WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services for People with Haemoglobin Disorders

North Middlesex Network

North Middlesex University Hospital NHS Trust

Visit Date: 4th February 2016

Report Date: June 2016

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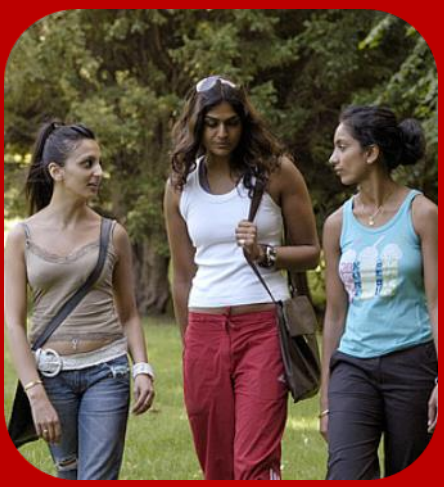

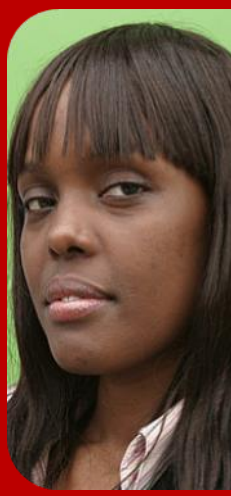

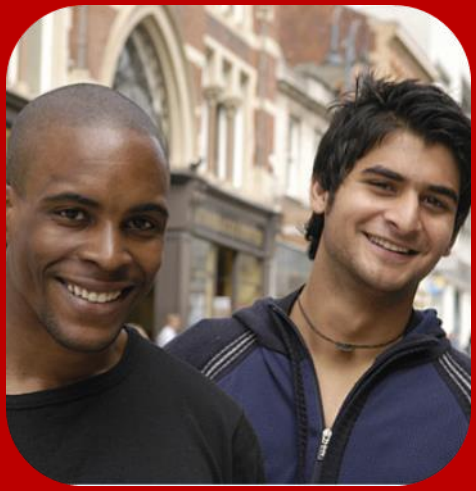

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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in North Middlesex University Hospital NHS Trust (part of the North Middlesex Network), which took place on 4th February 2016. 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:

- North Middlesex University Hospital NHS Trust
- NHS England Specialised Commissioning
- East and North Hertfordshire 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 North Middlesex University Hospital 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 NORTH MIDDLESEX NETWORK

Adults

Trust	Reviewed as:	No. of adults with sickle cell disease	No. of adults with thalassaemia	No. of adults on long term red cell transfusions
North Middlesex University Hospital NHS Trust	SHT	496	36	70
Cambridge University Hospitals NHS Foundation Trust	LHT	24	5	6
Norfolk and Norwich University Hospitals NHS Foundation Trust	LHT	19	<5	<5
East & North Hertfordshire NHS Trust	LHT	6	0	0
Princess Alexandra Hospital NHS Trust, Harlow	LHT	7	0	0

Children and Young People

Trust	Reviewed as:	No. of children with sickle cell disease	No. of children with thalassaemia	No. of children on long term red cell transfusions
North Middlesex University Hospital NHS Trust	SHT	251	5	22
Cambridge University Hospitals NHS Foundation Trust	LHT	35	<5	<5
Norfolk and Norwich University Hospitals NHS Foundation Trust	LHT	5	<5	<5
East & North Hertfordshire NHS Trust	LHT	36	0	<5
Princess Alexandra Hospital NHS Trust	LHT	14	0	0

ADULT SERVICES – NORTH MIDDLESEX UNIVERSITY HOSPITAL

Emergency Care

From the August after their 16th birthday, emergency care for adults was accessed through the Emergency Department (ED). An electronic patient record indicated the preferred analgesia and a first dose of analgesia was prescribed and given by ED staff. The specialty team was contacted to assess and admit patients. The team consisted of the clinical nurse specialist (CNS) and haematology core trainee during normal working hours or the specialty core trainee (oncology and HIV) out of hours. If there were any delays a second dose of analgesia was given by ED staff. A sub-group of 20 frequently-presenting patients accessed the Sickle Day Unit directly. Acutely sick patients were transferred to the 'resus' area where they were jointly managed by haematology or specialty and ED staff. Admission was usually to Podium One Ward. Workload in the ED had almost doubled in recent years which had created significant overcrowding and increased waiting times across all patient groups.

