

Health Services for People with Haemoglobin Disorders

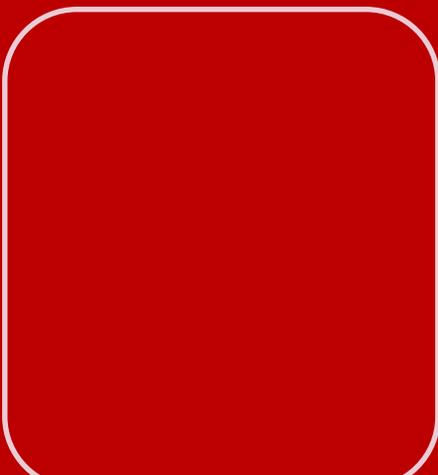
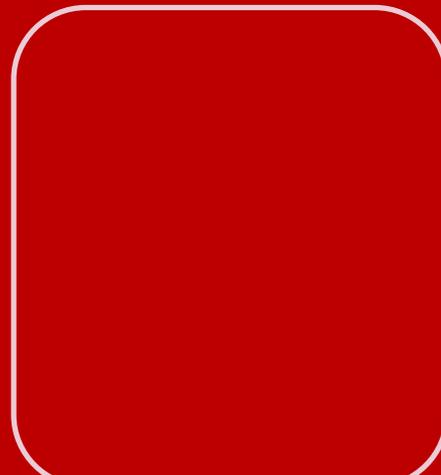
West Midlands Network

University Hospitals Coventry and Warwickshire NHS Trust

Visit Date: 13th October 2015

Report Date: April 2016

Images courtesy of NHS Photo Library



INDEX

Introduction.....	3
Haemoglobin Disorders Services in West Midlands Network.....	4
Review Visit Findings	7
Network	7
Specialist Team: University Hospitals Coventry and Warwickshire NHS Trust - Adult Services.....	10
Local Team: University Hospitals Coventry and Warwickshire NHS Trust - Paediatric Services	11
Commissioning	12
Appendix 1 Membership of Visiting Team	13
Appendix 2 Compliance with the Quality Standards	14
Specialist Services for People with Haemoglobin Disorders	15
Haemoglobin Disorders Clinical Network	42
Commissioning	46

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in University Hospitals Coventry and Warwickshire 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:

- University Hospitals Coventry & Warwickshire NHS Trust
- NHS England Specialised Commissioning
- NHS Coventry & Rugby 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 University Hospitals Coventry and Warwickshire 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 WEST MIDLANDS NETWORK

At the time of the visit University Hospitals Coventry and Warwickshire NHS Trust 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.

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
University Hospitals Coventry and Warwickshire NHS Trust	SHC	100	18	17

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
University Hospitals Coventry and Warwickshire NHS Trust	LHT	48	11	8

University Hospitals Coventry and Warwickshire NHS Trust (UHCW) served the population of Coventry and Warwickshire. Coventry had a more diverse ethnic population than in the rest of the county and was a high prevalence area for haemoglobinopathies with up to 1000 carriers counselled a year.

In 2014, a new haemoglobinopathy team was set up, with the appointment of two Clinical Nurse Specialists (CNS), based and managed at UHCW but providing both acute and community care. The lead nurse covered paediatrics but there was cross-cover with the adult CNS. The previous adult lead consultant had retired and the replacement substantive post-holder was appointed with three programmed activities (PAs) dedicated to the haemoglobinopathy service. The adult deputy lead was based the Hospital of St Cross in Rugby where haemoglobinopathy patients were seen. A lead paediatrician with 0.5PAs for the service held a dedicated haemoglobinopathy clinic. The named deputy lead for the paediatric haemoglobinopathy service was on maternity leave at the time of the review.

The service aimed to provide integrated, equitable and effective haemoglobinopathy lifespan care, reduce morbidity and mortality, co-ordinate patients' care between hospital and community services especially at times of transition and to improve the experience of all patients. The adult services aimed to be recognised as an SHC, within a clinical network spanning the West Midlands and the haemoglobinopathy team was fully engaged with other clinicians and commissioners working towards this goal. The paediatric service worked closely with Birmingham Children's Hospital and was building on previous arrangements further to improve the care for children. The team worked closely with other specialties within the Trust and with IT and Quality teams to innovate and establish solutions to overcome some of the obstacles to timely care for this group of patients. A quality manager based within the haematology service helped with the alerts and was developing databases to improve the quality and timeliness of ongoing audits.

