

Health Services for People with Haemoglobin Disorders

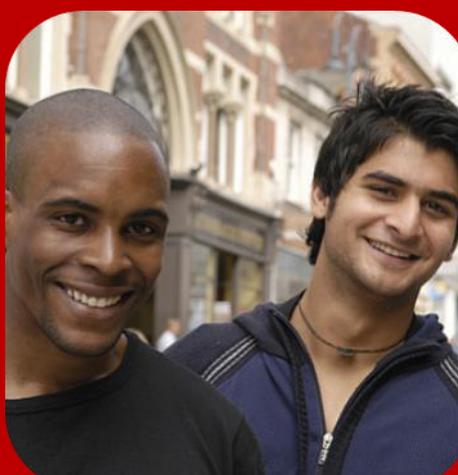
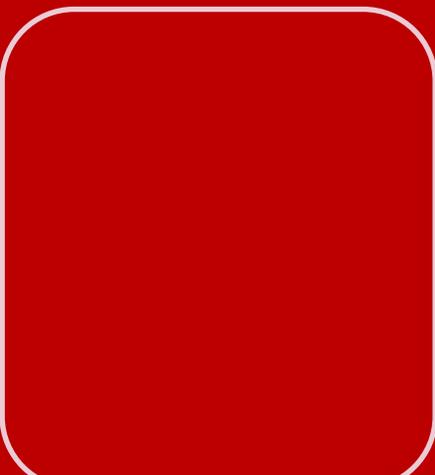
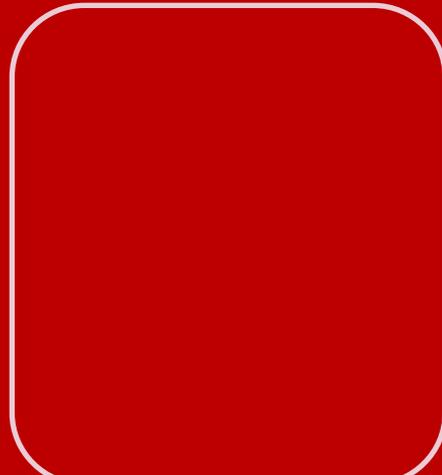
North West London Network

Imperial College Healthcare NHS Trust

Visit Date: 5th November 2015

Report Date: April 2016

Images courtesy of NHS Photo Library



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INTRODUCTION

This report presents the findings of the peer review of health services for people with haemoglobin disorders in Imperial College Healthcare NHS Trust (part of the North West London Network), which took place on 5th November 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:

- Imperial College Healthcare NHS Trust
- NHS England Specialised Commissioning
- NHS West London, Central London, Ealing, Hounslow, Hillingdon, Brent, Harrow and Luton Clinical Commissioning Groups

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 Imperial College Healthcare 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 WEST LONDON NETWORK

At the time of the visit Imperial College Healthcare NHS Trust (ICHT) was part of the North West London Network which also included London North West Healthcare NHS Trust (LNWH) both of which were Specialist Haemoglobinopathy Centres.

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 |
|--|--------------|--|---------------------------------|--|
| Imperial College Healthcare NHS Trust (Hammersmith Hospital) | SHT | 367 | 30 | 56 |
| Chelsea and Westminster Hospital NHS Foundation Trust (West Middlesex University Hospital) | LHT | 30 | 7 | 9 |

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 |
|---|--------------|--|-----------------------------------|--|
| Imperial College Healthcare NHS Trust (St Mary's Hospital) | SHT | 166 | 19 | 34 |
| Luton and Dunstable University Hospital NHS Foundation Trust | LHT | 58 | 21 | 15 |
| West Hertfordshire Hospitals NHS Trust | LHT | 29 | 0 | <5 |
| Chelsea and Westminster Hospital NHS Foundation Trust- (West Middlesex University Hospital) | LHT | 17 | 5 | <5 |
| The Hillingdon Hospitals NHS Foundation Trust | LHT | 17 | 5 | <5 |

ADULT SERVICES

EMERGENCY CARE

The in-patient services were based at Hammersmith Hospital. All patients with haemoglobin disorders under regular follow-up were issued with an access card ('passport') with information on how to contact and access the haematology triage service via a dedicated telephone number if urgent assessment was required for symptoms related to their condition. The triage service was provided 24/7 through a nurse bleep holder who directed the patient to attend either the Haematology Day Care Unit (from Monday to Sunday between 8am and 8pm), Specialist Medicine Assessment Centre (SMAC) or, if clinically indicated, to dial 999. If a patient presented their 'passport' to London Ambulance Service (LAS) they were taken to SMAC and the LAS team gave

advance notification of the patient's arrival. If immediate treatment for a medical emergency was required a patient was taken to the nearest hospital with a full Emergency Department (ED) service, usually St Mary's Hospital.

IN-PATIENT CARE

Patients in the Haematology Day Care Unit were initially assessed by the triage nurse, then the Day Care Specialist Registrar. If admission was deemed necessary patients were transferred directly to the haematology ward (usually D7) or if a haematology bed was not immediately available, to SMAC. During normal working hours, patients who attended SMAC directly were assessed by the Red Cell Specialist Registrar and outside working hours, by the on-call SHO covering haematology. If the Red Cell team or on-call SHO was unable to attend immediately then the acute medicine team on SMAC assessed the patient, prescribed initial treatment including analgesia according to individual protocols and monitored the patient until the haematology team arrived. ICHT had three designated haematology wards. Ward D7 accommodated the majority of patients with haemoglobin disorders. An increase in the proportion of patients with more complex needs had been observed over the previous few years. The average length of stay for patients with sickle cell disease and thalassaemia disorders was 6.8 (median 3.0) and 4.3 days respectively.

DAY CARE

The service had comprehensive day care facilities for transfusion, ambulatory care and apheresis in a purpose-built unit which operated between 8am and 8 pm every day. The Haematology Day Care Unit had four beds and six reclining chairs, with an additional six chairs allocated for routine infusions, including transfusion. The apheresis service was relocated on the ground floor of the Garry Weston Centre. This service provided additional space in the designated day care/ambulatory area which incorporated a dedicated triage, assessment and day pain service for patients with sickle cell disease from four dedicated chair or bed spaces. The apheresis service was provided by day care nursing staff who had undertaken additional apheresis training and competence assessment. Six registered nurses participated in the weekend on-call rota. In addition the haemoglobinopathy CNS was trained to perform automated red cell exchange. Three Spectra Optia machines for use by adults with haemoglobin disorders operated in Haematology Day Care Unit and one was located at Charing Cross Hospital. These could be transported to in-patient areas as necessary.