A haematology specialist trainee was on-call 24/7 and was available if patients were sick. The consultant 24/7 on-call rota was in a rotation of one week in five.

In-Patient Care

The five consultants in haematology operated a monthly ward-attending system. During this time they were responsible for the care of all in-patients. Patients admitted during the day were seen by the ward consultant on a post-take ward round. Patients admitted during the evening or at night were seen by the consultant the following morning, or during the night depending on acuity. Approximately 50% of haematology admissions were patients with sickle cell disease and 50% were haematology oncology patients. Before the twice weekly consultant rounds the whole team met to discuss patients, reviewing their blood results and diagnostic imaging. One of the three specialist trainees was responsible for ward patients at any one time.

Day Care

Two day care facilities were used. The Red Cell Day Unit had seven 'recliner chair' stations where transfusions were given to the patients with thalassaemia or sickle cell disease. The unit was open from 9am to 9pm on Thursday and Friday and from 9am to 5pm on alternate Saturdays. It was staffed by two of the five specialist nurses based at the George Marsh Centre and a healthcare support worker.

The nurse-led 'Sickle Day Unit' (SDU) was staffed by two nurses plus a healthcare support worker. It was open from 8am to 8pm every day and was used by a subgroup of patients who had chronic or acute pain which they had found difficult to manage at home with their usual analgesia. This cohort of patients could attend on successive days if necessary. They were assessed on arrival and received up to four injections of their preferred analgesia, if required. Some of the patients were attending the Unit more frequently than was intended if service usage was considered to be excessive a multi-professional case conference was held lasting 45 to 60 minutes. An individual patient, with a friend or relative if they wished, was invited to come, review their health problems and plan towards ways of managing pain more independently. The case conferences were led by the psychologist as part of the monthly multi-disciplinary team meeting.

Out-Patient Care

Weekly afternoon and evening haemoglobinopathy clinic sessions were held. On the first Tuesday of the month, the paediatric haematologist held a clinic for teenagers and young adults. The clinics on the remaining weeks were run by the haematologist for adult patients. Clinics were attended by the specialist trainee, the CNS and the transfusion practitioner, who met with patients to plan transfusions. Patients for annual review were given longer clinic slots. Phlebotomy was open until 5 pm and a phlebotomist was available in the clinic area until 6pm. After that, the transfusion practitioner or one of the clinic doctors took samples until the clinic closed at around 8.30pm.

Community-Based Care

The purpose-built George Marsh Centre for Sickle Cell and Thalassaemia was located in Tottenham and had opened in 1989. The Centre was managed by nursing staff employed by North Middlesex University Hospital NHS Trust (NMH). Antenatal counselling and prenatal diagnosis was provided, working from clinics in North Middlesex, Edgware and Barnet. The centre received the newborn screening results for Barnet, Enfield and Haringey, visited the families of affected newborns at home and provided support to affected families in the early weeks. The centre provided a popular home-care pain service. Staff visited patients in their homes for assessment and management of pain episodes. This service was available every day from 9 am until 5pm.

A monthly parent support group was held at the centre. It also provided a base for the adult Sickle Cell Support Group. Educational resources were provided for patients, carers and the community with a library and IT facility.

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CHILDREN AND YOUNG PEOPLE – NORTH MIDDLESEX UNIVERSITY HOSPITAL

Emergency Care

Children with sickle cell disease or thalassaemia had 'fast-track' direct access to the Rainbow or Starlight paediatric wards. Additionally severely unwell children could be managed in the resuscitation bay in the ED area. At their initial clinic visit, the families were given a 'pink passport' and invited to phone the ward to discuss any concerns. Nursing staff provided advice by phone or advised attendance at the ward for assessment. If a child with a haemoglobin disorder did present to ED the paediatric team on the ward was called to assess and admit if necessary.

In-Patient Care

The Starlight Ward functioned as the acute day assessment unit and incorporated a nine-bedded short stay area. The Rainbow Ward was a 25-bedded ward and included two high dependency (HDU) beds. Patients who required admission for longer than 48 hours were admitted to this ward. One bay was designated for older children and adolescents. Facilities for parents to stay with their child were provided. A school and teenage room was available. A play area was available on both wards.