Access was available for specialist support for adult patients from renal, cardiology, endocrinology, obstetrics, neurology, urology, ophthalmology, general surgery, dieticians and orthopaedics on site. Patients were referred to other Trusts for more specialised services for example, reproductive medicine and complex orthopaedics. For adults there was a dedicated haematology clinical psychologist and support from a final-year trainee psychologist was often provided.

Paediatric In-patients and out-patients were supported by the play team. “Young carers” provided some support too. All paediatric specialist care was provided by Birmingham Children’s Hospital (BCH) and an outreach clinic was held by the specialist team from BCH.

EMERGENCY CARE

Adults:

During normal working hours if a bed was available on ward 34 (adult haematology ward) and the patient phoned in they were admitted directly to the ward. Otherwise they attended via the Emergency Department (ED).

Paediatrics:

Paediatric patients/parents contacted either the CNS or Children’s ED in working hours, or children’s ED out of hours. An alert email was sent to the haemoglobinopathy team to let them know a patient had presented. A CNS, senior registrar or consultant review was undertaken within half a working day but often within an hour. If outside normal hours the review took place the next morning.

Patients with sickle cell disease of all ages had alert cards with individual care plans and the bleep numbers of the team.

IN-PATIENT CARE

Adults:

Care was provided for all haematology in-patients on ward 34 which was a 17 bedded unit. There was a “ring-fenced” bed for patients with neutropenic sepsis, new acute leukaemia or acute sickle crisis. Usually about two adult patients with sickle cell disease were in-patients at any time. The haematology consultant of the week looked after all in-patients. Regular review by the named haemoglobinopathy lead consultant took place at least weekly but daily for complex patients. The specialty trainee or consultant reviewed all patients prior to transfer to ward 34. The lead, or deputy lead consultant was available during normal working hours and was sometimes contacted in an emergency even if not on call. The consultant of the week was on call 24 hours a day, often along with a specialty trainee. Senior House Officer (SHO) level cover was by a haematology or oncology SHO at all times.

Paediatrics:

Three general paediatric in-patient wards with 55 beds were available. Patients were grouped by age and a dedicated adolescent unit was available. The resident on-call paediatric consultant was available until 10pm weekdays and from 9am until 5pm at weekends. A resident paediatric registrar was on call 24/7.

DAY CARE

Adult:

Adults attended ward 34 which had nine chairs for a mix of haematology patients. Saturday transfusions were carried out once a month for the nine transfusion-dependent thalassaemia patients. Manual and automated red cell exchange transfusions were carried out on the day.

Paediatrics:

The Medical Day Unit was used for transfusions for children during the normal working week. Two registered nurses were available.

OUT-PATIENT CARE

Adult:

Adults attended a weekly dedicated haemoglobinopathy clinic. A quarterly joint endocrine review clinic was offered for all patients on long-term transfusions and those with other endocrine problems. Clinics were led by the lead consultant and CNS. Ad hoc day unit reviews were organised if necessary.

Paediatrics:

A monthly dedicated paediatric haemoglobinopathy clinic was attended by the lead consultant and CNS, plus six-monthly joint clinics with the lead from BCH. Ad hoc reviews in general paediatric clinics were available if necessary.

COMMUNITY-BASED CARE

The two clinical nurse specialists providing community support were hospital-based, one for adults and one for children and young people. District nurses cared for children in the home. Patients used the community leg ulcer clinic if needed.

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. No questionnaires were reviewed.

