WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

West Midlands Network

The Royal Wolverhampton NHS Trust

Visit Date: 13th October 2015

Report Date: February 2016

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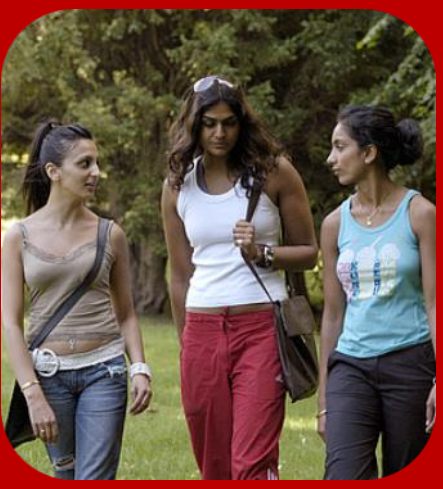

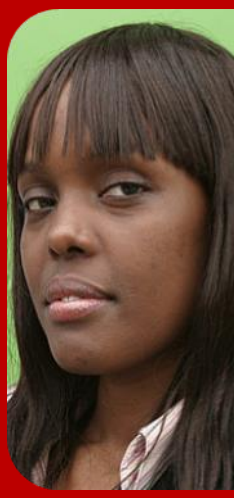

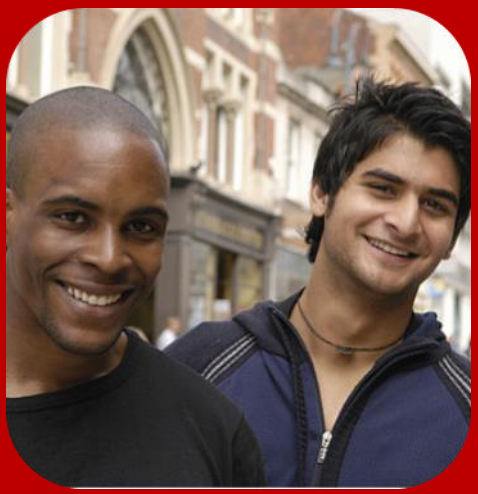

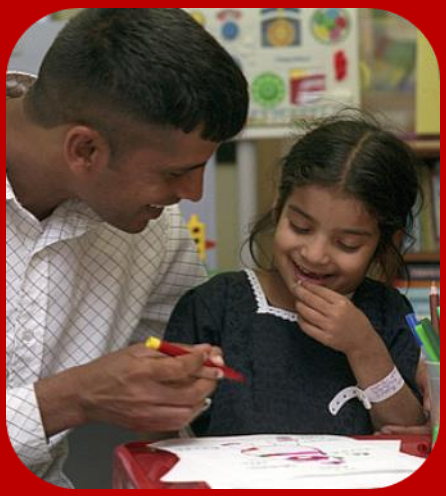

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INDEX

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in The Royal Wolverhampton NHS Trust (part of the West Midlands Network), which took place on 13th 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:

- The Royal Wolverhampton Hospitals NHS Trust
- NHS England Specialised Commissioning
- NHS Wolverhampton 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 The Royal Wolverhampton 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 Return to *Index*

HAEMOGLOBIN DISORDERS SERVICES IN THE WEST MIDLANDS NETWORK

At the time of the visit The Royal Wolverhampton NHS Trust (RWT) was part of the West Midlands Network. It was reviewed as a Specialist Haemoglobinopathy Centre (SHC) for adult services and as a Local Haemoglobinopathy Team (LHT) for paediatric services.

The Royal Wolverhampton NHS Trust (RWT) is a teaching hospital affiliated with the University of Birmingham Medical School. It serves the population of Wolverhampton, Cannock, Walsall and surrounding areas and includes New Cross Hospital (where Accident and Emergency Services are situated), Cannock Chase Hospital and West Park Hospital. Wolverhampton is a densely populated city with a high incidence of socio-economic deprivation and ethnic diversity. There are higher than average levels of unemployment and homelessness as well as children in care.

