WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

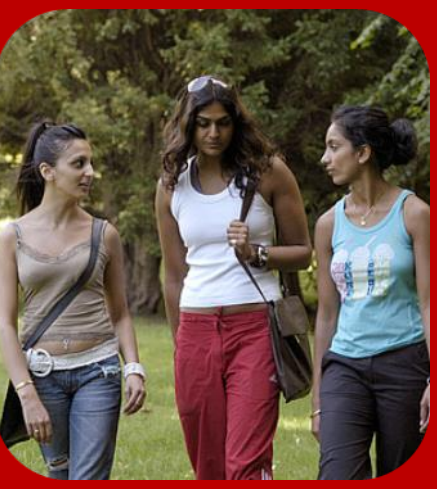
Wales

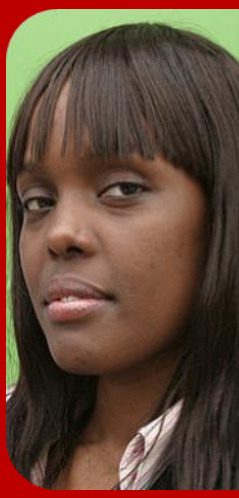
Cardiff & Vale University Health Board

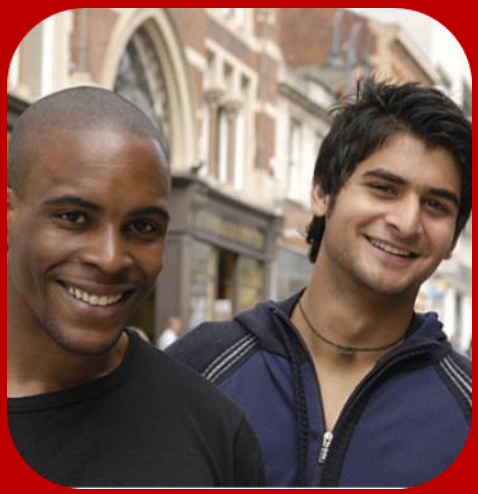
Visit Date: 3rd February 2016

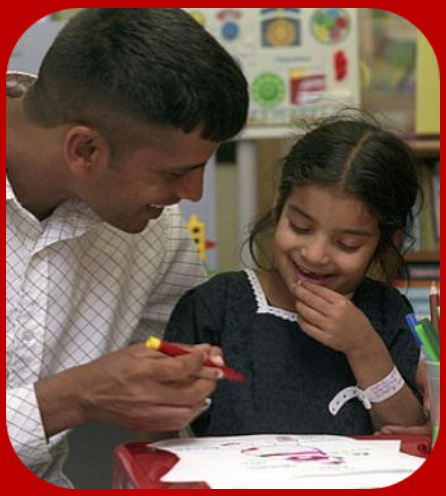
Report Date: June 2016

Images courtesy of NHS Photo Library









UKAS INSPECTION 8831

NHS

INDEX

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Cardiff & Vale University Health Board in Wales, which took place on Wednesday 3rd February 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 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 or commissioned by the following organisations:

- Cardiff & Vale University Health Board
- Welsh Health Specialist Services Committee (WHSCC) – Paediatric haemoglobinopathy services

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation liaising, as appropriate, with other commissioners. The lead commissioner for services for children and young people in relation to this report is the Welsh Health Specialist Services Committee (WHSCC).

Acknowledgements

We would like to thank the staff of Cardiff & Vale University Health Board 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

Return to *Index*

Haemoglobin Disorders Services in Cardiff and Vale University Health Board Network

Adults

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long term red cell transfusions
University Hospital of Wales	SHC	33	17	10

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
University Hospital of Wales (The Noah's Ark Children's Hospital for Wales)	SHC	33	<5	6

Adult Services – University Hospital of Wales

Services for people with haemoglobin disorders were developed initially in 1985 in Cardiff with a community-based service set up in Butetown Health Centre. This was followed by the development of the adult hospital service. A restructure of adult services took place in 2013 with community services moving to new premises at Loudon Square, a multi-purpose community hub. The clinical lead based at a neighbouring Health Board provided the adult service which included an in-patient service and a fortnightly out-patient service.