Common themes raised by patients and carers were:

- Patients and carers were appreciative of the work done by the clinical team and felt that the haematology team provided excellent clinical care
- Patients benefitted greatly from the adult psychologist
- Several patients commented on delays in receiving analgesia in the Emergency Department and the lack of morphine analgesia in ambulances
- There were delays in starting transfusions in the paediatric day unit despite patients attending in a timely manner, compounded by delays in obtaining venous access by paediatric day unit staff
- A lack of dedicated community nursing team and community-based patient support groups
- Not all schools were being visited for training teachers

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 NHS Trust (RHT) 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)	<ul style="list-style-type: none"> • University Hospitals Birmingham NHS Foundation Trust • The Dudley Group of Hospitals NHS 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)	<ul style="list-style-type: none"> • George Eliot Hospital NHS Trust • South Warwickshire NHS Foundation Trust
The Royal Wolverhampton NHS Trust	<ul style="list-style-type: none"> • Walsall Healthcare NHS Trust
Services for Children and Young People	
Birmingham Children’s Hospital NHS Foundation Trust	<ul style="list-style-type: none"> • 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: UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST - ADULT SERVICES

General Comments and Achievements

The adult service was a developing a progressive service with the clinical and corporate intentions of establishing as a specialist centre. Patients were satisfied with the quality of care received in the haematology department.

Progress since Last Visit

The adult service had progressed considerably since the last review which took place in 2012 and a number of recommendations from the previous review had been implemented. The haemoglobinopathy service had an important and strategic role in the Trust business plan. Notable achievements were the substantive appointment of the lead clinician, following the retirement of the former lead, with a job plan which adequately reflected workload, the establishment of an automated red cell exchange programme and appointment of two haemoglobinopathy nurses to provide a combination of acute and community-based care to haemoglobinopathy patients. In addition a psychologist had been appointed to work closely with the clinical team. Saturday transfusions had been established and patients received pre-transfusion crossmatch blood tests in the community.

Good Practice

- 1 An efficient electronic clinical alert system was in place for all Emergency Department (ED) attendances by haemoglobinopathy patients, which allowed the responsible clinical team to follow up the patients according to their clinical needs. Direct electronic links to the clinical guidelines were available in every haemoglobinopathy patient record at the ED, which enabled the ED team easily to access clinical guidelines. A comprehensive nurse training package was available with evidence of good attendance and feedback.
- 2 Although some of the expected audits were not completed, an extensive audit programme was in place and the reviewers noted evidence of some good quality audit.

Immediate Risks: No immediate risks were identified.

Concerns

- 1 Insufficient community-based nursing support was available, especially given the expanding patient numbers. Patients and carers expressed their difficulty in obtaining community support from the nursing staff who were engaged in supporting and expanding the acute service. The acute haemoglobinopathy nurses were not able to provide adequate community-based nursing support via the outreach model because of their in-patient and acute duties.

Further Consideration

- 1 Systems and processes in the Emergency Department and wards were good although patient feedback on the day was not fully reflective of the processes in place and concerns were raised regarding waiting time to analgesia in the ED. It may be helpful to continue the analgesia audit on a regular basis so the cause for delays can be identified and resolved.
- 2 It will be important for the Trust to ensure that workforce and service planning reflects the increasing patient numbers particularly in light of the designation of Coventry as a dispersal city for refugees.
- 3 Care plans were not being shared with all patients. Reviewers considered the service should ensure that copies of both clinic letters and formal care plans are sent to patients.
- 4 Reviewers commented that it will be important to re-establish the haemoglobinopathy user support group, increase patient involvement with service feedback and review written information for patients.

Return to [Index](#)

LOCAL TEAM: UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST - PAEDIATRIC SERVICES

General Comments and Achievements

The paediatric service was embedded within a strong and cohesive paediatric directorate with excellent facilities and support services. The paediatric service was led by an experienced consultant and strong links existed with the specialist service at Birmingham Children's Hospital NHS Foundation Trust. Prior to the visit the haemoglobinopathy nurse specialist was employed by the Trust to provide in-patient and community service to children and young people and her work was appreciated by the parents and carers who were present on the day of the review. The wards were age-specific and were therefore able adequately to provide age-appropriate facilities for patients including those of older teenagers. Play specialist support was available for seven days a week for twelve hours a day.

Good Practice

- 1 Good patient information leaflets were available.
- 2 The clinical alert system in the ED ensured that all ED attendances were notified to the clinical team.
- 3 Link nurse development in clinical areas ensured dissemination of good practice and service quality even when the nurse specialist was not on site.

