WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

South East London Network

King's College Hospital NHS Foundation Trust

Visit Date: 8th July 2015 Version 2 Report Date: October 2016

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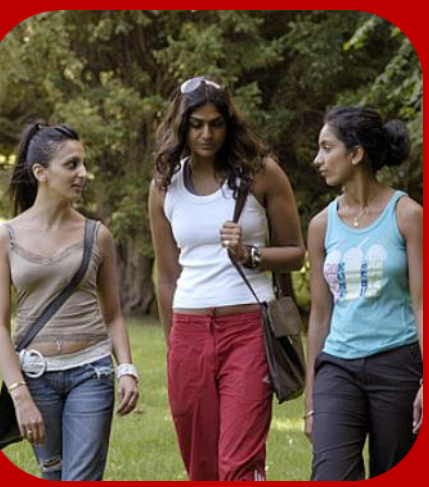

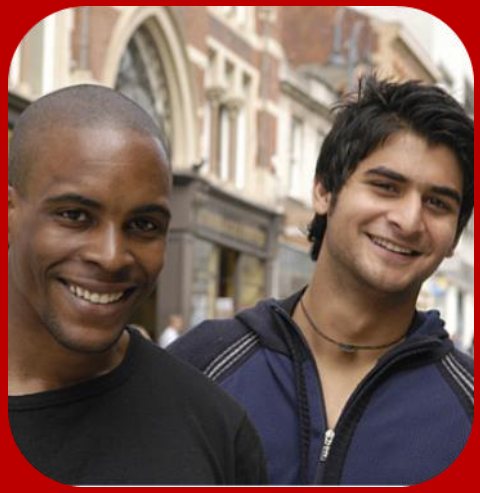

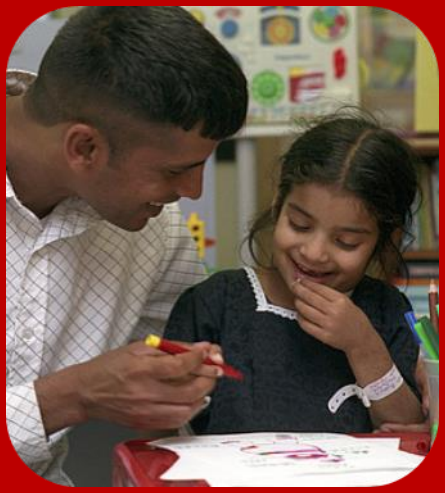

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Version No.	Date	Change from previous version
1	November 2015	N/A
2	October 2016	Includes final Network findings and compliance sections resulting from review of last Trust in Network

INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in King's College Hospital NHS Foundation Trust (part of South East London Network), which took place on 8 July 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:

- King's College Hospital NHS Foundation Trust
- NHS England Specialised Commissioning
- NHS Southwark 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 King's College Hospital NHS Foundation 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 by NHS organisations in the West Midlands to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews - often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved. More detail about the work of WMQRS is available on www.wmqrs.nhs.uk

HAEMOGLOBIN DISORDERS SERVICES IN SOUTH EAST LONDON NETWORK

At the time of the visit King's College Hospital NHS Foundation Trust was part of the large South East London network and acted as joint network lead in haemoglobinopathies with Guy's and St Thomas' NHS Foundation Trust (GSTT) for the South East London network. In the network they worked closely with St George's University Hospitals NHS Foundation Trust.

The hospital was a large teaching hospital and was also part of King's Health Partners and an Academic Health Sciences Centre. At the time of the review there was a high prevalence of sickle cell disease in the local population and 1040 patients (adults and children) were registered on the National Haemoglobinopathy Registry for the Trust.

King's College Hospital was a specialist centre for other units in the South Thames region and around the country. Paediatric sickle cell disease outreach clinics were held at Queen Elizabeth Hospital, Woolwich, University Hospital Lewisham, Darent Valley Hospital, Medway Maritime Hospital and Croydon University Hospital. Children from other smaller units (for example, Princess Royal University Hospital, part of the King's College Hospital NHS Foundation Trust) attended the hospital for their annual reviews and Trans-Cranial Doppler scans.

SERVICE FOR ADULTS

Trust/Hospital	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
King's College Hospital NHS Foundation Trust	SHC	600	22	51

Emergency Care

The access to emergency care was via either the haematology day unit or the Emergency Department (ED). The haematology day unit, also referred to as the 'supportive care unit' provided a walk-in service between 9am and 4pm, Monday to Friday. Between one and three patients attended for pain management each day. Non-elective attendances and booked transfusion episodes were managed in the same clinical area but no capacity problems were reported. The ED saw between 30 and 50 patients with sickle cell disease per month with 484 attendances in 2014-15. The specialist haemoglobinopathy team reviewed patients in the ED during working hours. Patients with sickle cell disease were triaged as 'orange' and usually transferred to 'majors' or the resuscitation area if required. The aim was for first analgesia to be administered within 30 minutes of arrival. A knowledgeable and engaged 'link nurse' for patients with sickle cell disease met with the red cell team Clinical Nurse Specialist (CNS) on a regular basis. There was a 'Sickle Cell Disease Crisis Pathway Data Collection Sheet' to record audit data for time to analgesia, whether patients were admitted and if so, to where.

A regular teaching programme for nurses and doctors was in place for the ED.

