WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

South London Network

Croydon Health Services NHS Trust

Visit Date: 22nd October 2015

Report Date: March 2016

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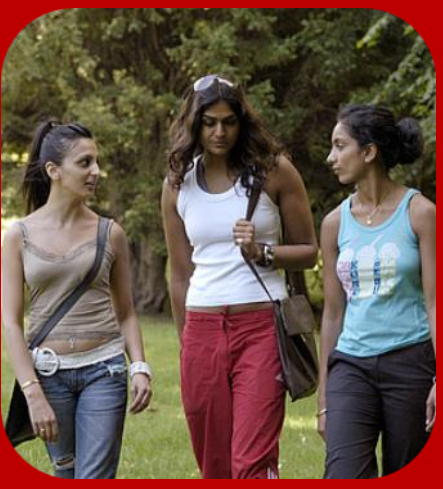

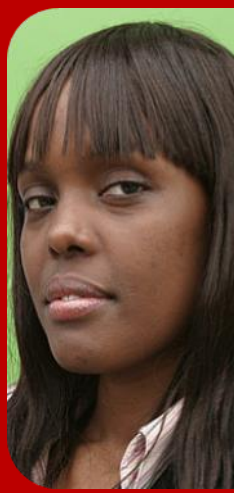

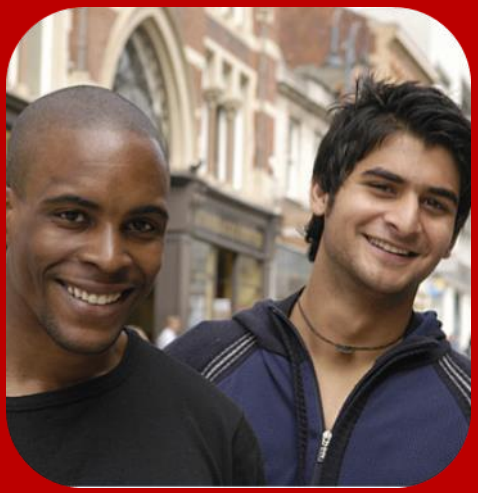

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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Croydon Health Services NHS Trust (part of the South London Network), which took place on 22nd 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:

- Croydon Health Services NHS Trust
- NHS England Specialised Commissioning
- NHS Croydon 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 Croydon Health Services NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the users and carers who took time to come and meet the review team. Thanks are also due to the visiting team (Appendix 1) and their employing organisations for the time and expertise they contributed to this review. The NHS Sickle Cell and Thalassaemia Screening Programme funded this peer review programme.

About West Midlands Quality Review Service

WMQRS is a collaborative venture between NHS organisations in the West Midlands to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews - often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved. More detail about the work of WMQRS is available on www.wmqrs.nhs.uk

HAEMOGLOBIN DISORDERS SERVICES IN SOUTH EAST LONDON NETWORK

At the time of the visit Croydon Health Services NHS Trust (CHS) was part of the South London Network. It was reviewed as an Accredited Local Haemoglobinopathy Team for adult services and as a local team for paediatric services. Strong links were in place with the specialist haemoglobinopathy teams at Guy's and St Thomas' NHS Foundation Trust (Guy's), King's College Hospital NHS Foundation Trust (King's) and to a lesser extent, St George's University Hospitals NHS Foundation Trust. Patients from Croydon accessed specialised services and elective red cell exchange in these centres. Clear referral pathways were in place for tertiary sub-speciality referrals within the network. The team at CHS regularly attended educational meetings hosted by the South Thames Sickle Cell and Thalassaemia Network (STSTN). The network functioned well, and including for discussion of difficult cases. Access to specialist multi-disciplinary team meetings was easily available, for example, neuro- vascular meetings.

