WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

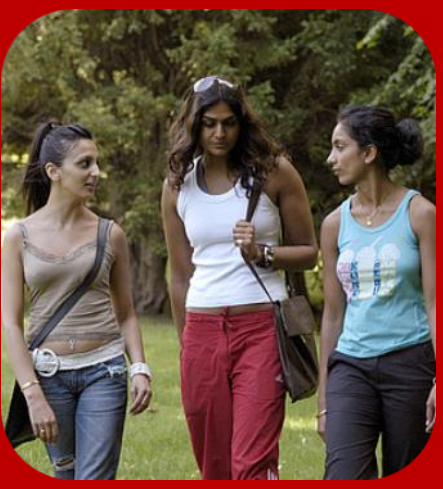
West Midlands Network

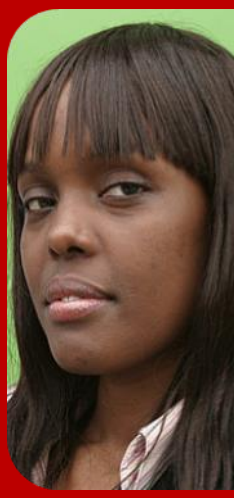
Sandwell & West Birmingham Hospitals NHS Trust

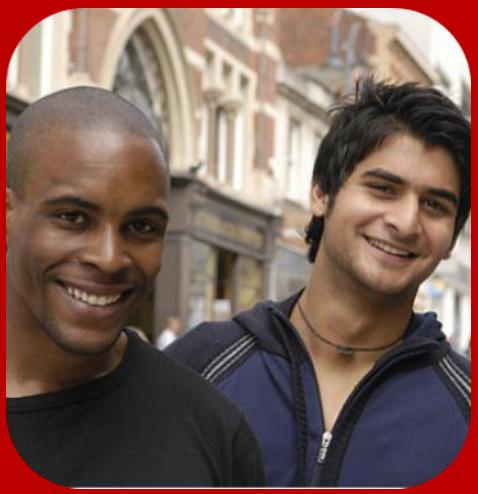
Visit Date: 14th October 2015

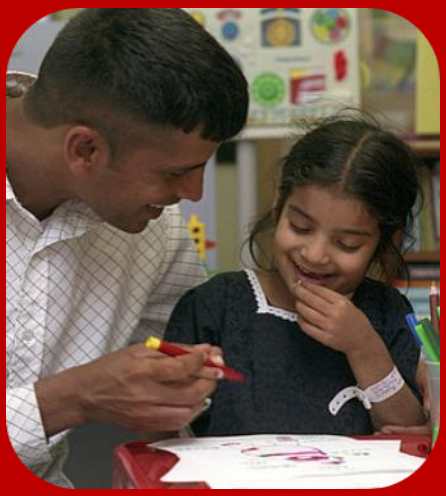
Report Date: February 2016

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 Sandwell & West Birmingham Hospitals NHS Trust (part of the West Midlands Network), which took place on 14th October 2015. The purpose of the visit was to review compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2, 2014 which were developed by the UK Forum on Haemoglobin Disorders working with the West Midland Quality Review Service (WMQRS). The peer review visit was organised by WMQRS on behalf of the UK Forum on Haemoglobin Disorders. 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:

- Sandwell & West Birmingham Hospitals NHS Trust
- NHS England Specialised Commissioning
- NHS Sandwell & West Birmingham Clinical Commissioning Group

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

Acknowledgements

We would like to thank the staff of Sandwell & West Birmingham Hospitals NHS Trust 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

