinic times by a haematology consultant or registrars in the haemophilia day unit if required. The small number of patients who attended QEUH were reviewed in the general haematology clinic held at the Victoria Hospital.

Community-Based Care

Specific community nursing services for haemoglobinopathy patients were not provided. Community based nursing care for haemoglobinopathy patients was provided by primary care in liaison with the hospital service.

CHILDREN AND YOUNG PEOPLE – ROYAL HOSPITAL FOR CHILDREN, GLASGOW (RHC)

Emergency Care

Patients had direct access to the haematology-oncology day ward during normal working hours or presented directly to ED. They were advised to contact the day care unit by phone in advance and then advised either to attend day care or in more urgent circumstances, to phone for an ambulance to take them to the nearest ED.

For out of hours admissions patients presented at the ED. Additionally, they were advised to contact the haematology-oncology ward staff in advance, if possible, who then advised both the on-call paediatric team and ED that a patient was due to present.

In-Patient Care

In-patient facilities were provided as part of a dedicated haematology-oncology ward with 22 beds.

Day Care

Patients attended the haematology-oncology day care unit for both scheduled and unscheduled reviews and for blood transfusion. They had direct access to the unit during normal working hours.

Out-Patient Care

Out-patient services were provided within the out-patient department at RHC which included paediatric phlebotomy and finger prick sampling. A dedicated sickle cell disease clinic was held monthly. This included provision of Trans-cranial Doppler scanning as a one-stop clinic.

Community-Based Care

Specific community nursing services for haemoglobinopathy patients were not provided. Community-based nursing care for haemoglobinopathy patients was provided by primary care in liaison with the hospital service. This included liaison with the school nursing services.

VIEWS OF SERVICE USERS AND CARERS

Adult Services:

The visiting team met a small number of patients and carers with sickle cell disease and received feedback from them. They reviewed responses to approximately ten questionnaires.

Common themes raised by patients and carers were:

- Positive feedback regarding the lead clinician and her efforts to improve services and accessibility
- Long delays for analgesia in the Emergency Department (ED) were reported including, on occasion, up to six hour waits
- Poor levels of awareness and education of ED staff in the care of people with haemoglobin disorders
- Difficult experiences in ambulance transfer with lack of understanding and distrust.
- Lack of access to out of hours transfusion

Services for children and young people:

The visiting team met a small number of patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They reviewed responses to 21 questionnaires.

Common themes raised by patients and carers were:

- Overall patient and carers were happy with the service
- Patients and carers tended to bypass the ED and come straight to the day unit
- Some awareness of the school care plan
- Schools were very supportive but the clinical nurse specialist (CNS) did not have time allocated to school visits
- Very complimentary about the care provided by the CNS

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REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

This was the first peer review visit of services for people with haemoglobin disorders in Scotland. Scotland has a low population density outside the densely populated central belt,. The majority of patients with haemoglobin disorders live in or near the large conurbations of Glasgow, Edinburgh and Aberdeen. Patients outside these areas were encouraged to attend their nearest large centre for care or annual review.

To facilitate equitable care a national Managed Clinical Network (MCN) had been established. The Scottish Paediatric and Adult Haemoglobinopathy (SPAH) MCN was funded by the National Services Division (NSD) and hosted by National Health Service (NHS) National Services Scotland. This network was established formally on 1st April, 2011 and was an excellent example of the delivery of an equitable service for patients with a low prevalence disease across a large geographical area. The highly functioning network had a variety of sub-groups developing guidelines, audit programmes and making cases for service development. The MCN had well-defined roles, protocols, patient engagement and an education programme. In addition, network-wide multi-disciplinary team meetings occurred on a regular basis.

Paediatric data were uploaded manually to the MCN haemoglobinopathy register allowing easy access to patient data throughout the country and data from the register was used to undertake clinical audits.

Good Practice

1 Network arrangements as a whole were highly commendable. The reviewing team considered SPAH to be an excellent example of a well-functioning network. Regular network-wide multi-disciplinary team meetings served as an excellent source of learning and development for the haemoglobinopathy clinical teams.

2 A national quarterly teleconferenced multi-disciplinary team meeting was held to discuss clinical cases

3 Active involvement of patients and carers in the work of the network was evident, including in service planning and regular network meetings.

4 Regular family and educational events took place.

Immediate Risks No immediate risks were identified

Concerns

1 Some of the audits listed in the Quality Standards were not performed at the time of the visit, such as waiting times to analgesia, extended red cell phenotype audit and waiting time to transfusions.