Adults

Trust	Reviewed as:	No. adults with sickle cell disease	No. adults with thalassaemia	No. adults on long term red cell transfusions
Croydon Health Services NHS Trust	Accredited Local Haemoglobinopathy Team	150	8	<5

Children and Young People

Trust	Reviewed as:	No. children with sickle cell disease	No. children with thalassaemia	No. children on long term red cell transfusions
Croydon Health Services NHS Trust	Local Haemoglobinopathy Team	245	<5	<5

EMERGENCY CARE

Adult patients with haemoglobinopathies requiring admission were admitted via the Emergency Department (ED). Patients presenting with acute sickle cell crisis were triaged as '2' and taken to the resuscitation area for initial evaluation and administration of analgesia. Patients were admitted to either the Acute Medical Unit or directly to the designated haematology Duppas Wards, depending on bed availability. They were reviewed by the duty medical team and subsequently referred to the haematology team who took over their care. Twenty-four hour haematology advice was provided by the on-call haematologist. The critical care outreach team reviewed unwell patients. Access to on-site high-dependency unit and intensive treatment unit facilities was available.

Paediatric patients were triaged and proceeded straight through to the paediatric ED area. They were seen by the paediatric team unless they met the criteria for admission to the resuscitation area. The patient was seen by a middle grade ED doctor if the paediatric team was delayed. If admission was required patients were admitted directly to the paediatric Rupert Bear Ward.

Between January and September 2015 a total of 160 adult and 111 paediatric patients with sickle cell disease attended the ED.

IN-PATIENT CARE

Adult patients with sickle cell disease admitted with painful crisis or other sickle-related complications were cared for in either the Acute Medical Unit or the Duppas 1 and 2 Wards. The Acute Medical Unit had six 'six bed' bays and six side rooms. Duppas 1 Ward had three 'six bed' bays and three side rooms and Duppas 2 had a single 'six bed' bay and two side rooms. Patients with haemoglobin disorders (mainly sickle cell disease) were managed under the care of the haematology team. The specialist nurses reviewed patients daily during their admission. Patients requiring admission for non-haemoglobinopathy-related problems were cared for by the corresponding team in the relevant wards such as renal, orthopaedic, surgical and maternity, with haematology input and daily reviews by the haematology team.

Paediatric in-patients with sickle cell disease were admitted to Rupert Bear Ward under the care of the paediatric consultant of the week, ward registrar and ward nurses. The sickle cell disease and thalassemia nurse specialist leading in paediatric care performed regular ward rounds and reviewed in-patients.

From January to September 2015 134 adults and 71 children with sickle cell disease were admitted to Croydon University Hospital (CUH).

DAY CARE

Adults and young people with haemoglobinopathies received regular and ad hoc top-up transfusions and manual exchange transfusions via peripheral access in the Lifeblood Suite haematology day unit. Consultations and clinical reviews were undertaken as needed by the haematology consultants, middle grade or junior doctor. The unit was undergoing expansion and major refurbishment and was expected to be operating in the new setting from the end of October 2015. The new unit had plans for two bays, one with seven chairs, as well as two procedure rooms.

Children with sickle cell disease who were on regular transfusions were managed in the Dolphin Unit which was staffed by paediatric trained nurses. Pre-transfusion blood samples were taken by the nurses in the community children's 'hospital at home' team or by paediatric phlebotomy in the Willows out-patient area. The sickle cell clinical nurse specialists arranged the transfusion dates and pre-transfusion phlebotomy. Blood was prescribed by the consultant paediatrician or duty paediatric consultant of the week. For any concerns during transfusion the duty paediatric registrar was available.

OUT-PATIENT CARE

Adult haemoglobinopathy patients were regularly reviewed at the main out-patient department by the haematology team, consisting of four consultants, a senior specialist registrar, a specialty doctor and a nurse consultant. Four haematology clinics were held on Tuesday mornings and five on Wednesday mornings. Another clinic was held on a Wednesday afternoon with four more on Friday mornings. The haematology out-patient clinics offered 22 new patient slots and 117 follow-up patient slots per week. In addition, the haemoglobinopathy nurse specialist for adults held a twilight clinic in the main Out-patient Department monthly on Mondays from 5pm to 8pm. Consultations were offered to patients with sickle cell disease and patients on hydroxycarbamide were monitored. Consultations of couples at risk of having a child with haemoglobin disorders took place on a weekly basis at the Sickle Cell and Thalassemia Centre and were organised by the haemoglobinopathy nurse specialist leading on antenatal screening.