Immediate Risks: No immediate risks were identified

Concerns

- 1 The clinical guidelines for the management of sickle cell disease were inaccurate and could lead to serious incidents. Urgent review by the paediatric team was required. The guidelines were mainly aimed at adult patients and reviewers recommended that separate paediatric specific guidelines are developed as soon as possible, ideally by adapting the guidelines already used at Birmingham Children's Hospital.
- 2 The review team was concerned that the nurse specialist's workload was excessive and could result in gaps in service provision. Clinical nurse specialist time available was insufficient to ensure high quality service provision in the community, in the wards and in out-patients.
- 3 The lead clinician PA's did not adequately reflect the increasing workload. It will be important to recognise this workload during succession planning.

Further Consideration

- 1 Few audits had been undertaken by the paediatric team. It will be important to establish a programme of audits in order to ensure that the standards of care are being adequately met.
- 2 Psychology support with an interest in care of children and young people with 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 ensure that good communication continues.

Return to [Index](#)

APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead

Dr Subarna Chakravorty	Consultant Haematologist	Kings College Hospital NHS Foundation Trust
------------------------	--------------------------	---

Visiting Team

Claire Foreman	Senior Service Specialist	NHS England
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
Dr Olu Wilkey	Consultant Paediatrician	North Middlesex University Hospital 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	44	36	82
Haemoglobin Disorders Clinical Network	9	1	11
Commissioning	3	0	0
Total	53	37	70

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	48	31	65
Haemoglobin Disorders Clinical Network	9	1	11
Commissioning	3	1	33
Total	60	33	55