Patients who required admission between 9am and 5pm were admitted under the haematology team. Out of hours admissions were via the ED under the medical team. The on-call haematology registrar was available for advice and to review patients. Care was transferred to the specialist haemoglobinopathy team on the next working day. This meant that patients admitted on a Friday evening might have to wait until Monday morning for haematology team input. However, this arrangement was under review with a plan for routine review by haematology specialist registrars during evening shifts and on Saturdays and Sundays. The changes were expected to be implemented soon after the visit.

In-Patient Care

The two consultant haematologists (the lead, and a locum) in post at the time of the visit devoted the majority of their combined 20 PAs (programmed activities) to the red cell service. One specialist registrar worked in the red cell service for four months at a time, on the wards, clinics and day care areas, and a core trainee doctor on the team rotated every three weeks.

Two Clinical Nurse Specialists were in place; one led on transition and worked with the young adult patients, and the other focussed more on patients of 25 years of age and above.

The main ward for patients with sickle cell disease was the 16-bedded Elf and Libra ward. About 60% of patients admitted with sickle cell disease could be accommodated here. It contained three bays and five side rooms. Patients were also admitted to the other haematology wards: Davidson, Derek Mitchell Unit and Waddington, as well as some medical wards. The consultant haematologists provided ward cover on a two-weekly rotation. Two full ward rounds took place every week and most new patients were reviewed the day after admission during week days, or sooner as needed. On average eight to ten in-patients with haemoglobin disorders were on the wards at any one time and up to a maximum of 18. In 2014-15 there were 502 in-patient spells. Length of stay data were not available. Ward staffing levels on Elf and Libra were good. It was noteworthy that there was a small fridge on every bedside locker, especially valuable to patients with sickle cell disease for whom plentiful oral fluid intake is a key part of treatment.

Automated red cell exchange was not available out of hours, but manual red cell exchange could be undertaken at any time for emergencies.

Day Unit Care

Haematology day care was provided in the Supportive Therapy Unit which contained three beds, nine chairs and a procedure room. Opening hours were from 8am until 8pm and emergency attendances were seen between 9am and 4pm. Top-up transfusions were carried out in the unit. The area was busy and a little cramped; some general haematology work for example, bone marrows, was also undertaken in the unit.

Automated red cell exchanges were usually undertaken on the Apheresis Unit. A number of other procedures also took place here, for example, stem cell harvests and plasma exchange. On average, seven procedures per day were undertaken at five apheresis stations. The area was in a rather restricted space with little room between stations.

A total of 780 day case episodes were recorded in 2014-15.

Sixty-one patients were on regular transfusions, 52 with sickle cell disease and nine with thalassaemia. Fifty of the patients with sickle cell disease were on automated red cell exchange programmes. Forty patients, 28 with sickle cell disease and 12 with thalassaemia, received iron chelation.

Out-Patient Care

A regular, weekly sickle cell disease clinic was held every Thursday afternoon. This was run by both consultants, one specialist registrar and one core trainee, a clinical research fellow and the CNSs. Thorough clinic preparation by the CNSs allowed easy identification of patients requiring annual review, Pneumovax booster and consent for National Haemoglobinopathy Registry. Care plans were reviewed at each attendance and a new copy was given to the patient with any updates. A second red cell clinic, originally for thalassaemia patients but subsequently including some patients with sickle cell disease and other red cell disorders, was held on Friday afternoons. This clinic was run by one consultant and one registrar. No out of hours clinic appointments were available.

Longstanding and successful joint specialist clinics for patients with renal, liver, or neurology complications took place in the haematology out-patient clinic alongside the sickle cell disease clinic. The pulmonary hypertension clinic also took place in the haematology outpatients but was separate from the sickle cell disease

clinic. Joint orthopaedic and obstetric clinics were held in their respective clinics. Ear, Nose and Throat (ENT) referrals were to the service at Guy's and St Thomas' NHS Foundation Trust (GSST) although acute problems could be managed on site by the maxillo-facial team.

Phlebotomy was available between 8am and 5.45pm on weekdays.

Sixty-five patients with sickle cell disease and less than five with thalassaemia were receiving hydroxycarbamide treatment.

The team did not have a named psychologist working with them. Patients requiring psychology support were referred to GSTT.

Community Based Care

Community haemoglobinopathy services were provided by nurses based at the South East London Sickle Cell and Thalassaemia Centre, managed by GSTT. The service covered Lambeth, Southwark and Lewisham boroughs, Evelina London Children's Hospital, Kings College Hospital and University Hospital Lewisham. Provision was available for antenatal/neonatal screening, home visits, review following discharge and for general health maintenance. Education groups were facilitated.

Views of Service Users and Carers

The visiting team met ten patients with sickle cell disease and a small number with thalassaemia and received feedback from them. The attendees had been phoned by members of the red cell team inviting them to attend.

The visiting team received responses to 51 questionnaires. In addition, the results of a transition survey completed in June 2015 were available. The survey was available for review and included responses from 41 young people, 34 parent/carers and 26 young adults who had previously transitioned to the adult service.