Emergency Care

Patients known to the service were given information with contact numbers for the day centre and haematology ward. Patients called if they needed emergency care. The hospital aimed to admit patients directly to the ward where possible but in-patient beds were not always available and so patients were sometimes advised to attend the Emergency Department (ED). The ED had access to departmental guidelines for managing emergency conditions such as painful crisis. Patients attending the ED were generally seen and admitted by the haematology medical staff (or 'hospital at night' outside normal working hours).

In-Patient Care

In-patients were usually admitted to the haematology ward, which was a 27-bedded unit for patients with acute complications of sickle cell disease and thalassaemia as well as patients having chemotherapy for malignant disease, blood and marrow transplantation and inherited or acquired bleeding disorders. In-patients were under the care of the attending haematology consultant and a haematology in-patient team of junior doctors. Outside normal working hours there was an on-call resident SHO grade doctor and an on-call haematology registrar and consultant. Specialist in-patient advice was provided on a consultative basis by the lead clinician who was based at a neighbouring Health Board.

Day Care

The Haematology Day Centre had two beds and three reclining chairs in a clinical treatment area. In addition there were eight transfusion spaces, a phlebotomy space and two apheresis machines with reclining chairs. The Centre catered for out-patient based transfusion therapy, chemotherapy, clinical review, harvesting stem cells and other procedures. Opening hours were between 9am and 6pm from Monday to Friday.

Out-Patient Care

A fortnightly out-patient clinic was held by the lead clinician at University Hospital of Wales.

Community-Based Care

The Sickle Cell and Thalassaemia Centre was based at the Loudon Square facility in Butetown, which also provided other services including General Practice. A full-time clinical nurse specialist (CNS) worked mainly in the centre providing nursing care and input to the out-patient service. Counselling was provided by the Medical Genetics Department and all counsellors had received training about haemoglobinopathies.

Return to *Index*

Children and Young People – University Hospital of Wales: The Noah's Ark Children's Hospital for Wales

Paediatric hospital services had developed since the appointment of a paediatric haematologist in 2008. Developments included the provision of a Trans-Cranial Doppler screening service and the introduction of newborn screening for Wales in 2013.

Emergency Care

All children with haemoglobin disorders had open access to the Rainbow Ward, the children's haematology-oncology ward. From Monday to Friday, between 9am and 5pm, patients were encouraged to ring and attend the Rainbow Day Unit for emergency assessments. For out-of-hours treatment, families rang the Rainbow Ward and were generally admitted straight to an in-patient bed. Occasionally nursing staff contacted the ambulance service to advise on emergency transport for unwell children to the ward. Rarely, children were admitted through the paediatric Emergency Department (ED). A care pathway for paediatric referral for patients with haemoglobin disorder was available in the ED. An agreed sickle cell disease guideline was available on the paediatric intranet pages.

In-Patient Care

All haematology and oncology patients were admitted to the nine-bedded Rainbow Ward. During bed shortages, there was capacity within the service to move some of the older children with malignancies to the Teenage Cancer Unit within the hospital, allowing for children with non-malignant disorders, including haemoglobin disorders to be admitted to the Rainbow Ward. The service operated a one-in-five on-call consultant rota involving two paediatric haematologists and four paediatric oncologists. The paediatric oncologists managed children with relatively uncomplicated haemoglobin disorders. They generally contacted the lead clinician or the deputy lead if any seriously ill child with haemoglobin disorders was admitted out of hours. Additionally, the haematologists operated a one-in-two rota to cover all non-malignant queries and reviewed all newly admitted haemoglobinopathy patients during the normal working week. All newly admitted children received a consultant review within 24 hours of admission. Children requiring patient-controlled analgesia (PCA) were moved to a surgical ward.