Clinical cover was provided on a weekly rotational basis by paediatric consultants. The 'admitting' consultant for the week covered Rainbow Ward for the long-term admissions and the 'ambulatory' consultant covered Starlight Ward. They took clinical responsibility for patients on these wards, liaising as necessary with colleagues if specialty patients were admitted. The paediatrician with an interest in haematology and the haematology team were informed of all admissions for this patient group. The haematology registrars and paediatric consultants conducted a daily ward round on the children's wards. Children were also seen by the haematology consultant on their twice-weekly ward rounds, and at other times, as necessary. More seriously ill children, including those needing emergency exchange transfusions, were managed in the two HDU beds. Patients requiring paediatric intensive care were transferred following discussion with the Children's Acute Transport Services (CATS) team.

Day Care

Experienced staff in the nurse-led paediatric day assessment unit undertook pre-transfusion assessment and cannulation. The unit opened daily from Monday to Friday between 8.30am and 5pm for review and treatment including blood transfusion. On some occasions, children of school age requiring blood transfusions could start after school and complete transfusions on the in-patient ward.

Patients with sickle cell disease were also assessed in the day assessment unit which was open 24/7 and staffed by a paediatric registrar, specialist trainees and nursing staff. Treatment could include a period of observation on the day assessment unit, short stay ward or transfer to Rainbow Ward if more appropriate.

Out-Patient Care

A dedicated paediatric out-patient department was located in the main hospital. Weekly joint paediatric haematology clinics were run by the lead paediatrician, the paediatric haematologist (joint appointment with Great Ormond Street Hospital) and the lead haematologist. A late adolescent clinic was held bi-monthly in the paediatric out-patients. A family clinic where all parents and children with haemoglobinopathies were seen together ran quarterly. On alternate weeks, the paediatric haematologist undertook a dedicated Trans-Cranial Doppler clinic list which ran alongside the paediatric haematology clinic. Children and their parents were seen by the nurse specialist for advice, education and support. A housing advice worker attended the clinic once a month. Children requiring blood sampling before transfusion used the day unit or the children's phlebotomy area, which was open from 1pm to 4.30pm during the week.

Community Based Care

The purpose-built George Marsh Centre for Sickle Cell and Thalassaemia was located in Tottenham and had opened in 1989. The Centre was managed by nursing staff employed by North Middlesex University Hospital NHS Trust (NMH). Antenatal counselling and prenatal diagnosis was provided, working from clinics in North Middlesex, Edgware and Barnet. The centre received the newborn screening results for Barnet, Enfield and Haringey, visited the families of affected newborns at home and provided support to affected families in the early weeks. The centre provided a popular home-care pain service. Staff visited patients in their homes for assessment and management of pain episodes. This service was available every day from 9 am until 5pm.

A monthly parent support group was held at the centre. It also provided a base for the adult Sickle Cell Support Group. Educational resources were provided for patients, carers and the community with a library and IT facility.

The paediatric specialist nurse also provided community-based care visiting schools, children and parents at home and attended safeguarding meetings when necessary.

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VIEWS OF SERVICE USERS AND CARERS

Adult services

The visiting team met a small number of patients and carers with sickle cell disease and thalassaemia and received feedback from them. They also reviewed responses to 101 questionnaires.

Common themes raised by adult patients and carers were:

- Appreciation for the work of the lead consultants and their caring attitude.
- Concerns about a variety of issues relating to performance and staff attitudes in the Emergency Department, including stigmatisation and delays in analgesia and review. Patients implied that the attitudinal issues were identifiable at all grades of medical and nursing staff within the ED.
- Patients expressed the feeling that a small group of patients received preferential treatment in the Sickle Day Unit.
- Transition service and clinics were highly effective.
- Thalassaemic patients also singled out the Transfusion Practitioner for particular praise.
- The availability of free car-parking was much appreciated.

Services for Children and Young People

The visiting team met a small number of patients with sickle cell disease and carers and received feedback from them. They also reviewed responses to 38 questionnaires.

Common themes raised by patients and carers were:

- Families were complimentary of the team and overall were pleased with the care they received.
- They were appreciative of the active parent group but were keen for more parents to attend.
- Parents expressed concerns about transitioning to the adult service particularly in view of the negative experiences of adults in the ED with waiting times and perceived unsympathetic attitudes of staff. Patients felt apprehensive about the potential for negative influences from a group of patients with complex needs and chronic pain.

- Parents felt disappointed by the delays in phlebotomy and the limited opening hours of the phlebotomy service.
- Parents were keen for more engagement between health professionals and schools, although they recognised the demands on the time of the nurse specialist. They also felt their children could benefit from more support at school.
- They were keen for more social work support.
- Young people who had recently transitioned were happy with the transition process.