Common themes raised by patients and carers were:

- They were very happy with the overall level of care provided by the red cell haematology team in all parts of the service.
- Several indicated that they did not know who to contact if they had problems or queries between visits, and would appreciate a named 'key contact' with a direct phone contact number. Some patients called the Supportive Care Unit if they had a query, but not all knew this was an option or had the phone number.
- The wait from arrival to start of transfusion on the day case units could be quite long, up to two hours. An audit had been undertaken.
- When admitted, patients sometimes felt they were in a 'holding area' until the red cell team had taken over their care on the next working day. The patients did not feel unsafe over weekends but were reassured when their familiar team returned on Monday morning.
- Most of the concerns expressed related to management in the Emergency Department (ED). Several patients said that, if at all possible, they would try to wait at home overnight until the Day Unit opened, and go there instead. ED was reported to be 'chaotic' and there were sometimes waits in the reception area before triage, then another wait after triage for a cubicle to become available. When the department was busy, they sometimes had to wait in chairs rather than being able to lie down. Even when individualised treatment protocols were in place, there were sometimes unaccountable delays in receiving analgesia. One patient reported calling an ambulance if he had to come in, hoping that he might receive speedier attention this way.
- Attitudes in ED were sometimes also problematic. Some ED doctors and nurses were sympathetic and understood the condition but this was far from universal and some staff appeared to be dismissive and disinterested.

SERVICES FOR CHILDREN AND YOUNG PEOPLE (CYP) UP TO THE AGE OF 19 YEARS

Trust/Hospital	Reviewed as:	No. of CYP with sickle cell disease	No. of CYP with thalassaemia	No. of CYP on long term red cell transfusions
King's College Hospital NHS Foundation Trust	SHC	477	10	39
King's College Hospital NHS Foundation Trust Princess Royal University Hospital	LHT	25		
Dartford and Gravesham NHS Trust Darent Valley Hospital	LHT	60		
Medway NHS Foundation Trust Medway Maritime Hospital	LHT	25		
Brighton and Sussex University Hospitals NHS Foundation Trust Royal Alexandra Children's Hospital	LHT	5		
East Sussex Healthcare NHS Trust Eastbourne District General Hospital and Conquest Hospital	LHT	7		
East Kent Hospitals University NHS Foundation Trust Kent and Canterbury Hospital	LHT	5		
Maidstone and Tunbridge Wells NHS Trust Maidstone Hospital	LHT	7		
Lewisham & Greenwich NHS Trust University Hospital Lewisham	LHT	180-200		
Lewisham & Greenwich NHS Trust Queen Elizabeth Hospital	LHT	370		
Croydon Health Services NHS Trust Croydon University Hospital	LHT	200		

In addition 25 to 30 children also came to the Trust from Norfolk, Plymouth, West Sussex, Kingston, Essex, Morden, Wandsworth, Darent Valley, Medway, Brent and East London. Outreach clinics were carried out in Lewisham, Woolwich and Croydon.

Emergency Care

The paediatric Emergency Department (PED) was separate from the main adult Emergency Department (ED) and treated children and young people up to the age of 16 years. Children beyond the age of 16 years who were in the process of transitioning to adult care could still be seen in the PED. On arrival all patients were triaged by a nurse. Most nurses were paediatric nurses but some were on rotation from the main ED.

The medical assessment and management of patients who presented at the PED were carried out in three streams:

1 Patients managed by the ED doctors. This rota was covered by Foundation Year 2 (FY2) trainees with support from Core Trainee (CT3) doctors and Speciality Training Registrars (StR). They were supported by five ED consultants with sub-speciality accreditation in Paediatric Emergency Medicine who provided consultant cover between 8am and 5pm on weekdays with cover from the general ED consultant on call. There was also one PED nurse consultant. ED staff assessed the majority of patients attending the PED. Exceptions were children under the age of 12 months with medical conditions, those patients referred by their GP to the paediatrician or by other hospitals to other specialities.

2 Patients assessed by the primary care team. GPs were scheduled to provide sessions as part of a co-located urgent care service. The GPs saw children of all ages following triage, if the triage nurse considered that they could be appropriately cared for within the remit of primary care and were unlikely to require speciality investigations or other input.

3 Patients assessed by the paediatric team. Medically unwell children under the age of 12 months were assessed by this team when it was deemed inappropriate for a GP to see them first. They also assessed patients who were referred from the ED staff and GPs for further evaluation. A senior house doctor (SHO) and a clinical fellow were usually based in the ED between 8am and 11pm. They were supported by the PED consultants and paediatric consultants from the Short Stay Unit (until 10pm) and the consultant of the week on-call for the main wards.

Children with sickle cell disease who presented at the PED could be managed in any one of the above streams, depending upon their presentation. A paediatric sickle cell disease clerking proforma was available on the King's Wiki intranet pages (ED KWIKI) which was intended for use by all ED and paediatric doctors in the initial assessment of a child with sickle cell disease. An algorithm for the management of pain in a paediatric sickle cell crisis was available which was updated in 2015 but at the time of the visit was yet to be uploaded onto KWIKI.

Children over 16 years old were assessed on a case by case basis as to whether they would be managed on a paediatric ward (by paediatricians) or an adult ward (by general medicine or adult haematology) if admission was necessary.

In-Patient Care

The main paediatric ward for patients with haemoglobinopathies was the 16-bedded Toni & Guy ward. The 11-bedded Princess Elizabeth unit was chiefly used for patients with surgical problems but also included some children with general paediatric problems. Children could also be admitted to the 18-bedded Hepatology ward, Rays of Sunshine, if they had associated sickle cell disease. The Short Stay Unit (situated next to the ED) was used to admit children who were likely to require less than 48 hours of hospital care.