The lead consultant was a neonatologist who also did haemoglobinopathy work. Outreach clinics took place every month where a consultant paediatric haematologist attended from Kings College Hospital accompanied by a vascular scientist to undertake transcranial Doppler scans. All children with sickle cell disease had regular follow-up appointments and annual reviews in the Willows. A consultant-led sickle cell disease clinic was held on four out of six weeks, with the clinical nurse specialist in attendance. A supervised paediatric registrar saw patients in some clinics. A paediatric phlebotomist was available during clinic sessions.

COMMUNITY-BASED CARE

Community care was based at the Sickle Cell and Thalassemia Centre which was part of the Trust. The three sickle cell and thalassemia nurse specialists held consultations with patients, carers and couples at risk of having a child with haemoglobin disorders. The specialist nurses also visited patients and carers in their homes when appropriate. The sickle cell support group held regular meetings at the centre involving, supporting and educating people with sickle cell disease and thalassaemia.

VIEWS OF SERVICE USERS AND CARERS

The visiting team met ten patients and carers with sickle cell disease or thalassaemia and received feedback from them. This included a senior representative from the local support group. The visiting team received responses to 11 haemoglobinopathy-specific questionnaires and viewed 30 'friends and family' survey responses.

All the patients and carers actively and enthusiastically contributed to the conversations based on their own experiences and that of family members. The reviewers also met additional patients on the ward. Although feedback about the lead consultants and specialist nurse was positive the users also discussed some of the problems they perceived with services.

Common themes raised by patients and carers were:

- Overwhelming praise for the nursing and medical teams for their dedication to the welfare of the patients and their easy accessibility.
- Almost all present reported that they had had poor experiences in the ED although some aspects had improved prior to the review visit. Possible causes were felt to be rapid turnover of staff, many of whom seemed unfamiliar with sickle cell disease. Despite having protocols and guidelines in place, the doctors did not appear to use them. Patients and carers felt that sometimes there was a little stereotyping of patients by ED staff linked to regular attendance and the use of pain relief medication.
- Patients supported the model of a day unit to bypass the ED. Patients felt they knew their condition so well that, when having a crisis, the opportunity to go straight to a day unit with staff experienced in treating haemoglobinopathies would improve services for example, access to a strong painkiller to ease the pain.
- Patients and carers were unaware of the availability of paediatric psychology support services. It was possible to access services at King's. The parents present thought that such services would be useful for their children but said they had not been made aware of the service.
- Patients welcomed the flexibility of transfusion appointments but expressed a view that even more flexibility, such as weekend access, would be helpful.
- The adult clinical nurse specialist was highly valued by the patients. Her presence was considered vital to the effectiveness of the service.
- Some of those present did not known about the paediatric to adult transition service provided by the team.
- The support group representative brought along the hospital packs provided by them for adults and children on the ward. The packs were excellent and included toiletries and other useful things. It was evident that some of those present had received packs at various times over the years from the support group. Funds were raised locally to source the packs and it was recognised as a valuable service by patients and carers. The reviewers thought the local support group should be commended for working with the Trust and patients and carers in such a helpful way.
- From the thirty 'family and friend' responses received in January 2015, 27 responded as 'highly likely' and two responded 'likely' to refer their family and friends to the haemoglobinopathy service. One

respondent 'did not know' whether they would do so. Patterns for February and March 2015 were similar.

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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 although the first visit for adult services took place in 2012. Since the last visit in 2012 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. Croydon Health Services NHS Trust was reviewed as an Accredited Local Haemoglobinopathy Team (A-LHT) for adult services. Lewisham and Greenwich NHS Trust was also an A-LHT within this network.

Specialist Haemoglobinopathy Centre	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)
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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ACCREDITED LOCAL TEAM: CROYDON HEALTH SERVICES NHS TRUST – ADULT SERVICES

General Comments and Achievements

A large population of patients were cared for by a small, highly motivated and well-led team. Many of the individuals worked above and beyond core requirements to ensure high standards and continuity of care. The visiting team was impressed by the passion and enthusiasm demonstrated for this service.