HAEMOGLOBIN DISORDERS SERVICES IN THE WEST MIDLANDS NETWORK

At the time of the visit Sandwell & West Birmingham Hospitals NHS Trust was part of the West Midlands Network and it was reviewed as a Specialist Haemoglobinopathy Centre (SHC). The Sickle Cell and Thalassaemia Centre (SCAT) at Sandwell and West Birmingham NHS Trust (SWBH) was based at City Hospital. The centre had been open for 15 years. In 2012 the service moved from a building on the edge of the hospital site to the main hospital corridor. The centre included a day unit that opened from Monday to Friday and provided a transfusion service with chelation therapy support, day-case pain management/urgent assessment, medical and nursing reviews. Out-patient clinics were also held within the SCAT and an outreach service was provided for in-patients. The SCAT was staffed by two consultants, a nursing manager and deputy nursing manager and a junior medical and nursing team. The service had around 500 patients on an updated database; the majority were patients from the Birmingham and Sandwell area. It had well-established informal links with neighbouring Trusts and provided specialist review for patients with more complex haemoglobinopathy issues. Network arrangements remained informal and discussions with specialist commissioners and other Trusts were ongoing. The SWBH team had visited the Trusts listed below to assess their patient demographics and their needs as Local Haemoglobinopathy Teams (LHT). Protocols had been shared and a model proposed for potential service level agreements. Patient numbers had increased over the last three years, in part due to a large number of patients transitioning from paediatric services. Forty patients had moved from the paediatric service in the previous 18 months of whom eight required regular transfusion support. A further 15 to 20 patients were expected to transition per annum. Hospital admissions had increased from 185 in 2010 to 285 over the year before the review visit. Trust-wide work on reducing in-patient beds and staffing was underway moving more care to the community in preparation for the planned Midland Metropolitan Hospital.

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
Sandwell & West Birmingham Hospitals NHS Trust	SHT	450	50	58
University Hospitals Birmingham NHS Foundation Trust The Dudley Group NHS Foundation Trust (Russells Hall Hospital) Heart of England NHS Foundation Trust University Hospitals of North Midlands NHS Trust (Royal Stoke University Hospital) The Shrewsbury and Telford Hospital NHS Trust (Royal Shrewsbury Hospital, Princess Royal Hospital) Worcestershire Acute Hospitals NHS Trust Wye Valley NHS Trust Walsall Healthcare NHS Trust	LHT	60	10	11

Emergency Care

A pathway for emergency care was in place but during SCAT opening hours patients could 'walk-in'. If patients required admission they were admitted directly to the ward from SCAT. Patients were required to attend the Emergency Department (ED) for admission when SCAT was full, if the patient was not known to the SCAT service or if presentation was outside the SCAT opening hours. The ED used the SWBH sickle cell disease protocol to facilitate appropriate care. In addition, some patients used a treatment card system that provided relevant patient information, including preferred pain treatment protocol. An email alert system was in place which informed the SCAT team when patients with haemoglobin disorders were admitted to ensure that they were reviewed at the earliest opportunity.

In-Patient Care

Haemoglobinopathy, gastroenterology and respiratory patients were admitted to Ward D16 if female (21 beds) and D15 if male (24 beds). Both wards were located very close to the SCAT. The majority of patients were cared for on these wards, but they might also be placed on the two acute medical admission wards. On average there were six to eight in-patients with haemoglobin disorders at any one time. In-patients were reviewed daily by the haemoglobinopathy team (medical and nursing) and daily at the weekend by a senior haematology doctor. A critical care unit was on site. An outreach nurse was provided daily from SCAT to support the nurses and patients/carers on in-patient wards.

Day Care

Four permanent nurses provided care and cover from a small pool of regular bank staff. SCAT was open Monday between 9am and 4pm, Tuesday between 9am and 6pm and from Wednesday to Friday between 9am and 5pm. SCAT had four chairs for blood transfusions and three beds for day-case pain management.

Out-Patient Care

Approximately 25 patients attended SCAT clinics on Tuesday afternoons and approximately 15 patients on Thursday mornings. In addition, specialist endocrine and orthopaedic clinics took place three to four times per year. Every two months the nurses attended the transition clinics held at Birmingham Children's Hospital.