Day Care

The Rainbow Day Ward operated between 9am and 6pm, from Monday to Friday. All routine top up transfusions took place in the day ward. Unplanned emergency assessments were also undertaken in the day ward. All nurses were able to access central venous access devices.

Out-Patient Care

Clinics were held in the purpose-built out-patient department within the Children's Hospital's. Haemoglobinopathy patients attended the weekly haematology and were reviewed in six-monthly annual review clinics where Trans-Cranial Doppler scans were undertaken by a vascular scientist from Bristol.

Community-Based Care

At the time of review, the paediatric services were not supported by any community-based care. The adult haemoglobinopathy lead nurse offered community-based support to a small number of families of children with haemoglobin disorders, which included home visits and advice regarding specialist medication. This was offered from the Butetown Community Centre in Cardiff. Parents of newly-diagnosed children with haemoglobin disorders were counselled by genetic counsellors from the Hospital Genetics Services, who covered all counselling for genetic disorders in the region. On request, school care plans were prepared by the clinical nurse specialist for non-malignant haematology.

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. Two questionnaires were used and 17 responses were reviewed.

Adult Services

Common themes raised by patients and carers were:

- Patients valued the clinical medical and nursing staff on the sickle team
- The day unit staff were praised for their professionalism and the good care they provided
- Patients were aware of how to contact the clinical team and valued direct access to the ward for admission.
- The direct ward admission process usually worked well but if there were capacity issues patients were directed to the Emergency Department. Some patients expressed concerns about ED care, both waiting times and staff knowledge
- Patients did not have care plans and felt these may be useful to improve care
- Patients and carers expressed concerns about changes in community provision over the last few years before the visit had resulted in decreased support, particularly for younger patients
- Patients did not feel that the Health Board listened to their views or concerns, in particular about the re-development of the community services
- Patients/carers thought that the transition process could be improved

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 nine questionnaires.

Common themes raised by patients and carers were:

- Overall satisfaction in quality of care for children and young people with haemoglobin disorders
- Unacceptable wait for care in the Emergency Department
- Parental satisfaction in having direct access to in-patient ward
- Need for further information regarding transition from paediatric to adult services

Return to *Index*

REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

University Hospital Wales is part of the Cardiff and Vale University Health Board and was the only Welsh centre reviewed as part of this Haemoglobinopathy Peer Review Programme. The majority of haemoglobinopathy patients in Wales reside within the catchment area of this Health Board. The structure of the Health Boards is outlined below in the commissioning section of the report. Adult and paediatric services sit within different Clinical Boards within the Health Board. The adult haematology service provides malignant haematology and specialist coagulation services for most of Wales, excluding one health board and would be well-placed to co-ordinate a network for haematology.

The Paediatric Haematology Unit at University Hospital of Wales provided services for all of Wales and would be ideally suited to co-ordinate a Welsh haemoglobinopathy network. The haemoglobinopathy service in University Hospital of Wales and Noah's Ark Children's Hospital of Wales did not operate within any network. Most patients resided within the Cardiff and Vale catchment area and clear treatment pathways were in existence for a small number of paediatric patients who lived outside the Cardiff area. A national newborn screening programme was in place.

Further Consideration

1 Whilst the majority of haemoglobinopathy patients live in Cardiff and Vale Health Board, a small number of haemoglobinopathy patients resided elsewhere in Wales and did not have access to comprehensive care. Reviewers suggested that the Health Board should continue discussions with the Welsh Health Specialist Services Committee (WHSCC) to develop a network for adult haemoglobinopathy patients residing in Wales.

2 Development of an adult haemoglobinopathy network will need clinical and managerial leadership which may need to be incorporated into the job plan of the adult clinical lead for haemoglobinopathies.

3 As the patient numbers were small it may be helpful to arrange formal links with another larger SHC.

NETWORK CONFIGURATION

The network configuration had not been agreed at the time of the review but it may be helpful to consider links with potential local teams. The team in Cardiff had contact with haematologists in the other Health Boards but formal designation as LHTs was not in place.