The Haemoglobinopathy Centre for adults was within the Clinical Haematology Department and provided a comprehensive clinical haematology service for Wolverhampton and Walsall although some patients with haemoglobin disorders from the Walsall area attended the Sandwell and West Birmingham Hospitals NHS Trust (City Hospital). The Wolverhampton-Walsall Haematology Service was partly integrated in 2000 following re-organisation of the service at Walsall. The service had five consultant haematologists at New Cross Hospital and two at Walsall Manor Hospital (part of Walsall Healthcare NHS Trust). All seven consultants worked as a team providing out of hours, on call clinical and laboratory haematology service in both Trusts.

Services for children and young people with haemoglobin disorders were reviewed as those provided by a local haemoglobinopathy team with a strong and long-standing relationship with the paediatric haemoglobinopathy Specialist Centre at Birmingham Children's Hospital NHS Trust (BCH). Children with haemoglobin disorders were seen within the paediatric department. Clinicians from BCH attended outreach clinics at RWT, trans-cranial Doppler scans were performed at BCH and acutely unwell children were discussed with and, if appropriate, transferred to BCH.

ADULTS

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
The Royal Wolverhampton NHS Trust	SHC	62	<5	<5

CHILDREN AND YOUNG PEOPLE

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
The Royal Wolverhampton NHS Trust	LHT	35	7	8

Emergency Care

Adult patients with haemoglobin disorders were encouraged to phone a dedicated 24/7 clinical haematology triage phone number before attending at hospital. During working hours, patients who required clinical reviews were assessed on the Durnell Unit day care unit. Out of hours, patients were usually assessed by the acute medical team and admitted directly onto the Acute Medical Unit (AMU). Small numbers of patients with haemoglobin disorders presented directly to the Emergency Department (ED). Whilst on the AMU patients were under the care of the acute medical team but were reviewed by the haematology team daily and all patients were seen by a consultant haematologist within 24 hours of admission.

Children with haemoglobin disorders presented directly to the paediatric assessment unit which was staffed by a paediatric middle grade at all times. Children rarely presented to the ED and if this occurred the paediatric team was called to assess them.

Day Care

The Durnell Unit was a triage unit with eight beds and six chairs for treating both oncology and haematology patients with supplementary therapies. The unit took telephone triage calls and treated an average of 30 to 50 day case patients per day and between three and 21 triage patients per day. From Aug 2014 to July 2015 there were 142 acute day unit attendances for patients with haemoglobin disorders. A specialist haemoglobinopathy nurse worked 22.5 hours working within a team of two other clinical nurse specialists who provided cover for absence.

Children and young people had access to a bay with four beds adjacent to the paediatric assessment unit where children of school age attended for elective blood transfusions. A fortnightly Saturday blood transfusion clinic was available. A total of 105 day care/elective episodes took place for haemoglobinopathy patients in the year before the review.

In-patient Care

Adult patients were admitted to the Clinical Haematology Unit (CHU)/B11 once a bed was available where they were under the care of the haematology team. The unit was a 26-bedded facility with six side rooms dedicated for haematology patients including patients with haemoglobin disorders. In-patients were reviewed daily by the haematology team. Between August 2014 and July 2015 there were 134 acute admissions, 34 of which were discharged on the same day.

Children and young people were admitted to a ward with 26 beds, including four high dependency beds, and an emergency room was used for paediatric patients with haemoglobin disorders. A paediatric assessment unit was adjacent to the ward with 11 beds and two triage beds where all new paediatric admissions were assessed and initial management commenced. There were 76 paediatric admissions of children with sickle cell disease over 12 months from August 2014 to July 2015 with an average length of stay of 1.72 days. During the week patients were reviewed by the paediatric haemoglobinopathy lead or, in their absence, by the deputy lead. The paediatric haematology team at BCH provided advice out of hours.

Out-patient Care

Out-patient clinics for adults were held in the Heart and Lung Centre and also in Deansley Centre. Designated haemoglobinopathy clinics were not held and patients could be under the care of any of the haematology consultants.