Community Based Care

Community care was also provided from the SCAT centre by Birmingham Community Healthcare NHS Trust. It was staffed by a service manager, who primarily ran the antenatal clinics, a paediatric nurse and a nurse covering transition and some adult services. An adult community nurse had previously been in post but this post had been vacant for around a year at the time of the visit. The transition/adult nurse had a large workload which included attending the SCAT clinics and multi-disciplinary team meetings, home visits for the adult patients, running the transition service and some antenatal work.

VIEWS OF SERVICE USERS AND CARERS

The visiting team met a small number of patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They received responses to 23 questionnaires.

Common themes raised by patients and carers were:

- The SCAT facilities and staff were highly praised and highly appreciated
- Concerns about care in ED where patients reported long waits for care and staff who were poorly informed about haemoglobin disorders and who did not follow the patients' treatment protocols
- Most of the patients and carers requested that the SCAT was open for longer hours and at the weekend and stated they would wait at home in pain until the unit opened. They understood that this might have dangerous consequences but were willing to take the risk rather than attend ED.

- Several patients commented about the lack of a psychologist and that they would find this service very beneficial
- Patients commented that the transition service had previously been poor but had gradually changed and they recognised that this aspect of care had improved
- Adult patients felt that a buddy system for transition patients may be beneficial and said they would be prepared to volunteer

Return to *index*

REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

Children and Young Peoples Services

Birmingham Children's Hospital NHS Foundation Trust (BCH) was the only SHT in the West Midlands for children and young people and had developed an informal/formal network across the region. The paediatric services at University Hospitals Coventry and Warwickshire NHS Trust (UHCW) and The Royal Wolverhampton NHS Trust (RWT) were operationally well-embedded within the Birmingham Children's Hospital NHS Foundation Trust (BCH) haemoglobinopathy network as Local Haemoglobinopathy Team (LHT). Outreach clinics were established and attended by a consultant from BCH. Clear referral pathways and escalation of care policies were in place.

Although no formal network arrangements had been agreed in the West Midlands a functional informal network was in place in line with the regional Paediatric Cancer Network, with BCH as the specialist haemoglobinopathy hub and a large number of local hospitals as 'spokes'. Outreach clinics for annual reviews were in place at the time of the review. Some clinics served to provide tertiary reviews to children with cancer as well as haemoglobin disorders, whereas others were solely for follow up of haemoglobinopathy patients. This arrangement was responsive to local needs. The lead and deputy consultants were easily available for advice and an on-call rota for paediatric haematology consultants was in place, providing round- the- clock consultant advice. Children with sickle cell disease, apart from those in Coventry, attended BCH clinics for annual Trans-cranial Doppler monitoring. The escalation of care policy for critically ill children was clear and the whole region was served by a single retrieval team (KIDS). About 120 children in the region received chronic blood transfusions and all MRI monitoring was undertaken at BCH. Data were reviewed centrally at BCH and uploaded regularly as part of the NHS England dashboard dataset. Shared protocols for research and audit were not yet in place.

Adult Services

Three Trusts in the West Midlands, SWBH, UHCW and RWT, had assessed themselves as Specialist Haemoglobinopathy Centres for adult services and were reviewed as such. Some commissioner and clinician engagement had taken place to formalise the network arrangement within the region.

SWBH had a long established specialist service for adult patients with both sickle cell disease and thalassaemia with excellent links with other specialist services for example, endocrine and orthopaedic, but the Trust did not provide all of the elements of a specialist service. The UHCW's strategic plan included provision of specialist services such as automated apheresis to the wider network within the region. UHCW provided some, but not all, of the elements of the specialist specifications and had less well-developed support from other specialist services.

These three Trusts had been in discussions with the commissioners about network development and, whilst there were no formal links with the linked teams, SWBH had met with most of them. Needs had been reviewed and an agreement had been drafted. In addition the three Trusts had produced a document for the specialist commissioners outlining a proposed network model. This model described UHCW and RWT as affiliated SHTs. This is not terminology recognised in the national service specification and these services may be better described in another way.