OUT-PATIENT CARE

Designated red cell clinics for patients with haemoglobin disorders were held weekly in the Catherine Lewis Centre, Hammersmith Hospital and in the main Out-patients Department at St Mary's Hospital. In addition, a monthly paediatric transition clinic was held at St Mary's Hospital and an obstetric haematology clinic for women with haemoglobin disorders at Queen Charlotte's and Chelsea Hospital was held on alternate weeks.

COMMUNITY-BASED CARE

Community-based care for the majority of patients was provided by Central London Community Healthcare NHS Trust (CLCH) which served the boroughs of Hammersmith and Fulham, Kensington and Chelsea and Westminster. The CLCH Sickle Cell and Thalassaemia Service was based at Richford Gate Primary Care Centre. The lead community specialist nurse attended the red cell and transition clinics and multidisciplinary meetings on a regular basis. Cover arrangements for annual and sick leave were not in place. It was not possible to review in detail community services for residents in Barnet, Brent, Luton, and other areas of Cambridgeshire and Hertfordshire.

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SERVICES FOR CHILDREN AND YOUNG PEOPLE

EMERGENCY CARE

Children requiring emergency review were seen in the Emergency Department (ED) at St Mary's Hospital where a paediatric specialist registrar was available. Both consultant paediatrician and anaesthetics support was also available at all times. The paediatric haematology team was primarily responsible for management of patients following initial triage by the nursing team and assessment by the paediatric specialist registrar. Protocols were available electronically and hard copies were accessed in the resuscitation suite. Patients' clinic letters and individualised pain protocols, produced for a small number of the older patients, were also accessible on a shared drive. A paediatric sickle cell pain protocol, utilising intranasal diamorphine on admission, had been introduced in Spring 2015. Patients requiring admission were transferred to the Paediatric Short Stay Unit for short term observation, if overnight admission was unlikely to be required, or transferred to the Great Western or Grand Union wards. In the period between April 2014 and March 2015 there had been 75 in-patient admissions and 60 of these were through the ED.

IN-PATIENT CARE

Great Western Ward at St Mary's Hospital was a general paediatric ward with facilities for ward attender reviews. The Paediatric Short Stay Unit (PSSU) which was also based on Great Western Ward admitted children with a range of conditions, including those requiring elective surgical procedures.

Grand Union Ward consisted only of single rooms which were mainly used for immunosuppressed patients (oncology and stem cell transplant) and children with infectious diseases. The ward had 14 cubicles, including four with HEPA positive pressure filtration and two with negative pressure filtration. Six of the cubicles had en-suite bathrooms.

Patients were primarily the responsibility of the attending paediatric haematology consultant. The ward-based medical team provided support as required. Nurses were experienced in acute and chronic pain management including the use of patient and nurse controlled analgesia (PCA/NCA). Regular education was supported by a named nurse educator. Multi-disciplinary team support was provided by paediatric pharmacists, physiotherapists, a dietician and a psychologist. The wards were closely supported by the paediatric intensive care team. Exchange transfusions could be arranged at any time. During normal working hours this service was provided by automated exchange transfusion performed by the paediatric haematology senior nurses. Out of hours a manual exchange service was facilitated by the paediatric intensive care team.

The Paediatric Intensive Care Unit (PICU) had eight beds including two cubicles, one with positive/negative pressure filtration. The unit had capacity for conventional mechanical ventilation and oscillation and haemofiltration/haemodialysis. The unit included two high dependency beds.

Playrooms were available on both children's wards staffed by qualified play specialists. Grand Union Ward had an enclosed playroom for use by children requiring isolation. Great Western Ward had a playroom shared with the Paediatric Short Stay Unit. The Unit had a Hospital School providing in-patient education either at the patient's bedside or in the school room.

DAY CARE

The Paediatric Haematology Day Unit (PHDU) located on the 6th floor of the Queen Elizabeth Queen Mother Building at St Mary's Hospital was utilised for day-care treatment including red cell top-up and exchange transfusions. The PHDU included the suite for the haemoglobinopathy clinic and consisted of four beds, one isolation cubicle and four sofa spaces. The ward was nurse-led with an allocated haematology registrar. Regular support was provided by the paediatric haemoglobinopathy clinical nurse specialist. The Unit had one Spectra Optia Apheresis system primarily used for elective day care based red blood cell exchanges. In 2015, the average number for top up transfusions was 22 and for exchange transfusions was 14.

OUT-PATIENT CARE

Children with haemoglobinopathies were seen in a designated consultant-led clinic in the PHDU on a Monday afternoon. Multi-disciplinary support was provided by the paediatric haematology registrar, paediatric haemoglobinopathy clinical nurse specialist and the community specialist nurse. Access to a paediatric phlebotomy service was provided. Transcranial Doppler imaging was performed at the same time as the clinic. Combined haemoglobinopathy/respiratory and haemoglobinopathy/endocrine clinics were held every three and four months respectively. A combined haemoglobinopathy/audiology clinic had been established.

A monthly paediatric haemoglobinopathy adolescent clinic was held on the second Tuesday evening of every month and was attended by both the paediatric and adult haemoglobinopathy consultants and specialist nurses to facilitate the transition of care to the adult service at Hammersmith Hospital.

Outreach clinics were provided at West Middlesex, Luton & Dunstable and Watford General Hospitals, on average three times per year at each centre. The Transcranial Doppler service was organised to run at the same time as these clinics. Between April 2014 and March 2015 there were 42 first attendances and 429 follow-up appointments at St Mary's paediatric haemoglobinopathy clinic.

COMMUNITY-BASED CARE

The Central London Community Health Care Trust service covered Hammersmith & Fulham, Kensington & Chelsea and Westminster. The service was supported by one substantive nurse specialist and an agency nurse for paediatric and adult patients. A haemoglobinopathy antenatal counselling service was provided. Home visits were offered to all children with sickle cell disease and thalassaemia major up to the age of two years. Children who failed to attend clinic appointments were followed up by the service.