Children were seen in the children's out-patient department by the lead paediatric consultant. A specialist clinic was run jointly with the lead consultant from BCH three times per year. All patients were seen at least annually in this clinic. Weekday elective blood transfusions and phlebotomy services were also available in the children's out-patients. From August 2014 to July 2015 there were 258 out-patient attendances for both adult and paediatric patients.

Community-based Care

The Sickle Cell and Thalassaemia Support Project was funded by the Clinical Commissioning Group and a service level agreement with the Trust. It provided antenatal and neonatal services and one of the community nurses also supported the adult service. Counselling sessions, an outreach service and antenatal screening were provided. Patients needing psychological support were referred to a community-based clinical psychologist based at Whitmore Reans Health Centre who had an interest in haemoglobin disorders and their chronic health conditions.

The Sickle Cell Care Centre in Bilston was a voluntary sector organisation offering outreach and holistic services.

Paediatric community nursing services formed part of the paediatric department. They were able to help with families who were not engaging with the hospital services. In addition they provided pre-transfusion blood checking.

Return to *Index*

VIEWS OF SERVICE USERS AND CARERS

The visiting team met a small number of patients and carers with sickle cell disease from the adult team and received feedback from them. One hundred and twenty five surveys were sent out to patients and responses from 12 adults and seven paediatric patients/carers had been received. A similar survey had been sent in 2014.

Common themes raised by patients and carers were:

- Very positive feedback from adult patients about the acute medical unit saying they received rapid assessment and analgesia and personal care. Several patients stated that many of the nurses had been in post for many years and had good levels of knowledge about sickle cell disease.
- Patient feedback about the ED was poor with patients saying they would avoid there if possible because of long waits for analgesia and difficulties in obtaining analgesia. Patients felt that the ED staff did not follow the individualised care plans.
- Feedback about the adult haematology ward was generally positive although patients did state that they were sometimes admitted to other wards where care was not so good if the haematology ward was full.
- Treatment on the day unit was good and had improved over the past one to two years although staff were overstretched.
- Long waiting periods for a bed with long waiting times for medication were reported
- Many of the patients were not sure who the sickle team was and were not aware of the sickle nurse or (more frequently) that there was a lead consultant.
- Patients had accessed community services but requested additional support for example, for more home visits.
- The patients did not have access to up to date information about their condition/treatment or consistent source of reliable information and did not really know where to turn for guidance. None were on hydroxycarbamide.
- Patients would welcome timely access to an obstetrician with experience in treating sickle cell disease.

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, Sandwell & West Birmingham Hospitals NHS Trust (SWBH), University Hospitals Coventry and Warwickshire NHS Trust (UHCW) and The Royal Wolverhampton Hospital NHS Trust (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 to 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.

Return to *Index*

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: THE ROYAL WOLVERHAMPTON HOSPITAL NHS TRUST – ADULT SERVICES

General Comments and Achievements

Significant changes and improvements in the service had been made since the previous peer review which took place in 2012, including the appointment of a lead clinician and lead nurse. The lead nurse had improved training in care of patients with haemoglobin disorders within the Trust and had developed sickle cell disease information boards on the wards. This had led to service improvements which were reflected in the patient feedback which praised the care received on the day unit, acute medical unit and haematology wards. Patients still expressed concerns about care in the Emergency Department (ED) and would avoid ED if they could not be admitted directly to the day unit or the acute medical unit. The low patient numbers made it difficult to develop specialist expertise but did allow the team to develop a personal and flexible approach to care, for example, patients who requested out of hours transfusions could easily be accommodated. A needs assessment had been carried out in June 2015 with representatives from health services, the voluntary sector, patients and carers. A culture of encouraging patient feedback existed and the service was responsive to patient comments.

Progress since Last Visit

1 Concerns about poor nursing support had been resolved by the appointment of the new clinical nurse specialist.

2 Clinical guidelines had been updated and expanded and were now available on the hospital intranet.

3 The service had developed a database of their patients so had accurate patient data and patient details were entered onto the National Haemoglobinopathy Registry.

4 Links and communication between the community and hospital team had improved.

5 The transition service was robust and worked well, receiving positive patient feedback.

Good Practice

1 The Annual Review Proforma was very clear and comprehensive and improved consistency of care. These were returned to the lead nurse/consultant who entered the details on the NHR. The back page of this proforma formed a care plan with details about analgesia.