UHCW would be able to provide many of the functions of an SHT and the specialist functions which it could provide should be specified but could include transfusion, annual reviews and apheresis. Additional support may be needed for certain patient groups for example, transfusion dependent thalassaemia and complex sickle cell disease patients as outlined in the draft document. It may be helpful for these patients to have their annual review at SWBH at in-reach or outreach clinics.

RWT would need additional support at least initially with patients having annual review at SWBH. Some of the patients with sickle cell disease from Walsall Manor Hospital attended SWBH for their out-patient care.

Progress since Last Visit

Since the previous visit in 2012, a number of steps had been taken to establish a formal haemoglobinopathy network. The haemoglobinopathy teams had met with specialist commissioners a number of times and a draft working document was in place. Additional resources had been made available by the commissioners to employ a network coordinator, who was to start shortly after the review visit.

The children's network was becoming formalised with a network coordinator appointed at BCH.

Good Practice

1 The document on adult haemoglobinopathy services produced for Specialist Commissioners showed good clinical leadership and collaboration between SWBH, UHCW and RWT.

2 SWBH had met with almost all the local hospitals in the West Midlands to clarify patient numbers and service needs and had begun to draft formal agreements for the support that would be provided.

Immediate Risks: No immediate risks were identified.

Concerns

1 Whilst good progress had been made, there was no formal designation of SHTs and no formal links with the local centres for adult patients. A meeting between clinical and management staff from SWBH, UHCW and RWT with specialist commissioners may be helpful to resolve the designation of adult services. It may be helpful to have an external facilitator at the meeting.

Further Consideration

1 Reviewers suggested that additional paediatric consultant time to provide strategic leadership to the paediatric network to improve service provision and patient satisfaction throughout the region and to engage in network-wide research and audit may be helpful.

2 Arrangements for adult services for patients with haemoglobin disorders with local teams should be clarified.

3 Introduction of Network review and learning meetings would be beneficial.

NETWORK CONFIGURATION

The network configuration at the time of the review was as follows. Although no formal network arrangements had been agreed in the West Midlands a functional network operated across the region.

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
Adult Services	
Sandwell and West Birmingham Hospitals NHS Trust (City Hospital, Sandwell Hospital)	• University Hospitals Birmingham NHS Foundation Trust • The Dudley Group NHS Foundation Trust (Russells Hall Hospital) • Heart of England NHS Foundation Trust • University Hospitals of North Midlands NHS Trust (Royal Stoke University Hospital) • The Shrewsbury and Telford Hospital NHS Trust (Royal Shrewsbury Hospital, Princess Royal Hospital) • Worcestershire Acute Hospitals NHS Trust • Wye Valley NHS Trust • Walsall Healthcare NHS Trust
University Hospitals Coventry and Warwickshire NHS Trust (Hospital of St Cross)	• George Eliot Hospital NHS Trust • South Warwickshire NHS Foundation Trust
The Royal Wolverhampton NHS Trust	• Walsall Healthcare NHS Trust
Services for Children and Young People	
Birmingham Children's Hospital NHS Foundation Trust	• Sandwell and West Birmingham Hospitals NHS Trust • The Royal Wolverhampton NHS Trust • University Hospitals Coventry & Warwickshire NHS Trust • Burton Hospitals NHS Foundation Trust • George Eliot Hospital NHS Trust • Heart of England NHS Foundation Trust • South Warwickshire NHS Foundation Trust • The Dudley Group NHS Foundation Trust • The Royal Wolverhampton NHS Trust • The Shrewsbury and Telford Hospital NHS Trust • University Hospitals of North Midlands NHS Trust • University Hospitals Birmingham NHS Foundation Trust • University Hospitals Coventry and Warwickshire NHS Trust • Walsall Healthcare NHS Trust • Worcestershire Acute Hospitals NHS Trust • Wye Valley NHS Trust