Children were admitted to other wards including the ten-bedded neurosurgical ward (Lion), the High Dependency Unit (HDU) (eight beds) and the Paediatric Intensive Care Unit (PICU) (16 beds).

All acute exchange transfusions were carried out on the HDU/PICU.

Day Unit Care

The Philip Isaacs unit contained nine spaces with a variety of beds and chairs and catered for children requiring investigations and treatments, such as transfusions that could be completed on a day case basis. It was open between 8am and 6pm, Monday to Friday with one Saturday per month specifically for transfusions. Intermittently, depending on staff availability, the unit stayed open until 8pm, Monday to Thursday.

Out-Patient Care

A paediatric haematology clinic was held weekly on a Tuesday morning with 36 slots available. The clinic was mainly for children with haemoglobinopathies but also included some general haematology cases. Additionally a joint sickle cell disease and neurology clinic was held every three months on a Friday afternoon. A joint sickle cell disease respiratory clinic was held every four months on a Friday afternoon. Extra Friday afternoon clinics were booked if there was a backlog of appointments. Annual reviews for children receiving regular blood transfusions were held on a Monday afternoon.

Community Based Care

Community based haemoglobinopathy services were provided by nurses based at the South East London Sickle Cell and Thalassaemia Centre, managed by GSTT. The service covered Lambeth, Southwark and Lewisham boroughs, Evelina London Children's Hospital, King's College Hospital and University Hospital Lewisham. Provision was available for antenatal/neonatal screening, home visits, review following discharge and general health maintenance. Education groups were facilitated.

Views of Service Users and Carers

The visiting team met a small number of patients and carers with both sickle cell disease and thalassaemia and received feedback from them. They received responses to 51 questionnaires. In addition, the results of a transition survey (completed June 2015) which included responses from 41 young people, 34 parent/carers and 26 young adults who had previously transitioned to the adult service was available for review. Patients thought that a texting service to let people know about the review would have been good.

Common themes raised by patients and carers were:

- Overall, complimentary feedback about the service and staff.
- There was much praise for the acute nurse specialist and community nurses.
- Parents and young people were appreciative of the monthly support group and nursing input.
- The needs of adolescents were well met.
- Young people were keen to have more information about the transition process.
- Young people were keen to meet the adult team and valued a joint clinic.
- Parents/carers remained actively involved in patient care and valued the transition handbook and information leaflets.
- Parents reported difficult experiences in the Emergency Department particularly with care plans not being available and staff not appreciating their concerns. They were keen for an emergency services - specific survey especially as the same concerns has been raised at the first review visit three years previously.
- Parents were keen to receive more frequent updates particularly when there was a potential delay with blood availability. They were keen for communication to improve and for a tracking system to be introduced.

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REVIEW VISIT FINDINGS

NETWORK

General Comments and Achievements

The South East London network encompassed Guy's and St Thomas' NHS Foundation Trust (Guy's), King's College Hospital NHS Foundation Trust (King's) as specialist haemoglobinopathy centres. Accredited Haemoglobinopathy Teams were based in Croydon Health Services NHS Trust and Lewisham and Greenwich NHS Trust. In addition the network had other linked hospitals. Evidence was available for clinical collaboration, patient stakeholder meetings and access to research across the network.

This was a well organised and functional network offering good links to highly specialised services. Relationships between the various parties were strong. A particularly notable and well-attended education programme was in place with sharing of expertise and good practice. Guidelines and patient information had been widely shared across the wider South Thames region.

Progress since Last Visit

This was the first peer review for children's services since 2010 and the first visit for adult services since 2012. Since the last visits a network administrator had been appointed based at King's who had responsibility for the collection of data for the network and for arranging meetings. A monthly tertiary outreach clinic was established between King's College Hospital and Croydon University Hospital. Transcranial Dopplers and annual reviews were undertaken at the tertiary clinic, attended by the lead paediatrician and a paediatric haematologist from King's.

Good Practice

1 Regular network meetings were in place and pathways for referral of complex cases into a range of specialist clinics were clear.

2 Strong informal clinical and educational links existed between the centres.

3 An excellent newsletter for patients and relatives contained information on services and articles of interest about developments in therapy and research.

4 A network website had been developed, as had patient conferences.

5 An outreach paediatric psychology service was established through King's College Hospital providing support to local patients at the Sickle Cell and Thalassaemia Community Centre in Croydon.

Immediate Risks: No immediate risks were identified.

Concerns

1 Formal engagement with the commissioners in defining the network and inter-relationships between the hospitals had not yet taken place.

Further Consideration

1 Although the pathways to relevant specialist services were in place further work was required to define more clearly the criteria used to decide which patients should be referred to which specialist service.

2 It will be important for the paediatric team at Croydon University Hospital to work collaboratively with the other local teams to ensure that the excellent work undertaken is maintained.

NETWORK CONFIRGURATION

The network configuration at the time of the review was as follows.