2 The lead nurse had developed an excellent learning package. This was a short PowerPoint presentation which ended with some self-test questions. It was available on the intranet and had been completed by the majority of nursing staff in the day unit, acute medical unit and haematology ward. This would be an easily transferrable package and the idea could be used by other Trusts.

3 The patient information provided by the voluntary sector was extensive and the 'Support for Carers' information booklet was particularly useful.

Immediate Risks: No immediate risks were identified.

Concerns

1 Patients were not receiving a specialist level of care for a variety of reasons:

   a. Patients with haemoglobin disorders were seen in general haematology clinics and were under the care of several different consultants. The specialist nurse tried to attend these clinics on an ad hoc basis. The development of a haemoglobinopathy clinic under a single consultant would allow the service to move towards provision of specialist care.

b. Although there were named links in other services, for example, in renal and orthopaedic services, in view of the small number of patients it was not clear that these other specialities had enough exposure to patients with haemoglobin disorders to develop specialist expertise.

c. Criteria for use of disease modifying therapy (hydroxycarbamide and transfusion) did not appear to be applied consistently and low numbers of patients were using these therapies

2 Several patients were still using pethidine as their primary or sole analgesia which did not comply with national guidance for care.

3 Patients did not have access to erythrocytopheresis or to specialist MRI scans (T2* for iron overload). The Trust should consider how liaison with other hospitals in the network to provide these services

4 Haemoglobinopathy multi-disciplinary team meetings were not in place, although patients were discussed as part of a departmental multi-disciplinary team meeting (MDT).

Further Consideration

1 Reviewers considered that the service would benefit from developing closer links with another SHC to ensure that all patients had access to specialist care. The review team was aware that discussions were ongoing with SWBH about development of these links. Whilst some of the specialist functions for example, annual review could be delegated to RWT, the Trust should consider obtaining support from SWBH for other specialist functions for example, review of patients with thalassaemia, complex sickle patients and management of pregnant patients.

2 The system of direct access to the day unit and acute medical unit was extremely effective, worked well and received good patient feedback. However patients on occasion would need to attend ED if they were new to the area or if AMU was full and patients expressed concerns about the waits for analgesia there and the knowledge of staff. The Trust should consider how this could be addressed, for example, by ensuring staff completed the training package which had been developed.

3 Reviewers suggested that the team could consider working with the acute pain team locally in relation to use of pethidine. It may be helpful to enrol external or voluntary organisations for example, Sickle Cell Society to provide patient support and education around this issue.

4 Setting up a specific MDT with representation from medical, nursing, community and psychology staff would improve coordination of care as well as meeting the expected standard.

5 Two community/voluntary organisations were providing patient services locally and links between the hospital and community had improved. The hospital-based service could consider signposting these services more clearly, continuing to improve communication with them and working to improve patient support and education.

6 Patient data were entered on the NHR and annual reviews were completed prospectively as part of this process. This had not yet been completed for all patients in part due to a lack of data support. Care plans were being completed prospectively as part of this process.

LOCAL TEAM: THE ROYAL WOLVERHAMPTON HOSPITAL NHS TRUST – PAEDIATRIC SERVICES

General Comments and Achievements

This was the first time this service had been reviewed and it was reviewed as a Local Haemoglobinopathy Team (LHT) with clear links to the SHT which was Birmingham Children's Hospital (BCH). It was providing a good local level of care and had close links to BCH, with outreach clinics three-times a year. Patients went to BCH for their trans-cranial Doppler scans. Acute in-patient care was also well supported by BCH with 24/7 telephone advice and a retrieval service for acutely unwell children. A needs assessment had been carried out in June 2015 with

representatives from health services, the voluntary sector, patients and carers. A culture of encouraging patient feedback existed and the service was responsive to patient comments.

The service had made several improvements in the past two years which included:

1 The appointment of a new lead consultant for haemoglobin disorders.

2 A paediatric multi-disciplinary team meeting had been set up which included medical, nursing and community staff as well as teachers, physiotherapists and dieticians.