Return to *index*

SPECIALIST TEAM: SANDWELL AND WEST BIRMINGHAM HOSPITALS NHS TRUST

General Comments and Achievements

The haemoglobinopathy team was a cohesive team providing excellent medical and nursing leadership and high quality clinical care which received very positive feedback from patients and carers. The sickle cell disease and thalassaemia team (SCAT) had been relocated since the previous peer review. Whilst some patients expressed concerns about the new facility the review team considered it was of high quality and its new location on the main hospital spine was of benefit for patient safety. Patients had very good access to the SCAT during working hours which led to rapid availability of pain relief. Time to pain relief was audited on every patient admission and results reported to the SCAT and Emergency Department (ED) on a monthly basis. The SCAT team was emailed automatically from ED about all patient admissions which had improved communication and handover. Patients were offered hand-held treatment cards which included their photograph and preferred pain protocol leading to improved communication in ED.

Progress since Last Visit

1 The appointment of additional permanent nursing staff on SCAT since the last visit had led to improvements in nursing care, more robust outreach patient support, improved patient feedback and improved nursing education on the wards and in ED.

2 A transition clinic was had been implemented at BCH and the transition process had improved significantly.

3 Links with the community team had improved and the community nurse attended MDTs (multi-disciplinary team meetings) and clinics.

4 MRI monitoring of iron overload was available on site or at other Birmingham hospitals.

5 Links with other speciality teams had improved with a regular sickle-orthopaedic clinic available and close links with the obstetric service.

6 The majority of patients were enrolled on the National Haemoglobinopathy Registry (NHR). Adverse events and annual reviews were being entered prospectively.

7 Clinical guidelines had been updated and expanded.

8 An improved education programme was offered across primary and secondary care.

Good Practice

1 The stand-alone SCAT Centre was the first service of its kind in the UK and continued to provide very high quality patient-focussed care that could be emulated by other centres

2 The transition service demonstrated good practice for several reasons

   a. Clear flow chart of the process

   b. Comprehensive guidelines

   c. Good leaflets

   d. Clear patient communication, for example, each patient was sent an individual letter after their first visit to the adult clinic welcoming them to the service

   e. Good patient feedback and audit of the service was in place

   f. Open evenings in the adult service for patients and carers

3 Communication from clinic was very patient-focussed. Information was sent to the patient with a copy circulated to the GP. Medical language was kept to a minimum in these letters to improve patient

understanding and they were individually tailored. In addition, more detailed letters were produced for the GPs if required and these were also clear and comprehensive, for example, letters to GPs with an explanation of iron chelation therapy.

4 Guidelines were clear and comprehensive, in particular the thalassaemia and chelation guidelines. In addition the pictorial guideline for nurses showing them how to set up Patient Controlled Analgesia was very clear.

5 The SCAT team was responsive to patient feedback and the 'talking board' displayed in the SCAT waiting area displayed their responses to this feedback and made this easily available for patients.

6 The 'did not attend' policy was very detailed and included multi-disciplinary teams held in the GP surgery for patients who failed to attend clinic on multiple occasions.

7 The SCAT staff were very engaged in improving patient adherence to iron chelation therapy, evidenced by chelation charts. The charts were available for patients and could be altered for the particular circumstance of each patient including through a variety of drug boxes for patient use.

8 Services for the supra-specialist care of haemoglobinopathies were well-developed with a regular endocrine and orthopaedic clinic available for patients.

Immediate Risks: No immediate risks were identified.

Concerns

1 An automated apheresis service was not available for the local patient population. Patients who required automated apheresis had to travel to London to receive this service and would have to pay for transport themselves. Several business cases had been submitted but had not been approved. Apheresis machines were not available in the Trust. Proposals had been made for the NBS to provide the service at another site. Whilst this would be an improvement, it was not clear to reviewers why this could not be provided at the City Hospital site in view of the large patient numbers.

2 Dedicated psychology support was not available for the patient population. Several business cases had been prepared but had not been approved. Provision of psychology services would be highly beneficial for this patient population, in particular to help management of chronic pain and adherence to medication.