Specialist Haemoglobinopathy Centre	Accredited / Local Haemoglobinopathy Teams
Guy's and St Thomas' NHS Foundation Trust:	• Dartford and Gravesham NHS Trust
	• East Sussex Healthcare NHS Trust
	• Medway NHS Foundation Trust
	• Queen Victoria Hospital NHS Foundation Trust
	• Frimley Health NHS Foundation Trust
	• West Hertfordshire Hospitals NHS Trust
	• East Kent Hospitals University NHS Foundation Trust
	• Croydon Health Services NHS Trust (Croydon University Hospital, Adults): Accredited Local Haemoglobinopathy Team (Adults)
	• Lewisham and Greenwich NHS Trust: Accredited Local Haemoglobinopathy Team (Adults and Children)
King's College Hospital NHS Foundation Trust:	• Maidstone and Tunbridge Wells NHS Trust
	• Western Sussex Hospitals NHS Foundation Trust
	• Brighton and Sussex University Hospitals NHS Trust
	• East Sussex Healthcare NHS Trust
	• Medway NHS Foundation Trust
	• Croydon Health Services NHS Trust (Croydon University Hospital, Paediatric)

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SPECIALIST TEAM: KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST – ADULT SERVICES

General Comments and Achievements

This was a large, well established service, which worked well and was highly appreciated by its users. Patients reported excellent care both from the consultants and the clinical nurse specialists. They felt that staff understood their condition and its treatment and were both approachable and helpful. Multidisciplinary care in the out-patient setting was excellent, with input from a range of highly specialist consultants working alongside the Red Cell Team. The need for some patients to attend frequently did not appear to be a problem.

Progress since Last Visit

One of the main concerns identified in February 2013 was staffing levels. Since that visit an additional NHS consultant post had been established in April 2015 and a locum was in post. An additional 1.6 w.t.e. clinical nurse specialist time had been secured. A business case to the Roald Dahl Charity for a nurse specialist to support young adults had been approved. Further nursing capacity in apheresis and data management support had also been approved although, at the time of the visit, data management was still being undertaken mostly by senior clinical staff. A business case had been submitted for a clinical psychologist for the service.

Other progress included the extension of opening hours on the day unit for elective transfusions and an increase in joint/multi-disciplinary clinics for neurology and obstetrics respectively.

Good Practice

1 The many 'shared clinics' with specialists in renal medicine, hepatology, orthopaedics and others worked well and were appreciated by patients.

2 An updated sickle cell disease pain guideline was clear and good, giving details of what to offer patients who did not have an individualised protocol.

3 The CNSs spent time before each clinic preparing the records, so it was easy to identify who needed annual review, Pneumovax or entering onto the National Haemoglobinopathy Registry. Care plans were reviewed with each patient at each attendance and patients were given a copy of the updated version.

4 The sickle cell disease link nurse in the Emergency Department was engaged and knowledgeable, and met regularly with the CNS, so that communication between the two teams worked well.

5 A 'drop-in' pain management service was available on the Support Unit during normal hours. This was appreciated, and not over-used, indicating good management.

6 There was a fridge on the bedside locker of every ward bed.

7 Pneumovax was available for immediate administration in clinic.

8 The network review and learning meetings appeared to be excellent.

Immediate Risks: No immediate risks were identified.

Concerns

1 At the time of the visit, there was no psychologist working with the team. A business case had however, been prepared.

2 Small parts of the content of the chelation guideline were not in line with the current international 'consensus statement' guidance, namely the treatment of cardiac failure in patients with thalassaemia and iron overload.

Further Consideration

1 A named 'key contact' did not appear to be allocated to the patients, who reported being uncertain who to contact with queries.

2 Evidence in audits during the 2013 haemoglobinopathy disorders review showed that 52% of the patients had received analgesia within the appropriate timeframe. Two audits presented to the review team both had similar figures and had not changed significantly. Also patients were not happy with their management in ED, reporting some long delays to analgesia and unsympathetic attitudes at times. Several stated that they preferred to wait at home until the day support unit opened, others called an ambulance knowing that they might otherwise have waited an undue time until they were seen and treated.

3 Patients admitted through ED over weekends remained under the care of the acute medical team until Monday morning, and reported feeling that they were just being 'held' until specialist input could optimise their care. A system of review by the haematology team during evening shifts and on Saturdays and Sundays was planned but was not yet in place.

4 Guidance for the management of thalassaemia patients was found in sections of different guidelines / the operating policy. Relevant elements were therefore rather scattered and not easy to find. Consideration should be given to pulling them together into a single thalassaemia clinical guideline which could be used across the network. The guideline on fever and sepsis in thalassaemia could be reviewed to include splenectomised patients and the risk of pneumococcal infection. Information for patients with thalassaemia, and for primary care colleagues, was also sparse.

5 Out of hours out-patient clinic appointments would be appreciated by patients in full time education or work.

6 Senior clinical time was inappropriately spent on data management and entering patients onto the National Haemoglobinopathy Registry.

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SPECIALIST TEAM: KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST - PAEDIATRIC SERVICE

General Comments and Achievements

This was an excellent, well organised and structured service. The team was cohesive and there were strong working relationships between the core members of the team, the community and other allied health professionals. A pro-active approach to patient management was reflected in the high usage of hydroxycarbamide and lower admission rate compared to the national average. The department had a strong commitment to research with an admirable publication record. Collaboration with the Camberwell School of Arts had helped facilitate the development of innovative educational tools for patients, parents and carers to help improve understanding of the conditions.