Progress since Last Visit

Significant progress had been made since the last visit which took place in 2012. The annual review process had been updated with the adoption of a new annual review form in accordance with the National Haemoglobinopathy Registry (NHR) requirements. Improvements in data entry onto the NHR and reporting of annual reviews and adverse events had been achieved.

Clear referral pathways for specialist input to the care of haemoglobinopathy patients within the South East London Network had been developed and implemented.

Well-organised teaching for nurses and doctors was offered. A designated slot at the nurse induction programme for teaching on sickle cell disease was allocated. A rolling teaching programme of 30 minutes daily for five days every three months was provided for staff in the ED, Acute Medical Unit (AMU) and Duppas Wards as well as for midwives. Teaching on sickle cell disease was offered including to foundation year doctors during their training day.

Link nurses were designated in wards where patients with sickle cell disease were receiving care. Teaching, training and regular meetings took place with the haemoglobinopathy nurse specialists to ensure the Royal College of Nursing competences were achieved. Link nurses attended the haemoglobinopathy team meetings.

A good range of high quality patient information of a high quality was available.. The patient leaflet regarding the Croydon service was particularly good.

Good Practice

1 Although there was a lead consultant, all four haematologists within the adult service took part in the care of patients, ensuring high levels of experience across the department in and out of hours.

2 Reviewers were impressed with the contributions which link nurses were making to education and training of other staff.

3 The service had an innovative approach to declining levels of junior doctors through upskilling of senior ward staff and ED paramedics enabling them to widen their roles. Consideration was being given for nurses on Duppas ward to receive training to undertake out of hours exchange transfusion in patients who required this intervention. The haematology on-call doctor or the clinical nurse specialists performed out of hours exchange blood transfusions if needed.

4 An excellent welfare advice service was available at the Community Sickle Cell Centre.

5 A strong culture of governance was evident, for example, Trust information systems allowed identification of patients attending the ED on a regular basis which in turn prompted multi-disciplinary team discussion of these patients.

Immediate Risks: No immediate risks were identified.

Concerns: No concerns were identified.

Further Consideration

1 Guidelines were available for all the required indications however these were often in narrative form and may be difficult to apply. Practical bullet points on the management of various complications may make these easier to use. A rolling programme to audit guidelines may also be helpful.

2 The newly opened Lifeblood Day Unit could be used as an access point for day case pain management.

3 The local pathway for access to psychology and neuropsychology services required further development.

4 Easier access to automated red cell exchange may be beneficial, especially given the large patient population.

5 Although administrative staff in the Sickle Cell and Thalassaemia Centre processed data for the National Haematology Registry (NHR), senior medical and nursing staff were inputting data onto the NHR. Reviewers suggested that data management support may be helpful.

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LOCAL TEAM: CROYDON HEALTH SERVICES NHS TRUST - PAEDIATRIC SERVICES

General Comments and Achievements- Paediatrics

The clinical team provided a cohesive and highly valued service to a large local paediatric patient group. Despite the post of paediatric sickle cell nurse specialist being vacant for several months the team worked extremely hard to ensure that high quality and responsive care was provided at a local level. Patients and staff were unanimous in their appreciation of the work done by the team, which was strongly led and forward looking.

A robust teaching programme for doctors and nurses was in place to ensure that haemoglobinopathy patients received prompt and consistently good care in the ED and on the wards.

Paediatric psychological support for children with haemoglobinopathies was provided locally at the Sickle Cell Centre

Good Practice

1 The establishment of a tertiary clinic for local treatment of haemoglobinopathy patients was valued by the patients and their families.

2 An outreach psychology service for paediatrics through the STSTN Network and King's College Hospital had been established.

3 The link nurse programme worked well in maintaining communication with the ward team and the specialist haemoglobinopathy team, as well as advocating for families.