3 Patient data including adverse events and annual reviews were being entered on the NHR but annual reviews had not been entered for all patients because of insufficient administrative support. The Trust had started discussions with linked hospitals but comprehensive network patient data were not yet being monitored annually.

4 Insufficient community nurse staffing levels meant that there was little time available for community support of some adult patients. Support and communication with the community team were good but the community staff covered a geographically distinct area of Birmingham many patients who attended City Hospital were not able to access community services close to their homes.

Further Considerations

1 Reviewers suggested that the Trust should consider extending the opening hours of SCAT to provide access to an acute pain service and transfusion therapy, at least to include seven days a week opening. A proposal for seven-day working had been made but the Trust was planning to provide only an outreach service on the wards at the weekend as a measure to improve discharge rates. All in-patients were reviewed by a haematology consultant at the weekends and it was therefore not clear to reviewers that this would lead to an improvement in patient care.

2 Patient numbers were increasing every year with growing numbers of in-patient and out-patient attendances as well as increasing complexity of patient's needs. Therefore this increased workload was being managed within the resources available at the time of the visit but the workload was not sustainable in the long term. Capacity planning for the services was not evident. Reviewers suggested that the Trust should review long term plans for capacity management.

3 Patients expressed concerns about treatment in ED, particularly waits for analgesia. High re-admission rates were noted. In addition, an out of hours transfusion service was not available.

Return to *index*

Local Teams: University Hospitals Birmingham NHS Foundation Trust, University Hospitals of North Midlands NHS Trust, The Dudley Group NHS Foundation Trust

General Comments and Achievements

The review team spoke to clinicians from the University Hospitals Birmingham NHS Foundation Trust, University Hospitals of North Midlands NHS Trust and The Dudley Group NHS Foundation Trust.

The Dudley Group NHS Foundation Trust: This Trust had 12 patients with sickle cell disease and some of those had not been seen recently. They had 13 acute admissions in 2014/15. A protocol for the acute treatment of pain crises was available and was being updated and expanded in line with the protocol from SWBH. All patients were offered annual review at SWBH but some patients did not take up this offer. All patients with complex disease were referred to SWBH. Acute admissions were admitted via the day unit under the haematology team in working hours and via the ED out of hours. Acute admissions were seen by the on call medical team out of hours and transferred to the haematology team the next day. Complex acute admissions were discussed with SWBH.

University Hospitals Birmingham NHS Foundation Trust: This hospital did not provide routine out-patient care for patients with haemoglobinopathies. These patient were referred to SWBH. The Local Ambulance Service usually took patients with sickle cell disease to SWBH but there were two to three attendances of patients with sickle cell disease in the ED per month. These patients were reviewed and transferred if possible, to SWBH. If transfer was not possible they would stay on the medical wards under the care of the medical team. The haematology consultant was asked for advice and reviewed patients at least daily. Protocols for acute care were in place and were the same as the protocols in SWBH. All acute admissions were discussed with SWBH and complex cases were transferred there.

University Hospitals of North Midlands NHS Trust: This trust had five patients with haemoglobinopathies. The patients with transfusion-dependent thalassaemia were seen several times a year at SWBH. The other patients were offered annual review at SWBH but did not always take up this offer. Complex acute admissions were discussed with SWBH who were considered to offer good support. Guidelines for emergency care were available but were based on the British Committee for Standards in Haematology (BCSH) guidelines and so may be out of date. All patients needing operations were reviewed pre-operatively at SWBH.

Return to *index*

COMMISSIONING

General Comments and Achievements

The review team met with two members of the West Midlands NHS England specialised commissioning team to discuss care of adult patients. Preliminary talks and meetings had been held with the proposed specialist centres and a draft document for the specialist commissioners had been prepared by the clinicians in those centres. Informal arrangements were in place to support the local centres and draft agreements of the support to be given to the local centres had been developed by the team at SWBH.