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

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-101 All	<p>Haemoglobin Disorder Service Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> 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		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-102 All	<p>Information about Haemoglobin Disorders</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> 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		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-103 All	<p>Information for Primary Health Care Team</p> <p>Written information should be sent to the patient's primary health care team covering available local services and</p> <ol style="list-style-type: none"> 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		Y	However information on how to change a clinic appointment was missing.
HN-104 All	<p>Care Plan</p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> 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 <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p>	N	Although a patient care plan was available in the form of a card it was not possible to confirm if letters were going to patients in a systematic way. An 'opt in' rather than 'opt out' policy for patient letters was used which needed to be more robust and formalised.	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-105 All	<p>School Care Plan (Paediatric Services Only)</p> <p>A School Care Plan should be agreed for each child or young person covering, at least:</p> <ol style="list-style-type: none"> School attended Medication, including arrangements for giving / supervising medication by school staff What to do in an emergency whilst in school Arrangements for liaison with the school 	N/A		Y	
HN-106 SHC (A-LHT)	<p>Transition to Adult Services</p> <p>Young people transferring to the care of adult services should be offered written information covering at least:</p> <ol style="list-style-type: none"> Their involvement in the decision about transfer and, with their agreement, involvement of their family or carer A joint meeting between children's and adult services to plan the transfer A named coordinator for the transfer of care A preparation period prior to transfer Arrangements for monitoring during the time immediately after transfer 	Y		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-107 SHC	<p>Information about Trans-Cranial Doppler Ultrasound</p> <p>Written information should be offered to patients and their carers covering:</p> <ul style="list-style-type: none"> a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated 	N/A		Y	
HN-199 All	<p>Involving Patients and Carers</p> <p>The service's involvement of patients and carers should include:</p> <ul style="list-style-type: none"> 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	A patient support group met.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-201 All	<p>Lead Consultant</p> <p>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.</p>	Y		Y	<p>Only 0.5PA was allocated to this job although the Trust recognised that this was insufficient.</p> <p>No Continuing Professional Development records were seen for the clinical lead.</p>
HN-202 All	<p>Cover for Lead Consultant</p> <p>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.</p>	Y		Y	<p>The named deputy was on maternity leave and the post was covered by a locum. The job plan of the deputising locum did not specify responsibilities for cover for the lead haemoglobinopathy consultant.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-203 All	<p>Lead Nurse</p> <p>A lead nurse should have appropriate time available for their leadership role and:</p> <ul style="list-style-type: none"> 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	However, documentation of competences of the lead nurse were not available.	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-204 All	<p>Staffing Levels and Competences</p> <p>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> Medical staffing for clinics and regular reviews Medical staffing for emergency care, in and out of hours Nurse staffing on the ward and day unit Clinical nurse specialist/s with responsibility for the acute service Clinical nurse specialist/s with responsibility for the community service Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. Clinical or health psychologist with an interest in haemoglobin disorders <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT).</p> <p>Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders.</p> <p>Cover for absences should be available.</p>	Y	However documentation for 'd', 'e' and 'f' was not seen.	Y	However evidence for 'g' was not seen although some evidence was provided in in the background report.
HN-205 All	<p>Competences and Training</p> <p>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).</p>	Y		Y	Lead nurse and all staff training was demonstrated really well. Staff were responsive to evaluations.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-206 SHC	Specialist Advice During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		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		Y	
HN-208 All	Safeguarding Training All staff caring for people with haemoglobinopathies should have undertaken appropriate training in: a. Safeguarding children and/or vulnerable adults (as applicable) b. Equality and diversity	Y		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		N	Evidence was not provided to demonstrate training opportunities for doctors in the care of people with haemoglobin disorders.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-210 SHC	<p>Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)</p> <p>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.</p>	N/A		Y	
HN-299 All	<p>Administrative, Clerical and Data Collection Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p>	N	No data manager support was in place yet.	N	No data manager support was in place yet.
HN-301 All	<p>Support Services</p> <p>Timely access to the following services should be available:</p> <ol style="list-style-type: none"> Psychologist with an interest in haemoglobinopathies Social worker Leg ulcer service Play specialist (children's services only) Chronic pain team Dietetics Physiotherapy Occupational therapy Mental health services (adult and CAMHS) <p>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.</p>	Y	An adult psychologist with time for patients with haemoglobinopathies was considered as a very positive thing that patients valued.	N	Access to a psychologist with an interest in haemoglobinopathies was not available.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-302 SHC	<p>Specialist On-site Support</p> <p>Access to the following specialist staff and services should be available on the same hospital site as the specialist team:</p> <ul style="list-style-type: none"> 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	Automated exchange service was available.	N/A	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-303 SHC A-LHT	<p>Specialist Services - Network</p> <p>Access to the following specialist staff and services should be available:</p> <ul style="list-style-type: none"> a. Erythrocytapheresis 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 <ul style="list-style-type: none"> 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 <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p>	Y		N	Specialist referral pathways were in place locally except for 'm'.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		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	
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	Saturday transfusion service was made available directly in response to patient feedback.	Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-501 SHC A-LHT	<p>Transition Guidelines</p> <p>Network-agreed guidelines on transition to adult care should be in use covering at least:</p> <ul style="list-style-type: none"> 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	Good practice was in place allowing patients to attend an adult clinic a month before their first adult transfusion.	Y	
HN-502 All	<p>Monitoring Checklists</p> <p>Checklists should be in use for:</p> <ul style="list-style-type: none"> a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) <p>Use of the checklists should cover both clinical practice and information for patients and families.</p>	Y	The annual review proforma was not seen in the notes. Clinic letters were very good and pertinent aspects were highlighted in bold.	Y	Although the annual review proforma was not seen in the notes.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-503 LHT	<p>Clinical Guidelines: LHT Management and Referral</p> <p>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.</p>	Y	<p>Network guidelines had not yet been agreed although development of these was progress.</p> <p>Informally other Trusts were using the same guidelines.</p> <p>Annual reviews were carried out.</p>	N	<p>Network-agreed guidelines were not yet in place. See main report.</p>