Specialist Haemoglobinopathy Centre	Suggested Local Haemoglobinopathy Teams
Cardiff & Vale University Health Board • University Hospital of Wales • The Noah's Ark Children's Hospital for Wales	Cardiff & Vale University Health Board • University Hospital Llandough (no A+E) • Cardiff Royal Infirmary • Barry Hospital • Whitchurch Hospital
	Abertawe Bro Morgannwg University Health Board • Morriston Hospital, Swansea • Princess of Wales Hospital, Bridgend
	Aneurin Bevan University Health Board • Nevill Hall Hospital, Abergavenny • Royal Gwent Hospital, Newport
	Cwm Taf University Health Board • Prince Charles Hospital, Merthyr Tydfil • Royal Glamorgan Hospital, Llantrisant
	Powys Teaching Health Board • No major A+E departments
	Hywel Dda University Health Board • Bronglais General Hospital, Aberystwyth • Glandwili General Hospital, Carmarthen • Withybush General Hospital, Haverfordwest
Patients with haemoglobin disorders attended centres in either Liverpool or Manchester.	Betsi Cadwaladr University Health Board • Glan Clwyd Hospital, Rhyl • Wrexham Maelor Hospital, Wrexham • Ysbyty Gwynedd, Bangor

Return to *Index*

SPECIALIST TEAM: (ADULT SERVICES) UNIVERSITY HOSPITAL OF WALES, CARDIFF

General Comments and Achievements

This service cared for a small number of patients with haemoglobin disorders and provided personalised care. The team had requested the peer review and staff were open and honest about their service, recognising that the improvements needed. The team was keen to look at innovative ways of addressing gaps in the services and improve patient care. The clinical and nursing teams were positive and caring and were valued by the patients and carers. Patients particularly valued the direct access to the wards and several patients remarked about the good care on the day unit.

Good Practice

1 Good access to the acute pain team and patient controlled analgesia (PCA) was in place

2 Reviewers found evidence of good liaison with other specialities, including a dedicated obstetric-haematology clinic which was attended by the lead consultant when haemoglobinopathy patients were pregnant, and good access to the bone health service.

3 All patients were given a card with contact numbers for the ward and staff. This enabled them to call the in-patient ward directly both within and outside normal working hours, including for direct access to the in-patient ward for emergency care.

4 The integrated care pathway for sickle cell disease was clear and effective. The 'trouble-shooting' section of the clinical guidelines appeared to be useful.

Immediate Risks: No immediate risks were identified.

Concerns

1 Limited patient information was available. Information should be expanded to ensure that patients are adequately informed about their condition. Numerous patient leaflets are available elsewhere in UK which could be used for this purpose.

2 Formal annual reviews were not taking place and, although the majority of issues discussed in an annual review were covered in routine out-patient appointments, the annual review process would benefit from being formalised. Clinic letters summarising changes to care were not routinely sent to patients.

3 A formal transition process was not yet in place.

4 The lead consultant was employed by a neighbouring Health Board and had only one programmed activity (PA) per week allocated to the haemoglobin disorders service. This did not provide sufficient time to lead and develop the service and was related to several non-compliances and related concerns, for example, poor protocol development and lack of teaching. In addition, reviewers had concerns about the sustainability of this role as it was undertaken by a consultant who had returned to work post-retirement.

5 The lead nurse had been appointed prior to the visit and at the time of the visit had not received training to cover the full scope of her responsibilities, including paediatric safeguarding training. This was raised at the time of the visit and the hospital planned to rectify this urgently. In addition, the lead nurse had not yet received training in the RCN competences in the care of children with haemoglobin disorders. Cover for the absence of the lead nurse was not available.

6 Access to a psychologist and neuropsychologist was not available.

7 Staff training was a concern for a number of reasons

   a. No training plan was in place for staff

   b. No formal training for nursing staff on wards, day unit or ED had taken place

   c. No formal for medical staff in haematology, medicine or ED was in place

   d. Training opportunities for junior haematology staff were limited with small numbers of in-patients and lack of opportunity to attend out-patient clinics. Specialist registrars may benefit from focussed teaching and, possibly, additional training at specialist centres with high numbers of patients with haemoglobin disorders.