Further Consideration

1 Undertaking network-wide research projects may be useful.

2 The specialist teams may wish to consider developing links with another Specialist Centre for support with, for example, staff training and access to specialist expertise.

3 Data were not entered into the National Haemoglobinopathy Registry. However, patient data were entered into the Scottish Clinical Audit System. The service may want to work with the NHR to support benchmarking the quality of care.

NETWORK CONFIGURATION

The network configuration at the time of the review was as follows. The Western Infirmary in Glasgow was due to close shortly after the review visit.

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
NHS Greater Glasgow & Clyde: Glasgow Royal Infirmary Queen Elizabeth University Hospital	• Royal Alexandria Hospital Paisley • Inverclyde Royal Hospital, Greenock • Vale of Leven Hospital, West Dunbartonshire • Western Infirmary Glasgow • Gartnavel Hospital, Glasgow
NHS Greater Glasgow & Clyde: Royal Hospital for Children, Glasgow	• Dumfries Royal Infirmary • Ninewells, Dundee • Royal Alexandra Hospital, Paisley • Wishaw General Hospital, Lanarkshire • Crosshouse Hospital, Ayr

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SPECIALIST TEAM: (ADULT SERVICES) GLASGOW ROYAL INFIRMARY AND QUEEN ELIZABETH UNIVERSITY HOSPITAL

General Comments and Achievements

There had been a slow but steady growth in patient numbers in the five years before this review visit. Rationalisation of hospital services in Greater Glasgow and Clyde had led to a centralisation of care for most patients with haemoglobin disorders to the GRI site although a small number of patients also attended QEH. The service was led by a highly motivated, enthusiastic lead clinician with clear intentions further to improve services offered to this group of patients. Patient feedback, particularly about the lead clinician, was good.

Due to the limited numbers of patients, the haematology team was involved with all those admitted.

Good Practice

1 Excellent 24 hour access to automated erythrocytopheresis was provided at all sites.

2 User-friendly stepwise pain management guidance was in use.

Immediate Risks: No immediate risks were identified.

Concerns

1 Specialist nurse support for adult patients was not available.

2 Little patient information was available, which may be related to the lack of specialist nurse input. Some patient information leaflets relating to the 'haemoglobinopathy service', 'how to help yourself', 'vaccinations and holiday advice' and 'priapism', were available and further development was planned.

3 Education and training of Emergency Department staff in the care of people with haemoglobin disorders was offered but this offer had not been taken up.

4 Arrangements to triage haemoglobinopathy patients as urgent were not in place within ED and patients reporting long waiting times for analgesia.

Further Consideration

1 Support from a psychologist with a special interest in haemoglobinopathies was not provided.

2 Although T2* MRI was provided within Glasgow adult patients had to travel to Forth Valley Hospital for ferriscan. This arrangement was established to allow patients in Edinburgh to access the same service but may lead to difficulties for patients having to attend for separate scans many miles apart.

3 In view of the small numbers of patients in the Greater Glasgow area reviewers suggested that consideration should be given to merging the QEH and GRI services to a single site.

4 A robust programme covering the audits outlined in the Quality Standards should be considered in order to ensure ongoing quality monitoring of the service.

5 Data management support for the input of data to the Scottish Clinical Audit System (CAS) database was not available.

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SPECIALIST TEAM: ROYAL HOSPITAL FOR CHILDREN NHS TRUST

General Comments and Achievements

The paediatric haemoglobinopathy service was provided by a cohesive, well-led team, appreciated by users, and based within the paediatric haematology and oncology department. Estates and facilities were of a high quality in a purpose-built hospital. The service was responsive to local population needs which resulted in the development and establishment of services to match the relatively recent increase in local haemoglobinopathy patient numbers. As part of a larger tertiary teaching hospital, the service planned to develop expertise in the non-haematological specialities, including in the care of haemoglobinopathy.

Good Practice

1 The central blood apheresis service provided 24/7 cover for planned and acute red cell apheresis. This had resulted in the development of expertise within the apheresis unit of managing chronic apheresis, such as obtaining peripheral access for red cell exchanges.

Immediate Risks: No immediate risks were identified.

Concerns

1 The review team was concerned by the lack of nursing support for haemoglobinopathy patients in the community. The hospital-based CNS was unable to provide school visits and health education due to her acute service workload.

2 The pain management audit had identified that only 25% of patients had received a first dose of analgesia within the recommended 30 minutes.