4 A proactive and strong patient support group was in place which raised funds and provided education and support for families in the area. They used the Sickle Cell and Thalassaemia Community Centre premises for their meetings and events.

5 The welfare rights adviser role within the community was highly valued and significantly reduced workload for the clinical nurse specialists

6 An excellent nurse induction package for the management of haemoglobinopathy was in place for new starters.

Immediate Risks: No immediate risks were identified

Concerns

1 Although the clinical team provided an excellent service to its large local population, the lead consultant's haemoglobinopathy workload was not appropriately represented in the job plan. Patient numbers in this service were significantly larger than at many specialist centres in the country with an associated large clinical workload for the team. The service envisaged that the appointment of a paediatric nurse specialist would enable an easing of some of the consultant workload and help with governance and service development. This development will not, however replace the need for adequate consultant time to undertake safe and effective clinical practice.

2 The hospital school service was being withdrawn by the local education authority. This was of particular concern for haemoglobinopathy patients who may be admitted frequently for short periods of time and will miss out on their education during their hospital stay.

Further Consideration

1 It will be important to undertake regular audits as expected by the Quality Standards.

2 Updated guidelines should be uploaded onto the Trust intranet system.

3 The lead consultant was primarily based at the neonatal unit with a heavy neonatal clinical workload in addition to haemoglobinopathy clinical duties and attendance at haemoglobinopathy continuing professional development (CPD) events was difficult. The reviewers felt that appointing a deputy lead clinician for haemoglobinopathy will ensure that workload is adequately shared and enough time is available for the consultants to undertake appropriate CPD particularly as the base for the lead clinician was not in the paediatric wards.

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COMMISSIONING

The reviewers met with the commissioner for London and a public health representative during the review visits at King's, Guy's and Croydon. At the time of the review the structure and roles 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 and sickle cell disease had been highlighted in the Joint Health Needs Assessment report. Commissioners were interested in addressing epidemiology changes and inequalities in the local services. Enhanced tariffs had been agreed for the SHC role in the past through local commissioning to support aspects of the service for the wider network. A quarterly specialised haemoglobin disorders commissioner and clinical leads meeting was in place across London where agenda items were raised proactively by the service providers.

Immediate Risks: No immediate risks were identified.

Concerns

1 Formal definition of the network and inter-relationships between the hospitals had not yet taken place. Although King's and Guy's were considered to be functioning as Specialist Haemoglobinopathy Centres (SHC) by the commissioners no formal designation had been made.

2 Commissioner representation at the network meetings had been absent since April 2013.

Further Consideration

1 The patient population cared for at both accredited centres (Lewisham and Greenwich NHS Trust and Croydon Health Services NHS Trust) was one of the largest in the UK. As a consequence of the size of the population both the hospitals should be in the position to offer the full range of acute services, including access to a 24-hour red cell exchange service. However, the review team felt that staffing levels would need to be reconsidered and suggested that consideration should be given to commissioning these Trust as SHC rather than A-LHT.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Leads:

Dr Subarna Chakravorty	Consultant Haematologist	King's College Hospital NHS Foundation Trust
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust

Visiting Team:

Dr Penelope Cream	Clinical Psychologist	St George's University Hospitals NHS Foundation Trust
Baaba Davis	User/Carer	Not applicable
John James	Service User	Sickle Cell Society
Karen Madgwick	Transfusion Practitioner	North Middlesex University Hospital NHS Trust
Elaine Miller	Coordinator	UK Thalassaemia Society
Gabriella Oguntoye	Senior Nurse	Barts Health NHS Trust
Dr Lola Oni	Specialist Nurse Consultant	London North West Healthcare NHS 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 Services	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	41	35	85
Haemoglobin Disorders Clinical Network	9	6	67
Commissioning	3	0	0
Total	53	41	77

Services for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	43	34	79
Haemoglobin Disorders Clinical Network	9	6	67
Commissioning	3	0	0
Total	55	40	73