HN-504 All	<p>Transfusion Guidelines</p> <p>Transfusion guidelines should be in use covering:</p> <ol style="list-style-type: none"> Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion Offering access to exchange transfusion to patients on long-term transfusions Protocol for carrying out an exchange transfusion Hospital transfusion policy Investigations and vaccinations prior to first transfusion Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. Areas where transfusions will usually be given Recommended number of cannulation attempts 	N	<p>The hospital transfusion policy was not provided and guidelines for 'e' were not seen.</p>	N	<p>The hospital transfusion policy was not seen.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-505 All	<p>Chelation Therapy</p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ol style="list-style-type: none"> Indications for chelation therapy Choice of chelation drug/s, dosage and dosage adjustment Monitoring of haemoglobin levels prior to transfusion Management and monitoring of iron overload, including management of chelator side effects Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 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. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible. 	Y	'f' was not applicable.	Y	'f' was not applicable.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-506 All	<p>Clinical Guidelines: Acute Complications</p> <p>Network-agreed clinical guidelines on the management of acute complications should be in use covering at least:</p> <p>For patients with sickle cell disease:</p> <ul style="list-style-type: none"> 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) <p>For patients with thalassaemia:</p> <ul style="list-style-type: none"> l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation 	Y	<p>The clinical guidelines were comprehensive succinct and user friendly. Doctors and nurses knew where to access them and issues around document control were really clear.</p> <p>ED was well prepared to give priority to patients with sickle cell disease.</p>	N	<p>The guidelines were not orientated to paediatric care.</p>
HN-507 All	<p>Specialist Management Guidelines</p> <p>Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ul style="list-style-type: none"> a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy 	Y		N	<p>Network agreed guidelines were not available.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-508 All	<p>Clinical Guidelines: Chronic complications</p> <p>Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least:</p> <ul style="list-style-type: none"> 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	The guidelines contained a good section on psychosocial issues.	N	Network-agreed clinical guidelines were not available.
HN-509 SHC	<p>Referral for Consideration of Bone Marrow Transplantation</p> <p>Guidelines for referral for consideration of bone marrow transplantation should be in use.</p>	Y		Y	
HN-510 All	<p>Thalassaemia Intermedia</p> <p>Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering:</p> <ul style="list-style-type: none"> a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy 	Y		N	Network-agreed clinical guidelines for the management of thalassaemia were not available.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		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	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-512 SHC	<p>Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)</p> <p>Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least:</p> <ul style="list-style-type: none"> a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established) 	N/A		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-601 All	<p>Service Organisation</p> <p>A service organisation policy should be in use covering arrangements for:</p> <ul style="list-style-type: none"> 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		Y	Although 'c', 'd' and 'h' were not covered.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-602 All	<p>Multi-Disciplinary Meetings</p> <p>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).</p>	Y		Y	However only one meeting had taken place at the time of the visit.
HN-603 All	<p>Service Level Agreement with Community Services</p> <p>A service level agreement for support from community services should be in place covering, at least:</p> <p>a. Role of community service in the care of patients with haemoglobin disorders</p> <p>b. Two-way exchange of information between hospital and community services.</p>	N/A	The community team was integrated within the hospital haemoglobinopathy team.	N/A	The community team was integrated within the hospital haemoglobinopathy team.
HN-604 All	<p>Network Review and Learning Meetings</p> <p>At least one representative of the team should attend each Network Review and Learning Meeting (QS Error! Reference source not found.).</p>	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	<p>Neonatal screening programme review meetings</p> <p>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.</p>	N/A		N	The neonatal screening review meeting had not taken place.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-701 SHC	<p>Data Collection</p> <p>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.</p>	Y		Y	
HN-702 All	<p>Annual Data Collection - Activity</p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances Length of in-patient stays Re-admission rate 'Did not attend' rate for out-patient appointments 	N	Data were available for 'a' but not 'b' or 'c'. The 'did not attend' numbers were not summarised but a list was provided. Evidence was not shown regarding the reduction of 'did not attend' rates.	N	Data were not available for 'b', 'c' and 'd'.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-703 SHC	<p>Annual Data Collection – Network Patient Data</p> <p>The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> 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: <ol style="list-style-type: none"> i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: <ol style="list-style-type: none"> 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	A formal network was not yet in place.	N	A formal network was not yet in place.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-704 All	<p>Audit Clinical audits covering the following areas should have been undertaken within the last two years:</p> <p>Achievement of screening follow-up standards:</p> <p>a. At least 90% of infants with a positive screening result attend a local clinic by three months of age</p> <p>b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age</p> <p>c. Less than 10% of cases on registers lost to follow up within the past year</p> <p>For patients with sickle cell disease:</p> <p>d. Proportion of patients with recommended immunisations up to date</p> <p>e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required</p> <p>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</p> <p>g. Availability of extended red cell phenotype in all patients</p> <p>h. Proportion of children:</p> <p>i. at risk of stroke who have been offered and/or are on long-term transfusion programmes</p> <p>ii. who have had a stroke</p> <p>For patients with thalassaemia:</p> <p>i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505)</p> <p>j. Proportion of patients who have developed new iron-related complications in the preceding 12 months</p> <p>All patients:</p> <p>k. Waiting times for transfusion</p>	N	<p>Audit data for 'e', 'j' and 'k' were not available.</p> <p>A compliance rate of 68% was reported for the NICE (National Institute for Health and Care Excellence) standard of 30 minutes to analgesia in 2014.</p>	N	<p>Audit information was only available for 'f' and 'g'.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-705 All	<p>Guidelines Audit</p> <p>The service should have a rolling programme of audit, including:</p> <ul style="list-style-type: none"> a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits. 	N	The audit of implementation of guidelines had not taken place.	N	The audit of implementation of guidelines had not taken place.
HN-706 SHC	<p>Research</p> <p>The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.</p>	Y		N/A	
HN-707 SHC	<p>Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)</p> <p>The service should monitor and review at least annually:</p> <ul style="list-style-type: none"> a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required 	N/A		Y	