The community nurse was responsible for preparing school care plans, school and nursery talks and attending child protection meetings. The community nurse attended the weekly paediatric and adult clinic, the monthly adolescent clinic and the monthly multi-disciplinary meeting. Quarterly training sessions on sickle cell disease and thalassaemia were organised for health visitors and other health professionals.

Cover arrangements for annual and sick leave were not in place. It was not possible to review in details community services for residents in Barnet, Brent, Luton and other areas of Cambridgeshire and Hertfordshire.

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VIEWS OF SERVICES USERS AND CARERS

The visiting team met a small number of adult patients with sickle cell disease and received feedback from them. They received responses to 25 patient satisfaction survey questionnaires circulated by the Trust and a further 14 using the WMQRS template. The WMQRS patient feedback template had been devised for use by local teams to support the collection of patient feedback specifically about services for people with haemoglobin disorders. Feedback was largely positive particularly in relation to the medical attention received from the lead clinicians.

Common themes raised by adult patients and carers were:

- The patients were confused about which location they should use if needing medical care out of hours. None of them seemed sure about the new system since the closure of the Emergency Department.
- All the patients were aware of the 24-hour telephone number but they were disappointed that the number was apparently answered by non-specialist staff who could not answer queries and could not help them when they enquired where they should go

- The patients reported that there were not enough in-patient beds on ward D7 and were critical of the standard of the ward facilities.
- Waiting times in clinic were felt to be a problem at the Hammersmith Hospital but not at St Mary's Hospital
- Patients suggested that some kind of social media support group would be welcome
- The patients all reported that they had, at some point, been referred to associated specialists and commented that the process was very efficient

The visiting team met a small number of carers of children and young people with sickle cell disease and received feedback from them. They received responses to more than 200 local questionnaires from between 2013 and 2015 surveying experience in out-patient departments, wards and day units although these were not exclusively haemoglobinopathy patients.

Common themes raised by paediatric patients and carers were:

- Patients and carers were overall complimentary of the staff and service, reporting that staff were professional, helpful and supportive
- Carers appreciated timely review in the out-patient clinic

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REVIEW VISIT FINDINGS

NETWORK

General Comments

Adults

The North West London Network was one of the first to be established. Specialist care was provided by two large Trusts, Imperial College Healthcare NHS Trust and London North West Healthcare NHS Trust. Significant reconfiguration of services had taken place across the region including the closure of the Emergency Department at Hammersmith and Central Middlesex Hospitals. Since the previous peer review visits Central Middlesex, Ealing and Northwick Park Hospitals had successfully merged and the closure of the ED at Ealing Hospital was planned.

As a consequence of ongoing regional changes, funding for the network coordinator had been lost and the activity of the Network had been constrained. At the time of the visit Network meetings were being re-established.

Services for children and young people

Specialist care for paediatric haemoglobinopathy patients was provided by St Mary's Hospital, Imperial College Healthcare NHS Trust and Central Middlesex/Northwick Park Hospitals (London North West Healthcare NHS Trust). The specialist centres supported a number of local hospitals in the region and were responsible for annual reviews. St Mary's Hospital provided high dependency in-patient care for children and young people. Children requiring high dependency care were transferred there from Northwick Park Hospital. Some children who lived near Central Middlesex also tended to go to St Mary's for their in-patient care.

The North West London Network held educational events and hosted paediatric guidelines on the website. Both centres engaged with these educational events but there was no evidence of them working together clinically.

Progress since Last Visit

An annual network educational meeting for patients had been established since the previous review visits which took place in 2013 for adult services and in 2010 for services for children and young people.

Immediate Risks: No immediate risks were identified.

Good Practice

- 1 Outreach clinics were established although data for local haemoglobinopathy teams were not reviewed.

Immediate Risks: No immediate risks were identified.

Concerns

- 1 Community nursing time across the region was insufficient and community-based services provided in some areas should be reviewed.
- 2 It was not clear that patients in the network were receiving reviews by a specialist SHC. Reviewers were particularly concerned that paediatric patients from Ealing Hospital may not have been having annual reviews with a SHC. Access to automated apheresis was also variable.

Further Consideration

- 1 At the time of the visit interactions between the regional SHCs were limited, reviewers suggested that closer cooperation between the centres would be helpful to the effective functioning of the network.

NETWORK CONFIGURATION

It was noted that adult patients from the LHTs listed for Imperial attended either University College London Hospitals NHS Trust or Guy's and St Thomas' NHS Foundation Trust.

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

| Specialist Haemoglobinopathy Centre | Local Haemoglobinopathy Teams |
|---|---|
| Imperial College Healthcare NHS Trust (Hammersmith Hospital, St Mary's Hospital) | • Luton & Dunstable University Hospital NHS Foundation Trust (Luton & Dunstable Hospital) - paediatric only |
| | • West Hertfordshire Hospitals NHS Trust (Watford General Hospital) - paediatric only |
| | • Chelsea and Westminster Hospital NHS Foundation Trust (West Middlesex University Hospital) |
| | • The Hillingdon Hospitals NHS Foundation Trust (Hillingdon Hospital) |
| London North West Healthcare NHS Trust (Central Middlesex, Ealing and Northwick Park Hospitals) | • Bedford Hospital NHS Trust |

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SPECIALIST TEAM: IMPERIAL COLLEGE HEALTHCARE NHS TRUST – ADULT SERVICES

General Comments and Achievements

Considerable improvements had been made since the previous visit which took place in 2013. The Hammersmith Hospital team was able to offer a comprehensive service to their patient population. The closure of the ED at Hammersmith had been well managed with the development of an assessment area for medical specialties. An ambulatory area was available from Monday to Friday, between 8am and 8pm which improved access for patients with haemoglobin disorders. Other improvements included the appointment of a further haemoglobinopathy consultant as Deputy Lead for the service in 2014, opening of the ambulatory service for management of acute painful episodes in January 2014, appointment of a full time psychologist for the service in November 2014, appointment of a red cell research nurse in May 2015 and the forthcoming appointment, jointly with the Royal Brompton Hospital, of a fourth red cell consultant with expertise in haemoglobin disorders.