Progress since Last Visit

Good progress had been made since the last review of services in May 2010 including greater provision of services on the Day Unit. The appointment of a transition nurse had increased engagement with adolescents. The opening of a short stay ward with consultant paediatrician presence until 10pm had helped with bed flow and reduced the need to transfer patients to other sites. Community care had improved following a comprehensive review of services. A proactive clinical nurse specialist counsellor in the community had helped dramatically to reduce 'did not attend' (DNA) rates and a welfare advisor was available to families.

A new paediatric haematology consultant post had been approved and an appointment made. Robust arrangements for psychology support were in place and the banding of the post had been upgraded.

The new electronic records system was functional and allowed for good record keeping.

Most children's details were entered on the National Haemoglobinopathy Registry and comprehensive annual reviews for children on long-term transfusions were in place.

Good documentation of mandatory training, including safeguarding, was in place.

Good Practice

1 The transition package was of a good standard and in particular:

   a. use of a check list was noted to be very useful

   b. a detailed patient/parents/carer survey had been analysed and a plan of action initiated.

2 School care plans were structured and functional.

3 Use of an annual report detailing the activity, challenges and work plan for the children and families of patients with sickle cell disease and thalassaemia was enhanced by involving psychology services.

4 The joint specialist clinics (neurology, neurosurgery, respiratory) were multidisciplinary and worked well.

5 The outreach clinics incorporated clinical assessment and Transcranial Doppler (TCD) scanning for all patients.

6 Presence of a senior nurse practitioner out of hours and use of the national early warning score aided early detection of deteriorating patients.

Immediate Risks: No immediate risks were identified.

Concerns

1 Specialist clinical nursing support was insufficient for the needs of the service (only 1 w.t.e.) and cover for absences was not available.

Further Consideration

1 The ED initial assessment arrangements were complicated, appeared inefficient and impacted on patient and carer satisfaction. This resulted in poor compliance with NICE guidance to ensure time to analgesia of 30 minutes. Nearly a quarter of children (24%) waited for more than 1 hour for the first dose of analgesia. Consideration should be given to standardising this pathway particularly with early involvement of a senior clinical decision maker.

2 Expanding patient numbers at local centres was impacting on capacity. Proactive involvement of the core team in supporting local centres with outreach clinics was also likely to impact on workload generally. Consideration should be given to reviewing resources across the network to accommodate this increasing workload.

3 There was no administrative support for data collection and entry. Reviewers suggested that the appointment of a dedicated administrator should be considered.

4 Robust arrangement for documenting training and competence assessment should be considered for ED training.

5 Robust arrangements for audit data collection and review should be considered.

6 Although the TCD scanning service was well established and an accredited training centre, the operational policy did not stipulate a formal process for quality assurance.

7 Although use of national and international guidance for thalassaemia and chronic complications of sickle cell disease was in place, the network may benefit from agreement around the use of these guidelines and more locally relevant guidelines. National and international guidelines should be cross-linked and referenced from local guidelines.

8 In contrast to sickle cell disease, little patient information was available for patients with thalassaemia. Consideration should be given to using resources available elsewhere.

9 A recent audit of pain management in ED identified most children (74%) only required simple analgesia when assessed in ED. In the year 2014/15 there were 316 ED attendances but only 44 children were admitted to hospital. Consideration should be given to addressing educational elements of health maintenance and self-care to avoid unnecessary usage of the ED.

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COMMISSIONING

The reviewers met with the commissioner for London and a public health representative. At the time of the review the structure of the responsible commissioning team was changing. The specialist commissioner was aware of the configuration of the network but had not formally described the services nor reviewed any agreements between centres. There had been involvement by public health in screening review of deaths. Sickle cell disease had been highlighted in the most recent Joint Health Strategic Needing Assessment (JHSNA) and there was interest in reflecting any epidemiological changes and inequalities in the local actions.

Immediate Risks: No immediate risks were identified.

Further Consideration

1 Although King's College Hospital NHS Foundation Trust was considered to be functioning as a SHC no formal designation had been made. Enhanced tariffs had been agreed in the past through local commissioning to support aspects of the service for the wider network.

2 Commissioner representation at network meetings had been absent since April 2013. The formation and management of the networks was led by the King's College Hospital NHS Foundation Trust team in conjunction with Guy's and St Thomas' NHS Foundation Trust.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Lead/s:

Dr Banu Kaya (paediatric lead)	Consultant Haematologist	Barts Health NHS Trust
Dr Anne Yardumian (adult lead)	Consultant Haematologist	North Middlesex University Hospital NHS Trust

Visiting Team:

Jon Currington	Head of Tertiary Partnerships	University Hospitals of Leicester NHS Trust
Dr Corrina McMahon	Consultant Haematologist	Our Lady's Children's Hospital, Dublin
Lurieteen Miller	Service Coordinator	Birmingham Community Healthcare NHS Trust
Gabriela Oguntoye	Clinical Nurse Specialist	Barts Health NHS Trust
Siobhan Westfield	User reviewer	
Julie Ravenhall	Acting Assistant Director, Specialist Services	Birmingham Community Healthcare NHS Trust
Dr Elizabeth Rhodes	Consultant Haematologist	St George's University Hospitals NHS Foundation Trust
Sekayi Tangayi	Service Manager / Nurse Lead and Specialist Nurse	East London NHS Foundation Trust

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varied depending on the nature of the service provided. Percentage compliance also takes no account of 'working towards' a particular Quality Standard. Reviewers often comment that it is better to have a 'No, but', where there is real commitment to achieving a particular standard, than a 'Yes, but' – where a 'box has been ticked' but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Adult Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	44	34	77
Haemoglobin Disorders Clinical Network	9	6	67
Commissioning	3	0	0
Total	**56**	**40**	**71**
Service for Children and Young People	**Number of Applicable QS**	**Number of QS Met**	**% met**
Specialist Services for People with Haemoglobin Disorders	50	41	82
Haemoglobin Disorders Clinical Network	9	6	67
Commissioning	3	0	0
Total	**62**	**47**	**76**

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

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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		Y	However information relating to staff (d) did not define role/title. Information relating to ward opening times (c) 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-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		Y	However general information on the thalassaemias was limited.