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-798 All	<p>Review and Learning</p> <p>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:</p> <p>a. Review of any patient with a serious adverse event or who died</p> <p>b. Review of any patients requiring admission to a critical care facility</p>	Y		N	Evidence was not seen for review and learning arrangements.
HN-799 All	<p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p>	Y		Y	

Return to [Index](#)

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		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: <ol style="list-style-type: none"> Lead consultant and deputy Lead specialist nurse for acute care Lead specialist nurse for community services Lead manager Lead for service improvement Lead for audit 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 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 Qs 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.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-501	<p>Transition Guidelines</p> <p>Network guidelines on transition to adult care should have been agreed covering:</p> <ul style="list-style-type: none"> 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) <p>Guidelines should be explicit about transition directly to any accredited LHTs.</p>	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.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-502	<p>Clinical Guidelines</p> <p>Network guidelines should have been agreed covering:</p> <ul style="list-style-type: none"> 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) <p>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.</p>	N	Network guidelines were not yet in place but Sandwell & 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	<p>Ongoing Monitoring</p> <p>The network should monitor on a regular basis:</p> <ul style="list-style-type: none"> 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.

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-702	<p>Audit</p> <p>The network should have an agreed programme of audit and review covering network-wide achievement of Qs HN-703, HN-704, HN-705 and HN-707.</p>	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	<p>Research</p> <p>The network should have agreed:</p> <ol style="list-style-type: none"> A policy on access to research relating to the care of patients with haemoglobin disorders 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	<p>Network Review and Learning</p> <p>The SHC should meet at least twice a year with its referring LHT teams to:</p> <ol style="list-style-type: none"> Identify any changes needed to network-wide policies, procedures and guidelines Review results of audits undertaken and agree action plans Review and agree learning from any positive feedback or complaints involving liaison between teams Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams 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

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HZ-601	<p>Commissioning of Services</p> <p>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:</p> <ol style="list-style-type: none"> Designated SHC/s for the care of people with sickle cell disease Designated SHC/s for the care of adults with thalassaemia Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia Community care providers 	N	Some work had been undertaken but was not yet completed.	Y	<p>Network development was an expressed intent by the commissioners once the network was formalised.</p> <p>The Trust had a CQUIN (Commissioning for Quality and Innovation) target for 2015/2016.</p>

Ref	Quality Standard	Adult Service		Service for Children and Young People	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HZ-701	<p>Clinical Quality Review Meetings</p> <p>Commissioners should regularly review the quality of care provided by:</p> <ul style="list-style-type: none"> 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	<p>Network Review and Learning</p> <p>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.</p>	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](#)