A strong quality and governance ethos was evident throughout the service. The quality management team performed all the required data entry onto National Haemoglobinopathy Registry (NHR) and also managed minutes and distribution of minutes from multi-disciplinary meetings, audits, incident reporting and morbidity/mortality meeting. There was evidence of high quality audit and service evaluation, each associated with action plans. This went far beyond the requirements set out in the Quality Standards.

The extensive portfolio of research was especially impressive. The appointment of a research nurse had enabled commencement of phase 1 studies.

Good Practice

- 1 Information for patients and staff on acute and chronic pain management was of high quality.
- 2 A range of scheduled educational sessions for all staff groups was available.
- 3 A social worker provided dedicated support for patients.
- 4 Regular user meetings and focus groups were held and allowed service users the opportunity to influence service developments.

Immediate Risks: No immediate risks were identified.

Further Consideration

- 1 Although protocols were available on the intranet, some of the staff were unable to access them when asked by the reviewing team.
- 2 Access to automated exchange at weekends was available but reviewers suggested that consideration should be given to extending the service hours on Mondays and Thursdays.
- 3 Reviewers suggested that consideration should be given to extending the Ambulatory Pain management service.
- 4 The environment of ward D7 was poor and cramped but a ward move was planned.
- 5 Access to adult neuropsychology services was not yet available.

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SPECIALIST TEAM: IMPERIAL COLLEGE HEALTHCARE NHS TRUST – PAEDIATRIC SERVICES

General Comments and Achievements

A well-functioning service was provided by a cohesive multi-disciplinary team. Strong medical and nursing leadership was evident. The managerial team was well-engaged with the service. Particular strengths of the service included the bone marrow transplant unit and the strong academic and research programme. The reviewers were particularly impressed by the dedicated team of quality managers. This team was a clear asset to the department. The nurse educator initiative had helped to train ward-based paediatric nursing teams in the use of patient/nurse controlled analgesia (PCA/NCA), helping to support timely pain management. The department was actively involved in quality improvement initiatives with a high turnaround of audit projects. The Paediatric High Dependency Unit (PHDU) facilities were of a high standard. A good training initiative was in place for nurse training. Local hospitals within the clinical Imperial College Paediatric Red Cell Disorders network felt well supported by the specialist centre.

Progress since Last Visit

Since the last review which took place in March 2010, a number of improvements had been implemented. The department was actively involved in quality improvement projects with audits of performance against key clinical standards. Babies identified through the newborn screening programme were reviewed in the recommended timescale.

Good Practice

- 1 Overall the clinical guidelines were of a high standard. The layout was particularly user-friendly and the guidelines were accessible both electronically and in hard copy format.
- 2 The multi-disciplinary team meetings were well-organised and well-attended. Documentation relating to discussion of individual cases was clearly recorded.
- 3 Good working relationships existed with other teams within the hospital, including with Paediatric Critical Care Unit staff who were particularly supportive.
- 4 The 24-hour telephone support provided for families by the senior nursing team was highly commendable.

Immediate Risks: No immediate risks were identified.

Concerns

- 1 Community nursing time for the local population from the Central London community service was insufficient to meet the needs of the population with only one w.t.e. and an agency nurse in place.
- 2 Administrative support to facilitate coordination of the network meetings, improve accrual of data, support governance and host guidelines on a managed website was insufficient to meet the service needs.

Further Consideration

- 1 Although the provision of psychology support was good, reviewers considered that additional psychology time would be desirable to support complex pain management. At the time of the visit psychology services were provided by Central and North West London Foundation NHS Trust (CNWL).
- 2 Evidence of regular teaching within the Emergency Department was provided, however a robust training programme for all healthcare professionals should be considered, as some nursing staff were unaware of the protocols and procedures relating to haemoglobin disorders.

- 3 Reviewers suggested that staffing of the automated exchange transfusion programme is reviewed to ensure staffing is sufficient for both elective and emergency procedures.
- 4 An operation policy/guideline detailing Trans-cranial Doppler scanning for children with sickle cell disease was seen. Inclusion of the formal process for internal quality assurance red within this document may be helpful. The reviewers also noted the recommendations for repeat scanning within the fail-safe arrangements for the different risk categories required review in order to align with latest recommendations.
- 5 Clinical guidelines on the management of chronic complications were incomplete and may benefit from review.

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ACCREDITED LOCAL TEAMS: CHELSEA AND WESTMINSTER, WEST MIDDLESEX, HILLINGDON AND EALING HOSPITALS

General Comments and Achievements

Several local hospitals with relatively small populations of patients with haemoglobin disorders worked closely with the team at Imperial. None of these were visited by the reviewers however consultant representatives from some of the services met the review team, plus a community nurse specialist from the Luton and Dunstable Hospital.

The haematology team at Chelsea and Westminster Hospital was employed by Imperial College Healthcare NHS Trust and provided care for approximately 30 to 40 adult patients. Annual reviews were performed on site but patients were referred to the Hammersmith Hospital team for exchange transfusion and discussion of hydroxycarbamide usage.

West Middlesex University Hospital had merged with Chelsea and Westminster Hospital and the consultant haematologists were employed by the Chelsea and Westminster Hospital NHS Foundation Trust. The population of patients with haemoglobinopathies was expanding. Patients were managed locally, including manual red cell exchange in some adult patients and annual reviews. All elective and emergency paediatric red cell exchanges, manual and automated, were undertaken at St. Mary's Hospital.

The team also met a consultant working in Hillingdon and Ealing Hospitals. A small population of patients with haemoglobinopathies was cared for mostly independently, including annual reviews and urgent exchange blood transfusions.

The hospital sites represented by the participating consultants were not formally visited as part of the review programme so review of compliance with the Quality Standards was not possible. All three consultants felt that their teams were well supported and had easy access to colleagues in Imperial College Healthcare NHS Trust both in and out of hours.

The community nurse specialist in Luton was responsible for supporting paediatric and adult patients.

Immediate Risks: No immediate risks were identified.

Further Consideration

Insufficient community-based services within the network were available and reviewers suggested that a network-wide review of community-based service provision may be helpful.

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COMMISSIONING

General Comments and Achievements

The visiting team met with a specialised commissioner during the visit. Also, during the visit to London North West Healthcare NHS Trust (LNWH), reviewers were informed that there had been meetings with the specialised commissioners over the previous 12 months.