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REVIEW VISIT FINDINGS

NETWORK

General Comments, Progress and Achievements

North Middlesex University Hospital NHS Trust (NMH) provided specialist support for an extensive geographical area extending to the Norfolk coast. Since the previous review of adult service, which took place in 2012, significant developments in provision of care had been made. Lead clinicians in the local Trusts had been identified. Outreach clinics had been established in Norwich and Cambridge. Advice in-and out-of-hours was available when required with triggers for referral clearly identified in a range of network approved guidelines.

The paediatric Network served a wide area and consisted of the NMH as specialist centre with linked hospitals in North London as well as parts of Hertfordshire, Cambridgeshire, Bedfordshire, Essex, Suffolk and Norfolk. In addition, links were in place with Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Hospitals NHS Foundation Trust (UCLH). Good collaboration existed between these sites with sharing of guidelines and regular network learning and review meetings. Since the previous review visit, which took place in 2010 for services for children and young people, the Network had continued to develop with increased specialist outreach clinic provision for annual reviews and TCD scanning for children at the linked hospitals. Cambridge and Hertfordshire also had a designated paediatric specialist nurse and some allocated psychology time. Local teams valued the multi-disciplinary network education and learning meetings and felt well supported by the specialist team.

Good Practice

1 Network-wide meetings and education were in place.

2 Strong relationships with centres in Norwich and Cambridge for services were functioning effectively.

3 All children with sickle cell disease at the linked hospitals who required a Trans-Cranial Doppler scan could have this organised at their annual review by the visiting paediatric haematologist.

4 Attempts had been made to collate information on patients within the network. Presentation and review of data as an annual network report was noteworthy.

Immediate Risks: No immediate risks were identified.

Concerns

1 Specialist nurse support was not available outside NMH.

Further Consideration

1 The number of patients and standards of care in the less-directly linked hospitals in the wider network were not yet clear. Further work on this may be helpful.

2 Most patients from Barnet Hospital attended NMH, at least for annual review but some attended UCLH, clarity on this may be helpful.

3 The lack of data management support for the networks meant that data entry onto the National Haemoglobinopathy Registry was incomplete across the network.

4 Limited access to psychological support was available for adult patients outside of North Middlesex University Hospital.

5 Collaboration between the SHC and linked hospitals to encourage network-wide research activity for adult and paediatric services would be beneficial, although reviewers recognised that this may be problematic due to the wide geographical area covered and the need to include several clinical research networks.

6 Although patients had access to automated exchange outside the network, provided by University College London Hospital NHS Trust, better local access would be more convenient and reduce concern about the possibility of omission or duplication occurring due to split site care.

NETWORK CONFIRGURATION

The linked hospitals listed had links either with the SHC or to the one of the local hospital teams but it was not clear if this included all patients. Some patients with haemoglobin disorders from Bedford were seen in Cambridge. The network configuration at the time of the review was as follows:

Specialist Haemoglobinopathy Centre	Local Haemoglobinopathy Teams
North Middlesex University Hospital NHS Trust (North Middlesex University Hospital, St Ann's Hospital)	• Cambridge University Hospitals NHS Foundation Trust (Addenbrooke's Hospital)
	• Norfolk and Norwich University Hospitals NHS Foundation Trust (Norfolk and Norwich University Hospital)
	• East and North Hertfordshire NHS Trust (Lister Hospital)
	• Princess Alexandra Hospital NHS Trust (Princess Alexandra Hospital)
	• The Royal Free London NHS Foundation Trust – Barnet Hospital
Hospitals Linked to Cambridge and Norwich	• Hinchingbrooke Health Care NHS Trust - Hinchingbrooke Hospital • Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust - The Queen Elizabeth Hospital • Bedford Hospital NHS Trust – Bedford Hospital • The Ipswich Hospital NHS Trust – Ipswich Hospital • West Suffolk NHS Foundation Trust - West Suffolk Hospital • James Paget University Hospitals NHS Foundation Trust - James Paget Hospital

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SPECIALIST TEAM: ADULT SERVICES: NORTH MIDDLESEX UNIVERSITY HOSPITAL NHS TRUST

General Comments and Achievements

The service was well-led by a small number of energetic and innovative individuals. Many staff were working well outside their contracted hours.