The reviewers also met with two members of the West Midlands regional NHS England commissioning team to discuss care of children and young people with haemoglobin disorders. The commissioning team had had several operational meetings with the paediatric haemoglobinopathy clinicians in order to formalise network arrangements within the region. A network coordinator post had been developed with additional funding from commissioners for a period of 12 months. Engagement with the clinical team was positive and the intention to formalise a clinical network was clear.

Concerns

1 Formal designation of specialist centres for the services for adults with haemoglobin disorders had not taken place and the proposed SHTs were providing markedly different levels of specialist care. This needs to be resolved with some urgency to allow formalisation of the geographical area and to provide equitable clinical care across the region.

Further Consideration

1 Reviewers suggested that a meeting between clinical and management staff from SWBH, UHCW and RWT with specialist commissioners may be helpful to resolve the designation of adult services. It may be helpful to have an external facilitator at the meeting.

2 Regular meetings between the commissioners and the paediatric clinical team should be considered to endure that good communication continues.

Return to *index*

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead

Dr Jo Howard	Consultant Haematologist	Guy's and St Thomas' NHS Foundation Trust

Visiting Team

Sajid Hussain	Service User	Not applicable
John James	Service User	Patient Representative, Sickle Cell Society
Dr Krishna Kotecha	Consultant Oncologist	University Hospitals of Leicester NHS Trust
Aldine Thomas	Clinical Nurse Specialist	Barts Health 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	45	34	76
Haemoglobin Disorders Clinical Network	9	1	11
Commissioning	3	0	0
Total	**57**	**35**	**61**

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Haemoglobin Disorders Clinical Network	9	1	11
Commissioning	3	1	33
Total	**12**	**2**	**17**

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*

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-101 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199)	Y	Although information for 'g' and 'h' 'i' and 'iii' was not obvious in the documentation patients were knowledgeable about these aspects of the service.

		Adult Service	
Ref	**Quality Standard**	**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	Y	
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	Good letters about iron chelation were provided for GPs.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
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).	Y	Patients had hand-held records and copies of all letters.
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	
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	Y	

		Adult Service	
Ref	**Quality Standard**	**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	
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	The annual survey was fed back to patients with a 'talking board'. Also letters were written to patients about the changes in service.
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	Two consultants were available.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y	
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	Y	

		Adult Service	
Ref	**Quality Standard**	**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	A clinical or health 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).	Y	The clinical nurse specialist taught within the Trust regularly.
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y	
HN-207 All	**Training for Emergency Department Staff** The service should offer regular training in the care of patients with haemoglobin disorders to: a. Clinical staff in the Emergency Department b. Nursing staff on general wards to which patients with haemoglobin disorders may be admitted	Y	Although training was offered not all nurses in the Emergency Department had attended or were released to attend.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y	
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	
HN-210 SHC	**Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A	
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 not adequate for the number of patients cared for by the service.
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	A psychologist with an interest in haemoglobin disorders was not available.

		Adult Service	
Ref	**Quality Standard**	**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	
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	Access was not available to erythrocytopheresis and neuropsychologist services. Patients were travelling to University College London Hospital NHS Foundation Trust for exchange transfusion. Although R2 MRI (liver and cardiac) was available – cardiac T2* was not yet available but staff were being trained so this was expected to become available.

		Adult Service	
Ref	**Quality Standard**	**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	
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	
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	Less than five patients had requested out of hours care which had been provided but on request at another hospital. Access to the pain service was not available out of hours.
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	Y	Letters were good and patient focussed. The flow charts were clear.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	Y	
HN-503 LHT	**Clinical Guidelines: LHT Management and Referral** Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	Y	Draft proposals of how the team planned to work with LHCs were seen which included which patients should be referred to the SHC.
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	Clear guidelines and proforma were in use.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-505 All	**Chelation Therapy** Network-agreed clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y	Very good guidelines with additional information about treatment of patients with renal failure were in use. Good chelation charts for patients were produced.
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y	The pain pathway flow chart was good.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
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	
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y	However 'g' needed further development.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	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	Y	Good guidelines had been developed.
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	