		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	Y		Y	However information relating to 'b', 'c' and 'e' was unavailable for paediatric sickle cell disease, although GPs in the area were not involved in prescribing hydroxycarbamide. Information for primary health care teams on thalassaemia was limited. See main report.
HN-104 All	**Care Plan** All patients should be offered: a. An individual care plan or written summary of their annual review including: i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).	Y	The patients who met the review team noted that they did not know who to contact. The care plans were extensive and of a good standard. See good practice section of the main report.	Y	Information relating to named contact 'a, iv' 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-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	The school care plans were of a high standard. See good practice section of the main report.
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 transition package was generally of a good standard. The transition 'check list' was particularly good. See good practice section of the main report.

		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	Information relating to 'c' was not available.
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	Overall there was much evidence of patient and carer feedback, however action plans following some of these surveys were incomplete.

		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	Supporting documentation of job plan and appropriate time allocation was not available for review.
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y		Y	The named locum consultant was listed in the operational policy as providing cover for the lead.

		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	No lead nurse job plan/job description was available for review and RCN competences were not documented.	Y	

		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.	N	At the time of the review there was no specialist routine 'out of hours' review of admitted patients and there was no psychologist with an interest in haemoglobin disorders to support adult patients. Demonstration of nursing competences was not seen.	N	Specialist clinical nursing support was insufficient for the needs of the service (only 1 w.t.e.) and cover for absences was not available.
HN-205 All	**Competences and Training** A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).	Y		Y	

		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.	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	The programme of training was seen for adult ED nursing staff. Medical staff training was described although not evidenced.	N	Demonstration of regular training was not available.
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	Haematology specialist registrar trainees spent four months working in the haemoglobinopathy service, on wards, and in day care clinics.	Y	

		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		Y	Formal log books documenting annual scanning data were not available at the time of the review. Information relating to total annual scans available for the six sonographers was available. Four of these had undertaken at least 40 scans for 2014/2015).
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	There was no provision for administrative support especially in regard to data management. Entries on to the National Haemoglobinopathy Registry were being undertaken by senior clinical staff.	N	There was no provision for administrative support, especially in regard to data management. Entries on to the National Haemoglobinopathy Registry were being undertaken by senior clinical staff.

		Adult Service		Service for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-301 All	**Support Services** Timely access to the following services should be available: a. Psychologist with an interest in haemoglobinopathies b. Social worker c. Leg ulcer service d. Play specialist (children's services only) e. Chronic pain team f. Dietetics g. Physiotherapy h. Occupational therapy i. Mental health services (adult and CAMHS) In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.	N	A psychologist with an interest in haemoglobinopathies was not in post at the time of the review.	Y	All services were available except for chronic pain but this is an uncommon complication in childhood.
HN-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	Y		Y	

		Adult 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.	Y	There was no named clinician / contact number for a Neurologist but there was evidence of a joint clinic. ENT was available within the network.	Y	

		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	However on the whole facilities were cramped.	Y	
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	N	Out of hours out-patient clinics were not available.	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	N	The local transition guidelines in use were of a good standard, particularly the use of the survey for 'b' (see Good Practice section of the main report). However there were no network-agreed guidelines. Monitoring arrangements (f) were unclear.	N	The local transition guidelines in use were of a good standard, particularly the use of the survey for 'b', (see Good Practice section of the main report). However there were no network-agreed guidelines. Monitoring arrangements (f) were unclear.
HN-502 All	**Monitoring Checklists** Checklists should be in use for: a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) Use of the checklists should cover both clinical practice and information for patients and families.	Y	However, in the adult guideline, there appeared to be no section on treatments to offer in ED, on Day Care or taken at home. Also, the thalassaemia Out-patient Department guideline lacked focus on the importance of chelation treatment and adherence.	Y	.

		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/A	
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Offering access to exchange transfusion to patients on long-term transfusions c. Protocol for carrying out an exchange transfusion d. Hospital transfusion policy e. Investigations and vaccinations prior to first transfusion f. Review by specialist nurse or doctor prior to transfusion to ensure each transfusion is appropriate. g. Areas where transfusions will usually be given h. Recommended number of cannulation attempts	Y	However guidelines for adults with thalassaemia were not found in the transfusion sections; they were found in the operational policy. A further consideration is to pull all the guidance relating to thalassaemia care into one guideline (see the main report).	Y	

		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.	N	These guidelines required an update in line with current recommendations, specifically in regard to when referral to Cardiology should be considered and recommendations for managing heart failure in thalassaemia patients with iron overload, American Heart Association consensus statement 2013. Information relating to (g) was unavailable.	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	Y	In the guidelines no mention was found of splenectomised patients and the risk of pneumococcal disease for thaassaemia. Overall, guidelines may benefit from review to ensure they are more junior doctor-friendly. The adult acute pain guidelines were very good. See good practice section of the main report.	Y	However, information relating to acute renal failure 'h', haematuria 'l', and acute changes in vision 'j', was unavailable.
HN-507 All	**Specialist Management Guidelines** Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia: a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy	N	Network-agreed guidelines for paediatric and adult thalassaemia at the time of the visit were not available.	N	Network-agreed guidelines for paediatric and adult thalassaemia at the time of the visit were not available.