Further Consideration

1 It may be helpful for families to receive new diagnoses in their home setting by an appropriately trained nurse. This could be achieved by increasing capacity and extending the role of the acute haemoglobinopathy nurse specialist, similar to the existing model in haemophilia, if separate community nursing provision was not appropriate due to low patient numbers.

2 The service did not have adequate and dedicated psychology support including neuropsychology. Reviewers considered that the provision of four sessions of psychology support for the whole of haematology and oncology department was insufficient to meet the needs of haemoglobinopathy patients.

3 Implementation and dissemination of school care plans for all children with haemoglobin disorders should be considered. This could be achieved by extending the role of a nurse specialist to provide community support.

4 A transition service for patients with haemoglobin disorders was not established at the time of the review, as the paediatric service was awaiting a consensus about consolidation of the adult services to a single site. Reviewers suggested that the paediatric service should continue to implement the 'Ready Steady Go' transition programme that was initiated within the department in 2015.

5 A robust programme covering the audits outlined in the Quality Standards should be considered in order to ensure ongoing quality monitoring of the service.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Leads:

Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Subarna Chakravorty	Consultant Paediatric Haematologist	Kings College Hospital NHS Foundation Trust

Visiting Team:

Dr Marie Donohue	Consultant Haematologist	Nottingham University Hospitals NHS Trust
Dr Penelope Cream	Clinical Psychologist	St George's University Hospitals NHS Foundation Trust
Louise Smith	Sickle Cell CNS	Alder Hey Children's NHS Foundation Trust
Verna Davis	Specialist Nurse & Manager	Central Manchester University Hospitals NHS Foundation Trust
Joanne Bloomfiled	Specialist Nurse & Manager	Nottingham Sickle Cell and Thalassaemia Service
Sajid Hussain	Service User	Not applicable

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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

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	42	21	50
Haemoglobin Disorders Clinical Network	9	5	56
Total	51	26	51

Paediatric Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders – Service for Children and Young People	48	34	71
Haemoglobin Disorders Clinical Network	9	5	56
Total	57	39	68

Pathway and Service Letters

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

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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SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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)	N	Information for thalassaemia and 'h iv' was not available. Some of the information was out of date.	Y	Social services, benefit and spiritual support information was not yet in place.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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 leaflets were presented for c, gii and giii.	Y	More information was needed on vaccination and travel advice. Information for 'h' was not applicable.

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	Generally included in patient letters.	Y	
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	Patients did not routinely get a copy of clinic letters. The lack of a care plan was also commented upon in the patient survey.	Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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		N	School care plans were not yet in place for all patients. School visits were not in the clinical nurse specialist job plan and specialist community nursing support was not available.
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	The team was in the early stages of rolling out the 'ready steady go' programme. Transitioning numbers were small but were likely to increase over forthcoming years.	N	The team was in the early stages of implementing a 'ready steady go' programme but formal transition service arrangements were not yet in place.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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/A		Y	
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	Y	See comments in main report.	Y	A very good example was provided.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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		Y	
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		Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	Specialist nurse support was not available.	Y	Evidence of use of RCN competences in the personal development plan for the lead nurse was provided. The clinical nurse specialist (CNS) covered warfarin and haemophilia when the haemophilia nurse was on leave. The CNS also covered haemophilia clinic once a week.

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	Although there was adequate medical staffing and numbers of nurses within the medical assessment unit, support from a psychologist was insufficient and the lack of specialist nurse input was evident. Community services for people with haemoglobin disorders were not available.	N	Services for 'e' were not in place and 'g' was insufficient to meet service needs.
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).	N	Regular training for specialist haematology trainees was available. Training programmes for ward nurses were under development.	N	Regular training was provided for haematology doctors and paediatric ward doctors. Training programmes for ward nurses was under development.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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		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	N	The service did not offer regular training in the care of patients with haemoglobin disorders for Emergency Department staff.	N	Plans were in place to develop a training programme
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		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	If trainees wished to develop a specialist interest in haemoglobinopathy then additional experience would be arranged at a larger centre although this opportunity had not yet been taken up by a trainee.	Y	

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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.	N/A		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.	N	Administrative support was insufficient.	Y	
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	Access to staff with specific competences in the care of people with haemoglobin disorders was not available.	Y	However 'a' was insufficient and 'c' was not applicable.