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 Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-101 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199)	Y	An excellent range of relevant information was accessible.	Y	Information was comprehensive, clear and included a good range of child friendly information.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-102 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions	Y	Information for thalassaemia patients was limited.	Y	A range of good quality information was available.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-103 All	**Information for Primary Health Care Team** Written information should be sent to the patient's primary health care team covering available local services and a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service	Y	Excellent instructions and advice for GPs about sickle cell disease were available.	Y	
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	Care plans were available in hard copy in all clinical areas. Plans were in place to make them available on the intranet.	Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-105 All	**School Care Plan (Paediatric Services Only)** A School Care Plan should be agreed for each child or young person covering, at least: a. School attended b. Medication, including arrangements for giving / supervising medication by school staff c. What to do in an emergency whilst in school d. Arrangements for liaison with the school	N/A		Y	
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	Transition workshops were offered and twice yearly clinics were held.	Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-107 SHC	**Information about Trans-Cranial Doppler Ultrasound** Written information should be offered to patients and their carers covering: a. Reason for the scan and information about the procedure b. Details of where and when the scan will take place and how to change an appointment c. Staff who will be present and will perform the scan d. Any side effects e. Informing staff if the child is unwell or has been unwell in the last week f. How, when and by whom results will be communicated	N/A		N	However information did not cover 'c', 'd' and 'e'.
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	An example of an eye care leaflet was provided where the document had been altered as a result of feedback from patients.	Y	Results were provided from 14 WMQRS surveys and 30 friends and family Trust feedback surveys.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-201 All	**Lead Consultant** A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.	Y	Evidence of good leadership was seen by the review visit team.	N	The job description for the clinical lead was not clear and the PAs allocated for haemoglobinopathy work were not adequate for the workload.
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		N	A deputy was not named.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-203 All	**Lead Nurse** A lead nurse should have appropriate time available for their leadership role and: a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only)	Y	Positive feedback was provided for the lead nurse who clearly provided care above and beyond core requirements.	N	The lead paediatric nurse position was vacant at the time of the visit.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-204 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing for clinics and regular reviews b. Medical staffing for emergency care, in and out of hours c. Nurse staffing on the ward and day unit d. Clinical nurse specialist/s with responsibility for the acute service e. Clinical nurse specialist/s with responsibility for the community service f. Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. g. Clinical or health psychologist with an interest in haemoglobin disorders Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT). Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders. Cover for absences should be available.	Y	Although it was possible to access psychology services this was geographically inconvenient and there was little evidence that it was used. The local service, which was established prior to the review visit, may benefit from further development.	Y	
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	High levels of knowledge of the care of people with haemoglobin disorders were evident when the review team visited clinical areas.	Y	The nurse training plan was presented.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-206 SHC	**Specialist Advice** During normal working hours a consultant specialising in the care of people with haemoglobin disorders should be on call and available to see patients.	Y		Y	Good tertiary links existed with King's.
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		Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-210 SHC	**Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)** Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.	N/A		N/A	
HN-299 All	**Administrative, Clerical and Data Collection Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	N	Although administrative staff in the Sickle Cell and Thalassaemia Centre processed data for the National Haematology Registry (NHR), insufficient cover for NHR data entry was provided.	N	NHR data were uploaded by consultants.