Progress since Last Visit

Since the previous visit, which took place in November 2012, there had been significant changes to the haemoglobinopathy service:

- Increasing numbers of young people and adults were able to access automated red cell exchanges, provided at University College Hospital in Central London
- For a time after the hospital expansion, the adult service was without a 'home ward' but since June 2015 haemoglobinopathy care was based on 'Podium One Ward'
- A nurse-led Sickle Cell Day Unit (SDU) had been established for a group of 20 adult patients who were previously frequent ED attenders. Since this unit had opened a reduction in in-patient stays and ED attendances had been achieved for this group
- Pressure on the adult 'home-pain team' had reduced since the Sickle Day Unit had taken some of the frequently-seen patients, thus increasing availability of this service to other patients.
- A research portfolio for both adults and children had been established
- A systematic hospital-wide programme of reviewing, at team level, the records of any patient who had died was in place. Any issues or learning were fed through to a Mortality Review Group chaired by the Medical Director
- The team at NMH provided advice and outreach care to a large geographical area extending to the East coast. Since the last visit the availability of outreach clinics to linked hospitals had increased. Whole day network meetings had been established with associated provision of training and education to trainees in low prevalence parts of the network

Good Practice

1 Excellent Trust information booklets were available.

2 Interaction with paediatric team was good and strong transition arrangements were in place.

3 Regular well-documented multi-disciplinary team meetings took place.

4 A transfusion practitioner arranged and monitored transfusions and took an extended role in monitoring chelation programmes.

Immediate Risks: No immediate risks were identified.

Concerns

1 With a large and expanding population of patients the workload of the consultants and single specialist nurse was considered excessive by the review team. The forthcoming retirement of the lead clinician is likely to exacerbate this issue. Job plans showed clear delineation of time for haemoglobin disorders although Programmed Activity was insufficient for the size of the patient group

2 Long waiting times for analgesia within the Emergency Department were highlighted by recent audits and patient feedback. Concern was also expressed by patients about the attitudes of some ED staff to patients with sickle cell disease.

Further Consideration

1 The establishment of a Sickle Day Unit had resulted in a reduction in hospital admissions and reduced Emergency Department attendances. The patient feedback sessions highlighted that other patients would like the same level of access to care. It may be worth considering whether this could be achieved and, if not, whether better information for other patients is needed. The reviewing team was impressed with the services aspiration to develop an ambulatory care facility which would combine the two day units and allow open access for pain management without the need for ED attendance.

2 The red cell day unit was small and a larger facility may need to be considered as patient numbers increased.

3 Although a 0.5 w.t.e. psychologist was available this was considered to be insufficient for the size of the patient population.

4 Additional data management support was required to ensure full compliance with the National Haemoglobinopathy Registry data requirements.

5 The service had previously had a dedicated social worker, housing support and a benefits advisor. None of these was available at the time of the visit and re-instatement should be considered.

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

7 Reviewers noted plans to centralise specialist red cell laboratory services and suggested that the impact of this change needed to be closely monitored.

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LOCAL TEAMS

General Comments and Achievements

The linked centres were not visited by the team but reviewers were able to speak to lead clinicians from Norfolk and Norwich University Hospitals NHS Foundation Trust and Cambridge University Hospitals NHS Foundation Trust.

Outreach clinics were held in both hospitals and input of the NMH clinical team was highly valued. Advice was available at all times and clearly documented triggers were available for the teams to contact NMH clinicians. Linked hospitals had access to Network guidelines.

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SPECIALIST TEAM: PAEDIATRIC SERVICES: NORTH MIDDLESEX UNIVERSITY HOSPITAL NHS TRUST

General Comments and Achievements

This was an excellent cohesive service caring for a large local population of patients with haemoglobinopathies including those with complex needs. The numbers of births of babies with haemoglobin disorders in areas covered by the linked hospitals was increasing. The reviewers were impressed by the dedication demonstrated by the specialist staff to meet the needs of these patients, despite limited resources. The team provided a smooth transition from paediatric to adult services with good collaboration between the haematology and paediatric departments.

Progress since Last Visit

Since the previous visit, which took place in May 2010, the paediatric service at NMH had gained a purpose-built assessment unit and short stay ward, in addition to refurbishment of Rainbow, the paediatric in-patient ward. Progress had been made with the establishment of a research portfolio for both adults and children. Most patients had been registered with the National Haemoglobinopathy Registry. Good network links had been established.

Good Practice

There were many areas of good practice including:

1 The 'one-stop' approach to patient care allowed families to avoid unnecessary hospital visits a clinic provided for all the family members with haemoglobin disorders.

2 Provision of extended hours for clinic appointments and family clinics was excellent. This included a bimonthly adolescent clinic and quarterly family clinics where several generations could be present at the same appointment.