		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	However further consideration should be given to local and network guidelines for managing adults and paediatric patients with thalassaemia.	Y	
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	Y		Y	
HN-510 All	**Thalassaemia Intermedia** Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy	Y	Indications for splenectomy were not seen in the adult guideline.	Y	However a local or network specific policy was not in place for the paediatric service. See main report.

		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		N	The international guidelines in use for paediatric thalassaemia management and chronic complication management for sickle cell disease, although available on the internet, were not easily linked through local guidelines. Paediatricians were not aware of these guidelines.

		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		Y	The centre has much experience in Trans-Cranial Doppler (TCD) scanning. However evidence of 'j' was limited, and 'k' was not applicable.

		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 robust process for ensuring all patients were seen by a senior decision maker ('b') during weekends was not in place. There was no provision for out of hours transfusion ('d'). See further consideration section of the report. There were no out of hours out-patient clinic appointments.	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).	Y		Y	
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N	Although an appendix outlining levels of care was seen, a formal service level agreement was not available for review.	N	Although an appendix outlining levels of care was seen, a formal service level agreement was not available for review.
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.**).	Y		Y	Well-structured and attended network meetings were evident. See good practice section of the report.
HN-605 SHC	**Neonatal screening programme review meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	N/A		Y	

		Adult 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.	Y		Y	Most patients were registered, although it was noted that this required the time of senior clinicians to enter data.
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	However these data was incomplete, and related only to King's College Hospital activity.

		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	A robust process of data collection was not in place. Only Kings College Hospital data were provided and not all results were available.	N	A robust process of data collection was not in place.

		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	Y	Most of the audits had been undertaken although some were on a small sample size for example, time to analgesia and for thalassaemia, evidence presented was not of an audit, but a spreadsheet of patients with their iron results.	Y	However data were unavailable for 'e'. See further consideration section in the report.

		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.	Y		Y	
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	A strong ongoing commitment to research was apparent.	Y	An extensive programme of research was in place with an impressive publication record.
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	Although the reviewers were given access to the Trans-Cranial Doppler (TCD) scanning guideline, results of internal quality assurance ('b') and fail safe arrangements ('d') were not seen. 'c' was not applicable.

		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	An appropriate investigation had been completed for one serious adverse event, with 10 of the 11 actions completed.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	Y	Evidence of support for user events across the network was provided.	Y	Evidence of support for user events across the network was provided.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	Y		Y	
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-204 and HN-205.	Y		Y	An extensive and robust programme of education was evident.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	Good local guidelines were in place however formal network agreements were not defined.	N	Good local guidelines were in place however formal network agreements were not defined.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HY-502	**Clinical Guidelines** Network guidelines should have been agreed covering: a. Annual review (QS HN-502) b. Routine monitoring (QS HN-503) c. Transfusion (QS HN-504) d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303) g. Specialist management (QS HN-507) h. Thalassaemia intermedia (QS HN-510) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.	Y	The extent to which the guidelines had been adopted across the network was not clear.	Y	However differing guidelines for thalassaemia (local / international) were being used within network. The network would benefit from clarification of referral pathways for paediatric patients. Local and network guidelines for managing chronic complications in children with sickle cell disease could be considered. Also consideration should be given to local and network guidelines for managing paediatric patients with thalassaemia.
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	Network data were not yet monitored.	N	Network data were not yet monitored.

		Adult Services		Services for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HY-702	**Audit** The network should have an agreed programme of audit and review covering network-wide achievement of QSs HN-703, HN-704, HN-705 and HN-707.	N	However a preliminary audit programme was in place.	N	However a preliminary audit programme was in place.
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.	Y	A network research policy was in place. Both Croydon and Lewisham had access to trials via the network.	Y	Evidence of collaborative research was provided.
HY-798	**Network Review and Learning** The SHC should meet at least twice a year with its referring LHT teams to: a. Identify any changes needed to network-wide policies, procedures and guidelines b. Review results of audits undertaken and agree action plans c. Review and agree learning from any positive feedback or complaints involving liaison between teams d. Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams e. Consider the content of future training and awareness programmes (QS HY-202).	Y		Y	

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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	No formal designation of King's College Hospital NHS Foundation Trust as a SHC had been made though it was considered to be functioning as one. Commissioners reported that no additional funding was available to support the SHC role, though enhanced tariffs had been agreed in the past through local commissioning to support aspects of the service for the wider network.	N	No formal designation of King's College Hospital NHS Foundation Trust as a SHC had been made though it was considered to be functioning as one. Commissioners reported that no additional funding was available to support the SHC role, though enhanced tariffs had been agreed in the past through local commissioning to support aspects of the service for the wider network.
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	No formal meetings had taken place.	N	No formal meetings had taken place.

		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	The commissioners were not actively engaged in the Network review and learning meetings.	N	The commissioners were not actively engaged in the Network review and learning meetings.

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