8 The service was not enrolling patients, completing annual reviews or reporting adverse events on the National Haemoglobinopathy Registry, in part due to a lack of administrative and data collection support.

9 T2* MRI scanning was not available in Wales and patients travelled to London for this investigation although R2 scanning had become available shortly before the review visit at an adjacent hospital and could be accessed easily by patients.

10 Clinical guidelines were brief, incomplete and out of date. The hospital should address how these could be updated as a matter of urgency.

Further Consideration

1 In view of the small patient numbers, it was not clear how much specialist expertise in the care of people with haemoglobin disorders was available from other specialists and the service may benefit from linking with another service or from a national multi-disciplinary meeting for support with complex cases and to allow development of local expertise.

2 Reviewers suggested that the Health Board should review how the responsibilities of the Lead Consultant can be filled in the medium to long term. This may need appointment of a new post or restructuring of an existing post to enable adequate time within a consultant job plan. A review could also consider how absence of the lead consultant might be covered.

3 Patients had no access to an out of hours service for routine transfusion

4 A service organisation policy was not available.

5 Audits of the service had not been performed, including audit of time to analgesia

6 A recent multi-disciplinary team meeting (MDT) had been set up by the paediatric team and was attended by the adult team. At the time of the visit it was primarily used for discussion of new patients and abnormal laboratory results. Expansion of this MDT format, to include discussion of clinical cases, should be considered. This was the first peer review visit for this service.

Return to *Index*

SPECIALIST TEAM: (CHILDREN AND YOUNG PEOPLE SERVICES) THE NOAH'S ARK CHILDREN'S HOSPITAL NHS TRUST

General Comments and Achievements

The paediatric haemoglobinopathy service was provided by a dedicated and progressive team. Considerable service development had taken place following the appointment of the lead consultant in 2008. A haemoglobinopathy specialist clinic was established in 2008, Trans-Cranial Doppler monitoring commenced in 2009 and a second paediatric haematologist (deputy lead for haemoglobinopathy services) was appointed in 2012. The All Wales Universal Newborn Screening for sickle cell disease and beta thalassaemia major was established in 2013. A joint laboratory/clinical/medical genetics multi-disciplinary team meeting became operational in 2015. The first multi-centre phase III trial in paediatric sickle cell disease opened to recruitment in 2015. This was the first peer review visit for this service.

Good Practice

1 The establishment of a joint laboratory/clinical/medical genetics multi-disciplinary team meeting was suitable for local needs and provided a useful multi-disciplinary discussion platform

2 The review team was impressed by a departmental letter jointly signed by the lead and deputy lead to all families of children with sickle cell disease, alerting them to the need for annual influenza vaccination.

Immediate Risks: No immediate risks were identified.

Concerns

1 Limited patient information was available. Information should be expanded to ensure that patients are adequately informed about their condition. Numerous patient leaflets are available elsewhere in UK which could be used for this purpose.

2 The review team was concerned by the lack of a community specialist team supporting children and their families with haemoglobin disorders. The adult haemoglobinopathy nurse specialist occasionally

supported some paediatric patients on an ad-hoc basis, but this was not sufficient to meet the needs of the growing numbers of children with haemoglobin disorders.

3 Although some informal training was available to nurses and doctors in the management of haemoglobin disorders, formal training was not yet in place. It will be important to establish a rolling programme of teaching to in-patient staff in the care of children presenting with haemoglobinopathy.

4 Transition guidelines were not available at the time of the review and no transition pathway for young people from paediatric to adult services was in place. Patients who were present at the face to face meeting with the reviewers expressed concerns about their future care in Cardiff as adult patients.

5 The review team was concerned that mandatory audits were not yet in place within the service so it was not possible to determine whether adherence to the NICE guidelines for the timely management of painful episodes was achieved.