3 Out of hours transfusions were easily available for patients.

4 The transition service was robust and worked well, receiving positive patient feedback.

Good Practice

1 The Annual Review Proforma was clear and comprehensive which helped improve consistency of care. The back page of this proforma formed a care plan with details about analgesia. Data entry onto the National Haemoglobinopathy Registry was the responsibility of BCH.

Immediate Risks: No immediate risks were identified.

Concerns

1 Sickle cell disease specialist nursing support was not available.

Further Consideration

1 Patients travelled to BCH for their trans-cranial Doppler scans and the Trust should consider if this service could be provided on site. The BCH team already provide outreach clinics on site and the TCD clinic could be run alongside these outreach clinics to improve the patient experience.

2 Guidelines were in place and were adequate but were often brief. They may not be sufficient in the absence of the lead clinician and the team should consider addition of further details to the guidelines developed in conjunction with BCH.

3 Two community/voluntary organisations were providing patient services locally and links between hospital and community had improved. The hospital-based service could consider signposting these services more clearly, continuing to improve communication with them and working to improve patient support and education

4 Patient data were entered on the National Haemoglobinopathy Registry and annual reviews were completed prospectively as part of this process. This had not yet been completed for all patients in part due to a lack of data support. Care plans were being completed prospectively as part of this process.

5 Information for patients with thalassaemia was brief. Information about splenic palpation in sickle cell disease was not available. Although GPs were prescribing iron chelation and hydroxycarbamide there was no evidence of information for them about this.

6 The service had not completed all the recommended audits and did not have a rolling plan of audits.

7 An operational policy was not in place at the time of the visit

8 Support from a psychologist with an interest in haemoglobin disorders was not available.

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:

Elaine Miller	Coordinator	UK Thalassaemia Society
Aldine Thomas	Clinical Nurse Specialist	Barts Health NHS Trust
Dr Jenny Welch	Consultant Haematologist	Sheffield Children's NHS Foundation Trust
Cherryl Westfield	Carer	Not applicable

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	44	26	59
Haemoglobin Disorders Clinical Network	9	1	11
Commissioning	3	0	0
Total	**56**	**27**	**48**

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	43	25	58
Haemoglobin Disorders Clinical Network	9	1	11
Commissioning	3	1	33
Total	**55**	**27**	**49**

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 Service		Service 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)	Y	Information for thalassemia was inadequate as the joint leaflets were more focussed on sickle cell disease. A good range of leaflets were available asking for patient feedback.	Y	Information was aimed at carers rather than being child-orientated. Thalassaemia information was available despite small numbers.

		Adult Service		Service 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	Y	Good detailed information was provided including for carers though there was less thalassaemia information.	N	Information was not available on splenic palpation or smoking cessation.

		Adult Service		Service 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	Only standard information on vaccinations was provided in letters.	N	The template GP letter had some of this information. Some GPs prescribed iron chelation/hydroxycarbamide but guidance was not provided for 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	Although all patients were being offered annual review only one-third of annual reviews had been carried out at the time of the visit. The back page of the review proforma was a care plan.	N	The back page of the annual review document was a care plan but this was not completed for all patients.

		Adult Service		Service 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 patients were referred to the Sickle Cell and Thalassaemia Support Project, who issued the school care plan.
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		Y	The named co-ordinator was in the operational policy but not in the leaflet.

		Adult Service		Service 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	Birmingham Children's Hospital NHS Foundation Trust leaflet was being used.
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		Y	Five WMQRS surveys had been completed by telephone. The service user consultation in May had received 19 replies from 125 surveys for the age range from two to 60 years old with seven responses from children/carers. Themes from the WMQRS surveys included requests for more doctors and nurses that understand sickle cell disease, for Doppler scans to take place at New Cross, and praise for/satisfaction with the service.

		Adult Service		Service 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		Y	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	N	This Quality Standard was not met for a SHC, if operating at level of an A-LHT the lead consultant was covered by all consultants (on call) but specialist cover was not in place.	Y	

		Adult Service		Service 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)	Y		N	Dedicated sickle cell disease nursing support was not available and patient care would benefit from such a post.