From the perspective of LNWH local commissioned services, Brent CCG had supported the community sickle cell disease service for many years and had funded a support service for recently discharged patients in conjunction with the Sickle Cell Society. There appeared to be little contact between the CCG and the specialist commissioner in relation to the care of people with haemoglobin disorders.

Immediate Risks: No immediate risks were identified.

Concern

- 1 Evidence of engagement by specialised commissioners about services for people with haemoglobin disorders across both specialist haemoglobinopathy centres in the network was not presented to the review team.
- 2 The reviewers were concerned that not all patients were benefitting from access to a specialist centre for annual review and automated exchange, it is important for commissioners to clarify the arrangements for equitable access to services.
- 3 The commissioners should review the specialist support at Luton and Dunstable Hospital and in Ealing where the adults and paediatric teams were cared for by different specialist centres.

Further Consideration

- 1 Community services were under resourced for adult and paediatric patients within parts of the 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

| | | |
|-------------------|---|---|
| Edith Aimiwu | Paediatric Haemoglobinopathy Clinical Nurse Specialist | Whittington Health NHS Trust |
| Dr Penelope Cream | Clinical Psychologist | St George's University Hospitals NHS Foundation Trust |
| Dr Moira Dick | Consultant Paediatrician | Kings College Hospital NHS Foundation Trust |
| Sajid Hussain | Service User | Not applicable |
| Natasha Lewis | Lead Nurse Sickle Cell & Thalassemia | Homerton University Hospital NHS Foundation Trust |
| Elaine Miller | Co-ordinator | UK Thalassaemia Society |
| Siobhan Westfield | Service User | Not applicable |
| Dr Tullie Yeghen | Consultant Haematologist | Lewisham and Greenwich 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 | 44 | 42 | 95 |
| Haemoglobin Disorders Clinical Network | 9 | 8 | 89 |
| Commissioning | 3 | 1 | 33 |
| Total | 56 | 51 | 91 |

| Services for Children and Young People | Number of Applicable QS | Number of QS Met | % met |
|---|-------------------------|------------------|-----------|
| Specialist Services for People with Haemoglobin Disorders | 50 | 46 | 92 |
| Haemoglobin Disorders Clinical Network | 9 | 7 | 78 |
| Commissioning | 3 | 1 | 33 |
| Total | 62 | 54 | 87 |

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

| Ref | Quality Standard | Adult Services | | Services for Children and Young People | |
|---------------|--|----------------|--|--|---|
| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-101 All | <p>Haemoglobin Disorder Service Information</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> a. Brief description of the service, including times of phlebotomy, transfusion and psychological support services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. Staff of the service e. Community services and their contact numbers f. Relevant national organisations and local support groups g. Where to go in an emergency h. How to: <ol style="list-style-type: none"> i. Contact the service for help and advice, including out of hours ii. Access social services iii. Access benefits and immigration advice iv. Interpreter and advocacy services, PALS, spiritual support and HealthWatch (or equivalent) v. Give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns vi. Get involved in improving services (QS HN-199) | Y | <p>Information was available on the website but evidence of paper copies was not seen and patients stated that they did not have access to information.</p> <p>More clarity was needed on out of hours procedures and how to access the service.</p> | Y | <p>Patient information was available on the website. No hard copy was available for review. The transition information leaflet was not as comprehensive as other leaflets. Although the Focus group was mentioned, information on how to access it was not available.</p> |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-102 All | <p>Information about Haemoglobin Disorders</p> <p>Written information should be offered to patients and, where appropriate, their carers covering at least:</p> <ol style="list-style-type: none"> a. A description of the condition (SC or T), how it might affect the individual and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Splenic palpation and Trans-Cranial Doppler scanning (children only) e. Transfusion and iron chelation f. Possible complications, including priapism and complications during pregnancy g. Health promotion, including: <ol style="list-style-type: none"> i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Stopping smoking h. National Haemoglobinopathy Registry, its purpose and benefits i. Self-administration of medications and infusions | Y | Information was available on the website but evidence of paper copies was not seen and patients stated that they did not have access to information. | Y | Information about transfusions or splenic palpation was not seen although there was information about the spleen and immunisations needed before transfusions. Self-administration for chelation was covered but did not include pain relief. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-103 All | <p>Information for Primary Health Care Team</p> <p>Written information should be sent to the patient's primary health care team covering available local services and</p> <ol style="list-style-type: none"> a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). d. Immunisations e. Indications and arrangements for seeking advice from the specialist service | Y | | Y | GP letters were comprehensive. GPs were not involved in prescribing hydroxycarbamide. A leaflet on managing sickle cell disease in primary care was not yet in use but it was in the folder and provided useful information. An update of this was planned. |
| HN-104 All | <p>Care Plan</p> <p>All patients should be offered:</p> <ol style="list-style-type: none"> a. An individual care plan or written summary of their annual review including: <ol style="list-style-type: none"> i. Information about their condition ii. Plan for management in the Emergency Department iii. Planned acute and long-term management of their condition, including medication iv. Named contact for queries and advice b. A permanent record of consultations at which changes to their care are discussed <p>The care plan and details of any changes should be copied to the patients' GP and their local / specialist team consultant (if applicable).</p> | Y | | Y | Comprehensive GP letters were produced. Individual care plans were produced for those with unusual pain relief needs. |