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-512 SHC	**Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)** Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least: a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established)	N/A	

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-601 All	**Service Organisation** A service organisation policy should be in use covering arrangements for: a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together	Y	An excellent 'did not attend' policy was being used which included multi-disciplinary team meetings in GP surgeries.
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	

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
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 service level agreement for support from community services was not yet in place.
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS **Error! Reference source not found.**).	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	
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	All adverse events were entered onto the National Haemoglobinopathy Registry. 320 patients had been entered from 450. Annual reviews had been entered for about 60% of patients with sickle cell disease and 80% for thalassaemia patients without data or administrative support.
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	

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-703 SHC	**Annual Data Collection – Network Patient Data** The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia: a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network services during the course of the year: i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: i. Date seen in clinic ii. Date offered and prescribed penicillin d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year e. Number of network patients on long-term transfusion f. Number of network patients on chelation therapy g. Number of network patients on hydroxycarbamide h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients j. Number of network patients whose care was transferred to another service during the year k. Number of network patients who died during the year l. Number of network patients lost to follow up during the year	N	However data were available for 'a' and 'd-f'.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	Y	'J' was not covered separately but was combined with 'I'. Pain relief was monitored monthly and was sent to the Sickle Cell and Thalassaemia Centre and Emergency Department. Penicillin and vaccination audit data were fed back to patients.
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 for audit of guidelines 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	A poster was seen and the team was looking at starting to offer trials.

		Adult Service	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**
HN-707 SHC	**Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required	N/A	
HN-798 All	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility	Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y	

Return to *index*

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adult Service		Service 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.	Y		N	Mechanisms for involving patients and carers in the work of the network did not yet exist.
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	The process of development of the network was underway and a draft working document was provided but network leads were not yet identified.	Y	The process of development of the network was underway and a draft working document was provided but network leads were not yet identified. There was a Trust CQUIN (Commissioning for Quality and Innovation) target and the employment of a data manager was expected to help develop the network.
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	An education and training programme was not yet in place.	N	The intention for this was expressed by the team but a programme for education and training was not yet in place.

		Adult Service		Service 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	Network guidelines were not yet in place.	N	Formal network agreed guidelines were not yet in place but Birmingham Children's Hospital NHS Foundation Trust guidelines were widely used in the local hospitals.

		Adult Service		Service 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	Network guidelines were not yet in place but Sandwell and West Birmingham Hospitals NHS Trust guidelines had been shared with linked hospitals.	N	A draft working document for development of the network was seen but network agreed guidelines were not yet in practice.
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	Ongoing monitoring was not yet undertaken.	N	Data were not yet available but this was expected to change once the data manager started.

		Adult Service		Service 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	An agreed programme of audit covering the network was not yet in place.	N	Data for audit were not yet available but this was expected to change when data manager started.
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 network research policy or list of trials had not yet been agreed.	N	A network research policy or list of trials had not yet been agreed.
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	Network review and learning meetings were not yet in place.	N	Meetings had not yet been arranged but this was expected to change once the network was formalised.

Return to *index*

COMMISSIONING

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**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	Some work had been undertaken but was not yet completed.	Y	Network development was an expressed intent by the commissioners once the network was formalised. The Trust had a CQUIN (Commissioning for Quality and Innovation) target for 2015/2016.

		Adult		Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Comments**	**Met? Y/N**	**Comments**
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	Regular clinical quality review meetings for services for people with haemoglobin disorders were not yet in place.	N	Commissioners were not yet regularly reviewing the quality of services for children with haemoglobin disorders. Formal network arrangements were not yet in place although this was earmarked as a CQUIN (Commissioning for Quality and Innovation) for the Trust in the next financial year and it was planned to meet this Quality Standard in the next year.
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	Network review and learning meetings were not yet in place.	N	Network review and learning meetings were not yet in place.

Return to *index*