6 Access to a psychologist and neuropsychologist was not available.

7 The lead nurse had been appointed prior to the visit and at the time of the visit had not received training to cover the full scope of her responsibilities, including paediatric safeguarding training. This was raised at the time of the visit and the hospital planned to rectify this urgently. In addition, the lead nurse had not yet received training in the RCN competences in the care of children with haemoglobin disorders. Cover for the absence of the lead nurse was not available.

8 The service was not enrolling patients, completing annual reviews or reporting adverse events on the National Haemoglobinopathy Registry, in part due to a lack of administrative and data collection support.

Further Consideration

1 Reviewers considered that patients will benefit from a support group in the region. The haemoglobinopathy team could facilitate its start by providing logistical support.

2 Although some ad-hoc, informal psychology support was available for children with sickle cell disease on hydroxycarbamide through the cancer services, patients may benefit from more support from a psychologist with an interest in haemoglobin disorders.

3 Local clinical guidelines for the care of children with haemoglobin disorders need to be updated.

4 Reviewers suggested that documentation of the multi-disciplinary team meetings, such as agenda and minutes would be helpful.

5 It may be helpful to seek patients' opinions regarding the need for 'out of hours' transfusion and implementation of any changes according to local need. At the time of review, out of hours transfusion was not offered.

6 The clinical team recognised the need to establish collaborative links with other specialist centres with larger patient numbers in order to enhance expertise and the review team supported this endeavour.

7 Access to a social worker would improve community support for families.

8 Automated exchange transfusion as recommended by NICE guidelines was not available.

9 A service organisation policy was not available.

Return to *Index*

COMMISSIONING

The NHS in Wales is made up of seven Health Boards. Health Boards commission specialist services via the Welsh Health Specialist Services Committee (WHSCC), which included paediatric haematology. Bone marrow transplant and the cost of factor concentrate for haemophilia were the only specialist haematology services commissioned for adult patients at the time of the visit although the Cardiff and Vale University Health Board (CAV) clinical director was negotiating to commission all 'special haematology' which would include the regional role in malignancy as well as thrombotic thrombocytopenic purpura and haemoglobinopathies. Cardiff and Vale was the only Health Board aiming to provide specialist level care for haemoglobinopathy patients and patients attending other centres in Wales were not able to access specialist care.

Concerns

1 Limited information was available about the number of patients with haemoglobin disorders in Wales outside Cardiff and Vale University Health Board area. Information was not available about the level of health care they were receiving and whether they were accessing specialist care from outside Wales. A needs assessment exercise by commissioners would be useful to ascertain patient numbers and to support the development of specialist services for Wales.

Further Consideration

1 Paediatric haemoglobinopathy services were commissioned as part of the paediatric haematology and oncology specialist services by the Welsh Health Specialised Services Committee (WHSSC). Ring-fenced funding was not therefore available for the purpose of providing healthcare to children with haemoglobin disorders.

2 Reviewers considered that specialist commissioning of haemoglobinopathy services in Wales would help to ensure equity of access to specialist care for all patients of all ages with haemoglobinopathies in Wales.

Return to *Index*

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Leads

Dr Jo Howard	Consultant Haematologist	Guy's and St Thomas' NHS Foundation Trust
Dr Subarna Chakravorty	Consultant Haematologist	Kings College Hospital NHS Foundation Trust

Visiting Team

Sajid Hussain	Service User	Not applicable
John James	Patient Representative	Sickle Cell Society
Elaine Miller	Co-ordinator	Thalassaemia UK
June Okochi	Service User	Sickle Cell Society
Elizabeth Rhodes	Consultant Haematologist	St George's University Hospitals NHS Foundation Trust
Christine Wright	Consultant Haematologist	Sandwell & West Birmingham Hospitals NHS Trust

Return to *Index*

APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service 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	43	8	19
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	0	0
Total	55	8	15

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	49	19	39
Haemoglobin Disorders Clinical Network	9	0	0
Commissioning	3	1	33
Total	61	20	33