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

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-107 SHC | <p>Information about Trans-Cranial Doppler Ultrasound</p> <p>Written information should be offered to patients and their carers covering:</p> <ol style="list-style-type: none"> Reason for the scan and information about the procedure Details of where and when the scan will take place and how to change an appointment Staff who will be present and will perform the scan Any side effects Informing staff if the child is unwell or has been unwell in the last week How, when and by whom results will be communicated | N/A | | N | Information was available but 'c' was not covered. |
| HN-199 All | <p>Involving Patients and Carers</p> <p>The service's involvement of patients and carers should include:</p> <ol style="list-style-type: none"> Mechanisms for receiving feedback from patients and carers An annual patient survey (or equivalent) Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service Examples of changes made as a result of feedback and involvement of patients and carers | Y | A good response to circulated questionnaires was received. | Y | Evidence was provided of regular local satisfaction surveys for out-patient, in-patient and day care services. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-201 All | <p>Lead Consultant</p> <p>A nominated lead consultant with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan.</p> | Y | | Y | |
| HN-202 All | <p>Cover for Lead Consultant</p> <p>Cover for absences of the lead consultant should be available. In SHCs this should be a named deputy within the SHC with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHC. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHC advice and support.</p> | Y | | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-203 All | <p>Lead Nurse</p> <p>A lead nurse should have appropriate time available for their leadership role and:</p> <ul style="list-style-type: none"> a. Responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders b. Responsibility for liaison with other services within the network c. RCN competences in caring for people with haemoglobin disorders d. Competences in the care of children and young people (children's services only) | Y | | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-204 All | <p>Staffing Levels and Competences</p> <p>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:</p> <ol style="list-style-type: none"> Medical staffing for clinics and regular reviews Medical staffing for emergency care, in and out of hours Nurse staffing on the ward and day unit Clinical nurse specialist/s with responsibility for the acute service Clinical nurse specialist/s with responsibility for the community service Nurses with competences in cannulation and transfusion available at all times patients attend for transfusion. Clinical or health psychologist with an interest in haemoglobin disorders <p>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHC/LHT).</p> <p>Staff working with children and young people should have competences in caring for children as well as in haemoglobin disorders.</p> <p>Cover for absences should be available.</p> | Y | Community services had limited time for adult care and were considered to be under-resourced. | Y | However the 0.8 w.t.e. of psychologist time was limited for the needs of the patient population particularly for complex pain management. See main report. |
| HN-205 All | <p>Competences and Training</p> <p>A training plan should ensure that all staff are developing and maintaining appropriate competences for their roles in the care of patients with haemoglobin disorders (QS HN-204).</p> | Y | | Y | |