		Adult Service		Service 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.	Y		N	Evidence for 'd', 'e' and 'g' was not seen by the review team.
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	A good learning package had been developed.	N	A training plan was not available.

		Adult Service		Service 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.	N	Specialist care was not always 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	Training for Emergency Department nursing staff in the care of patients with haemoglobin disorders was not yet undertaken.	N	Training for Emergency Department nursing staff in the care of patients with haemoglobin disorders was not yet undertaken.
HN-208 All	**Safeguarding Training** All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		Y	
HN-209 SHC	**Doctors in Training** The service should ensure that doctors in training have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.	Y	This was provided three monthly in Birmingham as part of training rotation.	N	Doctors in training did not have the opportunity to gain competences in all aspects of the care of people with haemoglobin disorders.

		Adult Service		Service 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		N/A	All scans were carried out at Birmingham Children's Hospital NHS Trust.
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 available.	N	Administrative support was not available.
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.	Y		N	Access to a psychologist with an interest in haemoglobinopathies was not available.

		Adult Service		Service 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	However the level of specialist experience for 'c' and 'd' was not clear.	N	Access to on-site support was not available for 'a' or 'd'.

		Adult Service		Service 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	Specialist staff and services were not available for 'a', 'l' and 'm'. Other services had named contacts but the level of specialist experience was not clear.	N	Specialist referral pathways were in place locally except for 'a' and 'm'.

		Adult Service		Service 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	Children's facilities were being upgraded at the time of the visit.
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y		Y	

		Adult Service		Service 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	Y	However the guidelines would benefit from more detail.	Y	However the guidelines would benefit from more detail.
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	Checklists were not in use for 'a' and 'b'.	Y	Although 'c' was good, the other checklists were fairly generic.

		Adult Service		Service 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	Out-patients were all seen once yearly at BCH but there were no agreed network guidelines.
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	Although some of the recommendations were outside of nationally recommended practice.	Y	Guideline existed but they were brief particularly about indications for transfusion.

		Adult Service		Service 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.	Y	GPs were not prescribing.	Y	

		Adult Service		Service 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 were good but 'a' did not comply with national guidelines.	Y	All conditions were mentioned but were very brief.
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	Y		Y	All children attended Birmingham Children's Hospital NHS Foundation Trust.

		Adult Service		Service 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)	Y		N	Guidelines for chronic complications were not seen.
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 in use.	N/A	Referral was made to Birmingham Children's Hospital NHS Foundation Trust and discussed as part of the annual review there.
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		N	Network-agreed guidelines for the management of thalassaemia were not yet in use.

		Adult Service		Service 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.	Y		Y	

		Adult Service		Service 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/A	Scans were carried out at Birmingham Children's Hospital NHS Foundation Trust.

		Adult Service		Service 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 policy was not yet in use.	Y	

		Adult Service		Service 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).	N	The meetings were general and not specific to the care of people with haemoglobin disorders.	Y	
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	Y		Y	
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.	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		N/A	Screening was carried out at Birmingham Children's Hospital NHS Foundation Trust.

		Adult Service		Service 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 beginning to be entered into the registry.	N/A	
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		Y	

		Adult Service		Service 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	Monitoring was not undertaken for network patient data.	N/A	

		Adult Service		Service 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 covering the areas listed had not been undertaken within the last year.	N	Clinical audits covering the areas listed had not been undertaken within the last year.

		Adult Service		Service 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	The service did not have a rolling programme of audit.	N	The service did not have a rolling programme of audit.
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N	The SHC was not actively participating in research relating to the care of patients with haemoglobin disorders.	N/A	
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		N/A	

		Adult Service		Service 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		Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		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 but Sandwell and West Birmingham Hospitals NHS Trust guidelines had been shared with linked hospitals.	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.	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 **Error! Reference source not found.**)	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 Service		Service 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	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.
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 **Error! Reference source not found.** and QS **Error! Reference source not found.**. 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.

		Adult Service		Service 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 (**Error! Reference source not found.**) 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*