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

Return to *Index*

SPECIALIST SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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)	N	Information about sickle cell disease and thalassaemia was not yet provided on the wards or day unit. Information was not seen by the review team for 'a', 'b', 'c', or 'h ii-iv'.	N	Written information was not offered to patients.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	A guide for sickle cell disease and Thalassaemia International Federation (TIF) booklet was available.	N	Some aspects of the Quality Standard were not covered by the handbook.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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	N	Clinic consultant letters covered some of these aspects of care for example, immunisation, but not all.	Y	All repeat prescriptions were provided by the hospital team and not GPs Immunisations were carried out by the GPs.
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	Some patients received copies of their clinic letters but formal annual reviews were not being carried out and patients did not have individual care plans. Clinic letters were not routinely copied to patients.	Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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		Y	All school care plans were provided by the ward-based clinical nurse specialist on request although the review team did not see an example.
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	Transition information was not yet provided.	N	Transition information was not yet provided.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	However information for 'e' needed to be clearer.
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	An annual survey was seen for 2014 to 2015. A patient meeting had been held a few years earlier prior to changes in community services. Formal mechanisms were not yet in place for involving patients and carers in the services and limited examples of changes resulting from feedback were provided.	N	However, information for 'c' and 'd' was not provided.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	However, the lead consultant had only one programmed activity which was not sufficient to run and lead the service.	Y	However the job plan did not have clearly defined sessions allocated.
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.	N	Routine clinics were cancelled when the lead consultant was on leave and cover for urgent clinical queries was provided by the on call consultant. In the absence of the lead consultant urgent specialist advice was sought informally from another specialist centre.	Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	The clinical nurse specialist had only been appointed shortly before the visit she was clearly committed and enthusiastic but had not yet received appropriate training and had a broad scope of responsibilities.	N	The lead nurse was not yet aware of RCN (Royal College of Nursing) sickle cell disease competences and did not yet take part in guideline development, audit and training.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	The clinical nurse specialist had not yet developed all the appropriate competences for the role. A psychologist with an interest in haemoglobin disorders was not available. Insufficient consultant staffing with competencies in the care of people with haemoglobin disorders was available.	N	The clinical nurse specialist had not yet developed competence in 'f'. A psychologist with an interest in haemoglobin disorders was not available.
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	A training plan was not yet in place.	N	A training plan was not yet in place.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	The lead consultant only had one programmed activity but was available to provide specialist advice during normal working hours. Cover for absence was not available.	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	Regular training for ED staff was not yet available.	N	Training was available for doctors but not for nursing staff.
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	N	The adult nurse provided care for children in the community but had not yet undertaken paediatric safeguarding training. This concern was addressed at time of visit.	N	The adult nurse provided care for children in the community but had not yet undertaken paediatric safeguarding training. This concern was addressed at time of visit.
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.	N	No formal training sessions had taken place for at least 12 months. Opportunities to attend clinic were limited.	Y	Although a formal training programme was not seen.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	Inadequate data collection support was provided to allow collection of data for the National Haemoglobinopathy Registry.	N	Inadequate data collection support was provided to allow collection of data for the National Haemoglobinopathy Registry.
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	Timely access to a psychologist with an interest in haemoglobin disorders was not available.	N	Timely access to a social worker or a psychologist with an interest in haemoglobin disorders was not available.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	Good obstetric provision was available through a weekly obstetric –haematology clinic. The acute pain team reviewed all patients and access to patient controlled analgesia (PCA) was available.	N	However access to acute pain services was not available.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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.	N	In view of small patient numbers it was not clear how much specialist expertise was available locally. T2* was only available in London. Access to a neuropsychologist was not provided.	N	Access to a neuropsychologist with an interest in haemoglobin disorders was not available.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	Facilities were excellent.
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.	N	Out of hours transfusion was not available.	N	Out of hours transfusion was not available.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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	Transition guidelines were not yet available.	N	Transition guidelines were not yet available.
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.	N	Although the issues of annual review were being covered within the routine clinic, check-lists were not available.	Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	N	Transfusion guidelines for 'a' to 'd' were brief and out of date or were not available.	N	Transfusion guidelines did not cover 'f', 'g' or 'h'.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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.	N	Only a brief protocol for desferrioxamine was available.	N	Detailed guidance for chelation therapy was not yet available.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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 did not cover 'k', 'l' and 'm'.	N	Guidelines for thalassaemia were not seen.
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	N	Both 'a' and 'c' were out of date and 'a' was not in line with current practice.	N	Clinical guidance on 'a' was out of date.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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)	N	Clinical guidelines for 'd', 'f' and 'h' were not present.	N	Clinical guidelines for chronic complications were not available.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N	Guidelines for referral for consideration of bone marrow transplantation were not yet in use.	N	Guidelines for referral for consideration of bone marrow transplantation were not yet in use
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	Clinical guidelines for the management of thalassaemia intermedia were not yet in use.	N	Clinical guidelines for the management of thalassaemia intermedia were not yet in use.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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.	N	Clinical guidelines for the monitoring and management of acute and chronic complications were not yet available.	Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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)	N/A		N	Guidelines on Trans-Cranial Doppler ultrasound were not seen.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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	A service organisation policy was not seen.	N	A service organisation policy was not seen.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	The multi-disciplinary lab/clinical meeting was working well. The informal clinical MDT meeting held at the time of clinic needed formalising. Plans to amalgamate with the lab/clinical meeting may be appropriate.	Y	A multi-disciplinary team meeting had been introduced and was working well.
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	The community nurse was part of the same team.	N/A	The community nurse was part of the same team.
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).	N	Network review and learning meetings were not yet in place.	N	Network review and learning meetings were not yet in place.
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	However minutes were not yet being taken.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	Data were not entered onto the National Haemoglobinopathy Registry.	N	Data were not entered onto the National Haemoglobinopathy Registry.
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		N	The service was not monitoring annual data.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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	N	Limited information was available for the network.	N	The service was not monitoring annual data.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**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	Clinical audits were not yet undertaken.	N	Clinical audits were not yet undertaken.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	A rolling programme of audit was not yet in place.	N	A rolling programme of audit was not yet in place.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N	Research relating to the care of patients with haemoglobin disorders was not yet undertaken.	Y	
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 Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	This was undertaken as part of the haematology morbidity and mortality meeting.	Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Document control procedures were not yet followed.	Y	