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| | | 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 | Very few patients were admitted via the Emergency Department but a training package was in place. | Y | The reviewers were informed of regular training however a training plan was not seen. See 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 | |
| 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 | Red cell registrars had between six and eight weeks of experience only. | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-210 SHC | <p>Trans-Cranial Doppler Ultrasound Competences (Paediatric Services Only)</p> <p>Sufficient staff with appropriate competences for Trans-Cranial Doppler ultrasound should be available. Staff should undertake at least 40 scans per annum and complete an annual assessment of competence. Cover for absences should be available.</p> | N/A | | Y | Two sonographers participated in the service. An additional sonographer was scheduled to receive training. Formal accreditation data were seen for two individuals and one sonographer required supervision. Individual log books were available for review. |
| HN-299 All | <p>Administrative, Clerical and Data Collection Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.</p> | Y | Provision of data support and quality management was outstanding. | N | Administrative support for the Imperial College Paediatric Red Cell Disorders Network may enable greater coordination of the network meetings, to improve the accrual of data, to support governance and the hosting of guidelines on a managed website. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-301 All | <p>Support Services</p> <p>Timely access to the following services should be available:</p> <ul style="list-style-type: none"> 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) <p>In Specialist Centre's these staff should have specific competences in the care of people with haemoglobin disorders and sufficient time for patient care and for attending multi-disciplinary meetings (HN-602) if required.</p> | Y | | Y | Additional health psychology support may also benefit the management of children with chronic or complex pain. See main report. |
| HN-302 SHC | <p>Specialist On-site Support</p> <p>Access to the following specialist staff and services should be available on the same hospital site as the specialist team:</p> <ul style="list-style-type: none"> a. Manual exchange transfusion (24/7) b. Acute pain team including specialist monitoring of patients with complex analgesia needs c. Consultant obstetrician with an interest in care of people with haemoglobin disorders d. Respiratory physician with interest in chronic sickle lung disease e. High dependency care, including non-invasive ventilation f. Intensive care (note 2) | Y | | Y | A good training initiative was in place. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-303 SHC A-LHT | <p>Specialist Services - Network</p> <p>Access to the following specialist staff and services should be available:</p> <ul style="list-style-type: none"> a. Erythrocytapheresis b. Pulmonary hypertension team c. Fertility, contraception and sexual health services, including pre-implantation genetic diagnosis d. Consultant cardiologist e. Consultant endocrinologist f. Consultant hepatologist g. Consultant neurologist h. Consultant ophthalmologist i. Consultant nephrologist j. Consultant urologist with expertise in managing priapism and erectile dysfunction k. Orthopaedic service l. Specialist imaging, including <ul style="list-style-type: none"> i. MRI tissue iron quantification of the heart and liver ii. Trans-Cranial Doppler ultrasonography (children) m. Neuropsychologist n. DNA studies o. Polysomnography and ENT surgery p. Bone marrow transplantation services <p>Specialist services should have an appropriate level of specialist expertise in the care of people with haemoglobin disorders.</p> | Y | A pathway for neuropsychology was not yet in place. | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-304 All | Laboratory Services UKAS / CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MHRA compliance for transfusion should be available. | Y | | Y | |
| HN-401 All | Facilities Available The environment and facilities in phlebotomy, out-patient clinics, wards and day units should be appropriate for the usual number of patients with haemoglobin disorders. Services for children and young people should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages. | Y | The planned expansion of the in-patient facility should address the issues of medical outliers and difficulties in transferring some patients from local hospitals. The extension of ambulatory care was under consideration. | Y | Facilities were good but fairly cramped. |
| HN-402 All | Facilities for Out of Hours Care Facilities should be available for out of hour's transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. | Y | | Y | Friday evening transfusion service was available. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-501 SHC A-LHT | <p>Transition Guidelines</p> <p>Network-agreed guidelines on transition to adult care should be in use covering at least:</p> <ul style="list-style-type: none"> a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. A preparation period and education programme relating to transfer to adult care e. Communication of clinical information from paediatric to adult services f. Arrangements for monitoring during the time immediately after transfer to adult care g. Arrangements for communication between the Specialist Haemoglobinopathy Centres and Local Haemoglobinopathy Teams | Y | | Y | |
| HN-502 All | <p>Monitoring Checklists</p> <p>Checklists should be in use for:</p> <ul style="list-style-type: none"> a. First out-patient appointment (SHC & A-LHT only) b. Routine monitoring c. Annual review (SHC & A-LHT only) <p>Use of the checklists should cover both clinical practice and information for patients and families.</p> | Y | | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-503 LHT | <p>Clinical Guidelines: LHT Management and Referral</p> <p>Network-agreed guidelines on routine out-patient monitoring and management between annual reviews should be in use which specify the indications for telephone advice, early referral and immediate transfer to the Specialist Centre.</p> | N/A | | N/A | |
| HN-504 All | <p>Transfusion Guidelines</p> <p>Transfusion guidelines should be in use covering:</p> <ul style="list-style-type: none"> 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 | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-505 All | <p>Chelation Therapy</p> <p>Network-agreed clinical guidelines on chelation therapy should be in use covering:</p> <ul style="list-style-type: none"> 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 | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-506 All | <p>Clinical Guidelines: Acute Complications</p> <p>Network-agreed clinical guidelines on the management of acute complications should be in use covering at least:</p> <p>For patients with sickle cell disease:</p> <ul style="list-style-type: none"> a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision k. Acute splenic sequestration (children only) <p>For patients with thalassaemia:</p> <ul style="list-style-type: none"> l. Fever, infection and overwhelming sepsis m. Cardiac, hepatic or endocrine decompensation | Y | <p>However guidelines should include guidance for infected patients with penicillin sensitivity.</p> <p>Renal failure guidelines were short on the detail needed to aid acute management although separate Trust guidelines on management of acute kidney injury were available on the intranet.</p> | Y | The clinical guidelines were generally of a good standard. See good practice section of the main report. |
| HN-507 All | <p>Specialist Management Guidelines</p> <p>Network-agreed clinical guidelines should be in use covering the care of patients with sickle cell disease and thalassaemia:</p> <ul style="list-style-type: none"> a. During anaesthesia and surgery b. Who are pregnant c. Receiving hydroxycarbamide therapy | Y | | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-508 All | <p>Clinical Guidelines: Chronic complications</p> <p>Network-agreed clinical guidelines on the management of chronic complications should be in use covering at least:</p> <ul style="list-style-type: none"> a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain i. Liver disease j. Growth delay / delayed puberty (children only) k. Enuresis (children only) | Y | Excellent chronic pain guidance was available. | N | However, 'd', 'e', 'h' and 'k' were not available. |
| HN-509 SHC | <p>Referral for Consideration of Bone Marrow Transplantation</p> <p>Guidelines for referral for consideration of bone marrow transplantation should be in use.</p> | Y | | Y | |
| HN-510 All | <p>Thalassaemia Intermedia</p> <p>Network-agreed clinical guidelines for the management of thalassaemia intermedia should be in use, covering:</p> <ul style="list-style-type: none"> a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy | Y | | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-511 All | <p>Clinical Guideline Availability</p> <p>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.</p> | Y | Although guidelines and individual protocols were available staff in clinical areas had difficulty locating these on the intranet. | Y | Access to guidelines was easy electronically and hard copies were available if required in the ED. See good practice section of the main report. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-512 SHC | <p>Trans-Cranial Doppler Ultrasound Guidelines (Paediatric Services Only)</p> <p>Guidelines on Trans-Cranial Doppler ultrasound should be in use covering at least:</p> <ul style="list-style-type: none"> a. Identification of ultrasound equipment and maintenance arrangements b. Identification of staff performing Trans-Cranial Doppler ultrasound (QS HN-210) c. Arrangements for supervision of doctors in training performing Trans-Cranial Doppler ultrasound d. Ensuring all patients are given relevant information (QS HN-107) e. Use of an imaging consent procedure f. Guidelines on cleaning ultrasound probes g. Arrangements for recording and storing images and ensuring availability of images for subsequent review h. Reporting format, including whether mode performed was imaging or non-imaging i. Arrangements for documentation and communication of results j. Internal systems to assure quality, accuracy and verification of results k. Participation in the National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler ultrasound (when established) or local peer review arrangements (until NQAS established) | N/A | | Y | A guideline was in operation. There were two sonographers and both had completed external training. An additional sonographer was scheduled to receive training. An informal QA system was in operation though this was not described in the guideline/policy (j). 'c' was not applicable. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-601 All | <p>Service Organisation</p> <p>A service organisation policy should be in use covering arrangements for:</p> <ul style="list-style-type: none"> a. 'Fail-safe' arrangements for ensuring all children with significant haemoglobinopathy disorders who have been identified through screening programmes are followed up by a specialist SHC (SHC only) b. Ensuring all patients are reviewed by a senior haematology decision-maker within 12 hours of acute admission c. Patient discussion at multi-disciplinary team meetings (QS HN-602) d. Out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population e. Arrangements for liaison with community paediatricians and with schools (children's services only) f. 'Fail-safe' arrangements for ensuring all children and young people have Trans-Cranial Doppler ultrasound when indicated g. Follow up of patients who do not attend h. Transfer of care of patients who move to another area, including communication with all SHC, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHC, LHT and community services who will be taking over their care. i. Accessing specialist advice (QS HN-206) j. Two-way communication of patient information between SHC and LHTs k. If applicable, arrangements for coordination of care across hospital sites where key specialties are not located together | Y | | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-602 All | <p>Multi-Disciplinary Meetings</p> <p>Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community, other members of the service team (QS HN-204) and representatives of support services (QS HN-301).</p> | Y | Community staff found it very difficult to get to these meeting because of their workload. | Y | The multi-disciplinary meetings were well attended and clearly documented. See good practice section of the main report. |
| HN-603 All | <p>Service Level Agreement with Community Services</p> <p>A service level agreement for support from community services should be in place covering, at least:</p> <ol style="list-style-type: none"> Role of community service in the care of patients with haemoglobin disorders Two-way exchange of information between hospital and community services. | Y | The Trust had a memorandum of understanding in place with CLCH NHS Trust for community-based services. Both parties had approved this as an alternative to a formal service level agreement. | Y | The Trust had a memorandum of understanding in place with CLCH NHS Trust for community-based services. Both parties had approved this as an alternative to a formal service level agreement. |
| HN-604 All | <p>Network Review and Learning Meetings</p> <p>At least one representative of the team should attend each Network Review and Learning Meeting (QS HY-798).</p> | Y | | Y | |
| HN-605 SHC | <p>Neonatal screening programme review meetings</p> <p>The SHC should meet at least annually with representatives of the neonatal screening programme to review progress, discuss audit results (HN-704), identify issues of mutual concern and agree action.</p> | N/A | | Y | The screening review meetings were incorporated into the network review and learning meetings. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-701 SHC | <p>Data Collection</p> <p>Data on all patients, following patient or parental consent, should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.</p> | Y | Local teams did not have the capacity to submit NHR data. A small number attended Imperial for annual review but many underwent review in local hospitals. | Y | |
| HN-702 All | <p>Annual Data Collection - Activity</p> <p>The service should monitor on an annual basis:</p> <ol style="list-style-type: none"> Number of acute admissions, day unit admissions, Emergency Department attendances and out-patient attendances Length of in-patient stays Re-admission rate 'Did not attend' rate for out-patient appointments | Y | | Y | Clarification was required for 'd'. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-703 SHC | <p>Annual Data Collection – Network Patient Data</p> <p>The SHC should monitor on an annual basis, separately for sickle cell disease and thalassaemia:</p> <ol style="list-style-type: none"> a. Number of patients under active care in the network at the start of each year b. Number of new patients accepted by network services during the course of the year: <ol style="list-style-type: none"> i. Births ii. Transferred from another service iii. Moved into the UK c. For babies identified by the screening service: <ol style="list-style-type: none"> i. Date seen in clinic ii. Date offered and prescribed penicillin d. Number of network patients who had their comprehensive annual review undertaken and documented in the last year e. Number of network patients on long-term transfusion f. Number of network patients on chelation therapy g. Number of network patients on hydroxycarbamide h. Number of paediatric patients (HbSS and HbSB) who have had Trans-Cranial Doppler ultrasonography undertaken within the last year i. Number of pregnancies in network patients j. Number of network patients whose care was transferred to another service during the year k. Number of network patients who died during the year l. Number of network patients lost to follow up during the year | N | Annual data collection was not monitored for network patient data. | N | The specialist centre had been unable to collect this data in view of the limited data support available. The appointment of the data collection manager had begun to help facilitate local data collection. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-704 All | <p>Audit Clinical audits covering the following areas should have been undertaken within the last two years:</p> <p>Achievement of screening follow-up standards:</p> <ul style="list-style-type: none"> 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 <p>For patients with sickle cell disease:</p> <ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> i. at risk of stroke who have been offered and/or are on long-term transfusion programmes ii. who have had a stroke <p>For patients with thalassaemia:</p> <ul style="list-style-type: none"> 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 <p>All patients:</p> <ul style="list-style-type: none"> k. Waiting times for transfusion | Y | | Y | The Trust had participated in many audit projects and good demonstration of learning and action was seen. See good practice section of the main report. The reviewers noted poor compliance with the NICE recommendation of analgesia within 30 minutes of arrival in the ED although the reviewers noted the recent introduction of a new pain management protocol. |