3 An annual review of network data presented as an annual network report was noteworthy.

4 Information for families and children was displayed in a well-thought-out manner across the children's wards. The transition information package was particularly good.

5 A safeguarding nurse regularly attended the multi-disciplinary team meetings to discuss children who were of concern.

Immediate Risks: No immediate risks were identified.

Concerns

1 Although the specialist nurse was employed as a community-based nurse, she covered both the acute and community services. However, with the growing demands on the acute hospital-based service, she was unable to devote sufficient time to provide outreach care despite working beyond her contractual hours. Time allocated for acute care provision was also limited and cover for absence was not provided. Clinical commitments allowed little time for the expected leadership role.

2 Reviewers considered that insufficient time was allocated for health and neuro psychology provision within the service to meet the needs of the population.

3 Although much progress had been made with Trans-Cranial Doppler (TCD) scanning of patients across the network, the sustainability of this single-handed service was of concern in its current format. Urgent scans were difficult to schedule due to capacity issues which impacted on internal quality assurance processes. Results of fail-safe arrangements were not seen and the service had difficulty accommodating children for urgent scans in view of the limited capacity. The reviewers did note, however that a vascular ultra-sonographer had been identified to support the TCD service.

Further Consideration

1 Data management and administrative support was insufficient and impacted on data collection including annual review data submission for the National Haemoglobinopathy Registry.

2 Reviewers suggested that the service would benefit from additional social welfare support to help with the social needs of the families including benefits and housing advice.

3 More robust arrangements for out of hours transfusion and phlebotomy should be considered to benefit more children and their families. At the time of the review this was available only on an 'ad-hoc' basis.

4 Reviewers suggested that the service could consider one unifying operational policy to detail the operational elements of the service including fail safe arrangements. Elements of operational policy were included in several different documents.

5 The reviewing team recognised that the paediatric Emergency Department (ED) was rarely used by local families but commented that it will be important to ensure the training for ED staff is sustained in order to avoid delays in assessment and treatment for all those who do attend.

6 The reviewers noted a sizeable 'did not attend' rate in the out-patient clinic. Though recognising this issue is common to many centres, a review of the contributing factors for this service may be helpful.

7 Reviewers noted plans to centralise specialist red cell laboratory services and suggested that the impact of this change needed to be closely monitored.

8 Further standardisation of documentation of the multi-disciplinary team meetings may be helpful.

9 Audit data demonstrated that only 56% of paediatric patients with sickle cell disease received analgesia within 30 minutes of arrival to hospital despite the fast track process.

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ACCREDITED LOCAL TEAMS: PRINCESS ALEXANDRA AND LISTER HOSPITALS

General Comments and Achievements

The reviewers met the lead paediatrician from The Princess Alexandra Hospital in Harlow (Princess Alexandra Hospital NHS Trust) and spoke with the nurse specialist at the Lister Hospital in Stevenage (East & North Hertfordshire NHS Trust East & North Hertfordshire NHS Trust). The teams were highly appreciative of the support provided by the specialist team. Communication was good and network pathways and protocols had been established.

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COMMISSIONING

General Comments and Achievements

The reviewers met a specialised commissioning representative however commissioning arrangements had changed and he commissioner who attended was no longer actively involved in commissioning services for people with haemoglobin disorders. Evidence of work to address the Quality Standards was not available. Little evidence of CCG involvement in the care of people with haemoglobin disorders was available.

Immediate Risks: No immediate risks were identified

Concerns

1 Reviewers saw little evidence that commissioners were not engaged in commissioning services for people with haemoglobin disorders in this network.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Clinical Leads

Dr Banu Kaya	Consultant Haematologist	Barts Health NHS Trust
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust

Visiting Team

Nkechi Anyanwu	Clinical Nurse Manager Haemoglobinopathies	Guy's and St Thomas' NHS Foundation Trust
Marilyn Burton	Clinical Nurse Specialist	Central Manchester University Hospitals NHS Foundation Trust
Helen DeMarco	Senior Clinical Psychologist	University College London Hospital NHS Foundation Trust
Natasha Lewis	Lead Nurse - Sickle Cell & Thalassemia	Homerton University Hospital NHS Foundation Trust
Elaine Miller	Co-ordinator	UK Thalassaemia Society
Amrana Qureshi	Consultant Haematologist	Oxford University Hospitals NHS Trust
Aldine Thomas	Clinical Nurse Specialist Haemoglobinopathies	Barts Health 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 Service	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	42	34	81
Haemoglobin Disorders Clinical Network	9	4	44
Commissioning	3	0	0
Total	**54**	**38**	**70**