Return to *Index*

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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.	N	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.
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	N	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.
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.	N	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: 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. 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	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.
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.	N	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer 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-707.	N	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.
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	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.
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)	N	A haemoglobin disorders clinical network was not yet in place in Wales.	N	A haemoglobin disorders clinical network was not yet in place in Wales.

Return to *Index*

COMMISSIONING

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular: a. Designated SHC/s for the care of people with sickle cell disease b. Designated SHC/s for the care of adults with thalassaemia c. Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia d. Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	N	Only bone marrow transplant and the cost of factor concentrate for haemophilia were commissioned at the time of the visit although the Cardiff and Vale University Health Board (CAV) clinical director was negotiating to commission all 'special haematology' which would include the regional role in malignancy as well as thrombotic thrombocytopenic purpura and haemoglobinopathies.	Y	Although WHSSC commissioned as part of paediatric haematology services at Cardiff and Vale University Health Board there was no ring-fenced funding. Network activity was not yet in place.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by: a. Each service, in particular QS HN-703 b. Each network, in particular, achievement of QS HY-702 and QS HY-798. c. Service and network achievement of relevant QSs	N	Review meetings were not undertaken.	N	Information from clinical review meetings was not available at the time of the visit.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	WHSSC had audit days in the areas they commission but as services for people with haemoglobin disorders was not yet commissioned in this way these meetings did not cover care of people with haemoglobin disorders.	N	Meetings did not cover care of people with haemoglobin disorders.

Return to *Index*