		Adult Services		Services 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.	Y	All documented were within Operational policy.	Y	
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)	N/A	However most of these services could be accessed locally.	N/A	All specialist services were accessed via links with King's.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-303 SHC A-LHT	**Specialist Services - Network** Access to the following specialist staff and services should be available: a. Erythrocytopheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.	Y	Good relationships were established for various specialities with local centres for example, at Guy's, King's and St George's Hospitals.	Y	The service linked with King's and Guy's Hospitals.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-304 All	**Laboratory Services** UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available.	N	Accreditation was on hold whilst South London pathology hub was under development.	N	Accreditation was on hold whilst South London pathology hub was under development.
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.	N	Although some flexibility was provided during the day and through a nurse-led twilight clinic, regular out of hours transfusion was not available.	N	Out of hours service provision was not available.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-501 SHC A-LHT	**Transition Guidelines** Network-agreed guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams	Y		Y	Although 'b' was present in the policy evidence of this was not seen in the case notes during the visit.
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		Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-503 LHT	**Clinical Guidelines: LHT Management and Referral** Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.	Y		Y	
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		Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-505 All	**Chelation Therapy** Network-agreed clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. Choice of chelation drug/s, dosage and dosage adjustment c. Monitoring of haemoglobin levels prior to transfusion d. Management and monitoring of iron overload, including management of chelator side effects e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2 f. Where prescribing is undertaken through shared care arrangements with GPs, guidelines for GPs on prescribing, monitoring and indications for seeking advice from and referral back to the LHT/SHC. g. Self-administration of medications and infusions and encouraging patient and family involvement in monitoring wherever possible.	Y		Y	'f' was not applicable.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-506 All	**Clinical Guidelines: Acute Complications** Network-agreed clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) **For patients with thalassaemia:** l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation	Y		Y	
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	Evidence for 'a' was not provided during the visit.	Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-508 All	**Clinical Guidelines: Chronic complications** Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only)	Y		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		Y	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-511 All	**Clinical Guideline Availability** Clinical guidelines for the monitoring and management of acute and chronic complications should be available and in use in appropriate areas including the Emergency Department, clinic and ward areas.	Y	Guidelines were easily accessible.	Y	

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

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

		Adult Services		Services for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).	Y		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/A		N/A	
HN-604 All	**Network Review and Learning Meetings** At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).	Y		Y	
HN-605 SHC	**Neonatal screening programme review meetings** The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.	N/A		N/A	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-701 SHC	**Data Collection** Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	Y	Although administrative staff in the Sickle Cell and Thalassaemia Centre processed data for the National Haematology Registry, senior medical and nursing staff were entering data as administrative support insufficient .	Y	Data collection was undertaken by senior medical and nursing staff.
HN-702 All	**Annual Data Collection - Activity** The service should monitor on an annual basis: a. Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances b. Length of in-patient stays c. Re-admission rate d. 'Did not attend' rate for out-patient appointments	Y		Y	

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

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-704 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **Achievement of screening follow-up standards:** a. At least 90% of infants with a positive screening result attend a local clinic by three months of age b. At least 90% of cases of HbSS and HbSC have confirmation of result documented in clinical notes by six months of age c. Less than 10% of cases on registers lost to follow up within the past year **For patients with sickle cell disease:** d. Proportion of patients with recommended immunisations up to date e. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required f. Compliance with NICE Clinical Guideline on the management of acute pain, including proportion of patients attending in acute pain who received first analgesia within 30 minutes of arrival, and achieved adequate pain control within two hours of arrival g. Availability of extended red cell phenotype in all patients h. Proportion of children: i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke **For patients with thalassaemia:** i. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) j. Proportion of patients who have developed new iron-related complications in the preceding 12 months **All patients:** k. Waiting times for transfusion	Y		N	Clinical audit evidence did not cover 'c' to 'k'.

		Adult Services		Services for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HN-705 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	A rolling programme of audit was not in place.	Y	
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	N/A	Patients were being entered into clinical trials.	N/A	
HN-707 SHC	**Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)** The service should monitor and review at least annually: a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required	N/A		N/A	

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-798 All	**Review and Learning** The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died b. Review of any patients requiring admission to a critical care facility	Y		Y	
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	N	Evidence of document control procedures was lacking. Documents on the ward differed from those presented as evidence.	N	Documents in the ward were different from those presented as evidence.

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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	

COMMISSIONING

		Adult Services		Services for Children and Young People	
Ref	Quality Standard	Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
HZ-601	**Commissioning of Services** Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular: a. Designated SHC/s for the care of people with sickle cell disease b. Designated SHC/s for the care of adults with thalassaemia c. Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia d. Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	N	No formal designation of King's 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 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 HY-702 and QS HY-798). c. Service and network achievement of relevant QSs	N	Evidence of clinical quality review meetings for services for people with Haemoglobin Disorders and for the network was not seen.	N	Evidence of clinical quality review meetings for services for people with Haemoglobin Disorders and for the network was not seen.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HZ-798	**Network Review and Learning** Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.	N	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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