Service for Children and Young People	Number of Applicable QS	Number of QS Met	% met
Specialist Services for People with Haemoglobin Disorders	49	40	82
Haemoglobin Disorders Clinical Network	9	4	44
Commissioning	3	0	0
Total	**61**	**44**	**72**

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

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	Although rated as 'no' in the self-assessment, the appointment of a specialist nurse had allowed the team to address this Quality Standard.	Y	

		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	Excellent "Living well with…" booklets were provided.	Y	

		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		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		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	School care plans were clear and comprehensive.
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	Excellent information on transition was available. 'Seamless' transition was provided into adult services.	Y	An excellent range of information was available on transition to adult services. See good practice section.

		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		Y	Information was presented in a clear format.
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	A regular patient focus group was well-documented and attended by patients, carers and staff A large number of patient surveys was provided for the review team.	Y	A well-attended user group was operational with evidence of changes made following feedback received from patients and their families, particularly to the transition process.

		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	The lead consultant planned to retire in late 2016 and succession planning may become an issue.	Y	
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.	Y		Y	

		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)	N	The lead nurse had insufficient time available for clinical duties and leadership role. See concern section of the main report.	N	The lead nurse had insufficient time available for clinical duties and leadership role. See concern section of the main report.

		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.	N	The population and complexity of need were increasing. Staffing levels may be insufficient for the growing population. Although there was a 0.5 w.t.e. psychologist, the reviewers felt this allocation was **in**sufficient for the size of the patient population. Job plans showed clear delineation of time for haemoglobin disorders although Programmed Activity was insufficient for the size of the patient group.	N	Insufficient nurse specialist staffing levels were available to meet the needs of the service. At the time of the review the newly appointed clinical psychologist had 0.2 w.t.e. of 0.5 w.t.e. allocation for the haemoglobinopathy service. This was inadequate for the needs of the population. See concerns section of the main report.
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 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	
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	Regular sessions were held in ED.	Y	However see the further considerations in the main report.
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	The nurse responsible for safeguarding attended the multi-disciplinary team meeting.
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	Local trainees and trainees from hospitals in low prevalence areas within the network attended for specialist experience in haemoglobinopathies.	Y	Opportunities to gain competence were available for local trainees.

		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	The consultant paediatric haematologist was responsible for all Trans-Cranial Doppler scanning within the network. Participation in a training and quality assurance scheme was evident. However there was no cover for absences. See 'Concern' section in main report.
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	Insufficient administrative support was available. This had an impact on general data collection and annual review data input onto the National Haemoglobinopathy Registry.	N	Insufficient administrative support was available. This had an impact on general data collection and annual review data input onto the National Haemoglobinopathy Registry.
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	Access to a psychologist with an interest in haemoglobinopathies was insufficient for the size of the population and the support from a benefits advisor had been missed by patients.	N	Access to a psychologist with an interest in haemoglobinopathies was insufficient for the size of the population.

		Adult Services		Services for Children and Young People	
Ref	**Quality Standard**	**Met? Y/N**	**Reviewer Comments**	**Met? Y/N**	**Reviewer Comments**
HN-302 SHC	**Specialist On-site Support** Access to the following specialist staff and services should be available on the same hospital site as the specialist team: a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2)	Y	The acute pain team was not routinely involved but could be contacted easily when needed.	Y	Two high dependency beds were available for managing unwell children within the network. Children's Acute Transport Service (CATS) retrieval was required however if children required non-invasive ventilation or more intensive support.

		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	R2 MRI scans were performed at Whittington Hospital, T2* MRIs were performed at UCLH. Clear pathways for referral to larger specialised service in Greater London were in place.	Y	Some services were available within the network. Referral to other centres was required for other services: • Great Ormond Street Hospital – sleep studies and surgery, MRI under general anaesthetic, AVN(avascular necrosis)/osteomyelitis. • University College London Hospitals NHS Foundation Trust - fertility, DNA studies, urology. • St Mary' Hospital – bone marrow transplant. The clinical psychologist based at NMH was able to perform neuropsychometric assessments and plans were in place for additional support and supervision from a neuropsychologist. Paediatric intensive care was not available on site.