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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		Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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.	N	There had been no orthopaedic referrals. Neuropsychology support was not available. Ferriscan was only available at Forth Valley for the adult population.	N	Neuropsychology support was not available.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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		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		Y	
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	The facilities for out of hours transfusion was available but limited.	Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	Network agreed guidelines on transition were not yet in place.	N	Written guidelines were not available on transition. A named coordinator was not allocated and a transition clinic was not yet in place. 'Ready steady go' documents were presented to the review team and a few patients were initiated in the programme in 2015
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	The SPAH guideline was past its revision date.	Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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/A		N/A	
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		Y	Pre-surgical transfusion guidance needed to be reviewed and updated, in line with recommendation from the TAPS trial.

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	However the guideline lacked detail relating to dose adjustments and management of the severely iron-overloaded patient.	Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	N	Guidelines were in place for 'a', 'c', 'f' and 'g' others were under development.	Y	'j' was not covered by the guidance, although a rare occurrence in children and young people.
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		Y	Pre-surgical transfusion guidance needed to be reviewed and updated, in line with recommendation from the TAPS trial.

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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)	N	Network-agreed clinical guidelines on the management of chronic complications were not yet in use.	N	Network-agreed clinical guidelines on the management of chronic complications were not yet in use.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y		Y	
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	N	Network-agreed clinical guidelines for the management of thalassaemia intermedia were not yet in use.	Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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		Y	

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	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)	N/A		Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	A service organisation policy for haemoglobinopathy disorders was not yet in use.	N	A service organisation policy for haemoglobinopathy disorders was not yet in use.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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		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		N/A	
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	
HN-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/A		Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	Data were not entered into the National Haemoglobinopathy Registry. Demographic data were provided within the Scottish Clinical Audit system, but contained minimal clinical information due to lack of data manager support locally.	N/A	Data were not entered into the National Haemoglobinopathy Registry. However, patient data were entered into the Scottish Clinical Audit System.
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	N	The service was not monitoring activity on an annual basis. Data for the previous 12 months were provided for the peer review team but had to be gathered manually by the clinician due to lack of data manager support.	N	The service was not monitoring activity on an annual basis due to lack of data manager support.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	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	N	The service was not monitoring patient data on an annual basis.	N	The pain audit showed that the NICE criteria of 'analgesia within 30 minutes' was met 25% of the time.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	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	However a vaccination audit had been performed.	N	Some clinical audits covering the areas identified in the Quality Standard had not been undertaken within the last two years.

		Adult		Children and Young People	
Ref	Quality Standard	Met? Y/N	Comments	Met? Y/N	Comments
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.	N	An audit subgroup of SPAH had been established and was developing an audit programme.	N	An audit subgroup of SPAH had been established and was developing an audit programme.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N	The SHC was not actively participating in research relating to the care of patients with haemoglobin disorders.	N	The SHC was not actively participating in research relating to the care of patients with haemoglobin disorders.
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	N/A		Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	A teleconferenced multi-disciplinary team meeting was held quarterly. New cases, intensive care admissions plus other complex cases from across Scotland were discussed.	Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	Y	Patients and carers were involved with the SPAH steering group.	Y	
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	Y		Y	The network did not have 'd' or 'e' and 'c' was not applicable.
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-204 and HN-205.	Y		Y	

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Ageguidelines 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. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	However transition guidelines were under development.	N	However transition guidelines were under development and the implementation of the NHS 'Ready Steady Go' programme had commenced in 2015.

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HY-502	**Clinical Guidelines** Network guidelines should have been agreed covering: a. Annual review (QS HN-502) b. Routine monitoring (QS HN-503) c. Transfusion (QS HN-504) d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303) g. Specialist management (QS HN-507) h. Thalassaemia intermedia (QS HN-510) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.	N	Network guidelines for annual review and routine monitoring had been agreed.	N	For sickle cell disease network-wide protocols were agreed for acute paediatric complication and were available on the SPAH web site. Guidelines for chronic complications were being prepared. Network guidelines were approved by the network steering group before being added to the website.
HY-701	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	Y		N	The network did not monitor patient data or document annual reviews on the National Haemoglobinopathy Registry.

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QSs HN-703, HN-704, HN-705 and HN-706.	N	The network did not yet have an agreed programme of audit and review covering network-wide achievement.	Y	There was an agreed programme of audit but not all audits had been implemented
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	The network did not have an agreed policy on research.	N	The network did not had an agreed policy on research.
HY-798	**Network Review and Learning** The SHC should meet at least twice a year with its referring LHT teams to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from any positive feedback or complaints involving liaison between teams d. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams e. Consider the content of future training and awareness programmes (QS HY-202)	Y		Y	Local haemoglobinopathy team involvement in care of paediatric patients was limited.

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