		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.	Y	Reviewers noted plans to centralise specialist red cell laboratory services and suggested that the impact of this change needed to be closely monitored.	Y	Reviewers noted plans to centralise specialist red cell laboratory services and suggested that the impact of this change needed to be closely monitored.
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 a larger day care facility may need to be considered.	Y	Information displayed on the wards for the child and their family was well thought out and functional. See 'Good Practice' section of the main report.
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y		N	Out of hours transfusion was offered on an ad-hoc basis. See 'Further Consideration' section of the main report.

		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	Excellent transition information was available based on the 'Ready Steady Go' scheme.	Y	Guidelines were well-laid out and comprehensive.
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.	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		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	There was some uncertainty around the choice of chelation medication within these guidelines.

		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	Y		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	Less detail was available on chronic complications, though the reviewers noted this was less of an issue in children.
HN-509 SHC	**Referral for Consideration of Bone Marrow Transplantation** Guidelines for referral for consideration of bone marrow transplantation should be in use.	N/A		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		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		Y	Guidelines detailing this process were available.

		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		Y	Components of this were included in a number of policies. The service would benefit from a comprehensive operational policy which outlines all arrangements. See 'Further Consideration' section of the main report.

		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	Minutes were provided but may benefit from standardisation of recording patient discussions.	Y	Evidence of multi-disciplinary working was presented to the reviewers. However standardisation of the Multi-disciplinary Team meetings may be useful. See 'Further Consideration' section.
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		Y	

		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.	N	Although most patients were registered on the NHR, there was insufficient administrative support to allow for annual review data entry onto the NHR, see 'Further Consideration' section of the main report.	N	Although most patients were registered on the NHR, there was insufficient administrative support to allow for annual review data entry onto the NHR, see 'Further Consideration' section of the main report.
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	The reviewers noted a high 'did not attend' rate in the clinics. See 'Further Consideration' section of the main report.

		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	Good data collection and presentation in an annual network report was noteworthy (see 'Good Practice' section of the main report). However network patient data were incomplete.	N	Good data collection and presentation in an annual network report was noteworthy (see Good Practice section of the main report). However network patient data were incomplete.

		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	N	'a', 'b' and 'c' were not applicable. Reviewers questioned the accuracy of 'd' and 'e', which were assumed from annual review figures rather than from a specific audit.	Y	Evidence of proactive audit activity was provided. The reviewers noted only 56.7% of admissions conformed to the NICE guideline recommendation of analgesia within 30 minutes. See 'Further Consideration' section of the main report.

		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	The service did not have a rolling programme of audit for guidelines.	Y	
HN-706 SHC	**Research** The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	Research activity had increased since the last review.	Y	Research activity had increased since the last review.
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	Trans-Cranial Doppler screening for the network was performed single-handedly by the paediatric haematologist. Mechanisms for internal quality assurance were not yet in place though external annual assessment was evident. Results of fail-safe arrangements were not seen and the service had difficulty accommodating children for urgent scans in view of the limited capacity (see 'Concern' section of the main report).

		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.	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.	N	The network did not yet have mechanisms for involving patients and their carers from all services in the work of the network.	N	There was an active users group based at the SHC and evidence of regular surveys of the service. The reviewers noted a constructive attempt to address concerns raised. However this was not organised for all network patients.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	N	All network leads had not yet been agreed.	N	All network leads had not yet been agreed.
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	Some progress with network-wide training had been made.

		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.	Y		Y	

		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		Y	
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	Evidence of data collection and presentation was provided in the format of an annual network report, see good practice section of the main report. However these data was incomplete.	N	Evidence of data collection and presentation was provided in the format of an annual network report, see good practice section of the main report. However these data was incomplete.

		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	The network did not yet have an agreed programme of audit. However there was evidence of data collection and presentation was provided in the format of an annual network report, see good practice section of the main report.	N	The network did not yet have an agreed programme of audit. However there was evidence of data collection and presentation was provided in the format of an annual network report, see good practice section of the main report.
HY-703	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	This was under development at the time of the visit.	N	This was under development at the time of the visit.
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	The network had made good progress with regular meetings. These were valued by the local teams.	Y	The network had made good progress with regular meetings. These were valued by the local teams.

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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	Commissioners had not yet agreed the configuration of clinical networks providing services for people with haemoglobin disorders.	N	Commissioners had not yet agreed the configuration of clinical networks providing services for people with haemoglobin disorders.
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	Commissioners did not yet regularly review the quality of care provided in services for people with haemoglobin disorders.	N	Commissioners did not yet regularly review the quality of care provided in 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**
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	Commissioners had not yet attended a Network Review and Learning meeting.	N	Commissioners had not yet attended a Network Review and Learning meeting.

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