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|---------------|--|----------------|---|--|--|
| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-705 All | <p>Guidelines Audit</p> <p>The service should have a rolling programme of audit, including:</p> <ul style="list-style-type: none"> a. Audit of implementation of clinical guidelines (QS HN-500s). b. Participation in agreed network-wide audits. | Y | | Y | |
| HN-706 SHC | <p>Research</p> <p>The SHC should actively participate in research relating to the care of patients with haemoglobin disorders.</p> | Y | Outstanding commitment to research was evident. | Y | Evidence was provided of an extensive research programme. |
| HN-707 SHC | <p>Trans-Cranial Doppler Quality Assurance (Paediatric Services Only)</p> <p>The service should monitor and review at least annually:</p> <ul style="list-style-type: none"> a. Whether all staff performing Trans-Cranial Doppler ultrasound have undertaken 40 procedures in the last year (QS HN-210 and HN-512) b. Results of internal quality assurance systems (QS HN-512) c. Results of National Quality Assurance Scheme (NQAS) for Trans-Cranial Doppler Ultrasound (when established) or local peer review arrangements (until NQAS established) d. Results of 'fail-safe' arrangements and any action required | N/A | | Y | Individual log books for two sonographers were seen. Process for 'b' not described but results of external assessment available for review. Timeliness of scanning for individual risk categories in guideline requires review. See main report. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HN-798 All | <p>Review and Learning</p> <p>The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, audit results, incidents and 'near misses'. This should include:</p> <ul style="list-style-type: none"> 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 | <p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.</p> | N | Although document control processes were in place there did not seem to be a mechanism to ensure printed versions were kept updated. | Y | In some cases it was not clear if the guideline had been formally approved. |

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HAEMOGLOBIN DISORDERS CLINICAL NETWORK

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HY-199 | <p>Involving Patients and Carers</p> <p>The network should have mechanisms for involving patients and their carers from all services in the work of the network.</p> | Y | | Y | |
| HY-201 | <p>Network Leads</p> <p>The network should have a nominated:</p> <ol style="list-style-type: none"> Lead consultant and deputy Lead specialist nurse for acute care Lead specialist nurse for community services Lead manager Lead for service improvement Lead for audit Lead commissioner | Y | | N | However network leads had been agreed for the Imperial College Paediatric Red Cell Disorders Network. |
| HY-202 | <p>Education and Training</p> <p>The network should have agreed a programme of education and training to help services achieve compliance with Qs HN-204 and HN-205.</p> | Y | | Y | |

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|--------|--|----------------|---|--|--|
| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HY-501 | <p>Transition Guidelines</p> <p>Network guidelines on transition to adult care should have been agreed covering:</p> <ol style="list-style-type: none"> Age guidelines for timing of the transfer Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer Allocation of a named coordinator for the transfer of care Communication of clinical information from paediatric to adult services Arrangements for monitoring during the time immediately after transfer to adult care Arrangements for communication with Local Haemoglobinopathy Team (if applicable) <p>Guidelines should be explicit about transition directly to any accredited LHTs.</p> | Y | The clinical guidelines for adults and children with haemoglobin disorders produced by both SHCs within North West London had been reviewed and ratified by the protocol sub-group of the managed clinical network. | Y | Transition guidelines were available for both the Imperial College Paediatric Red Cell Disorders Network and North West London Haemoglobinopathy Managed Clinical Network. |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HY-502 | <p>Clinical Guidelines</p> <p>Network guidelines should have been agreed covering:</p> <ol style="list-style-type: none"> Annual review (QS HN-502) Routine monitoring (QS HN-503) Transfusion (QS HN-504) Chelation therapy, including guidelines for shared care with general practice (QS HN-505) Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-303) Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-303) Specialist management (QS HN-507) Thalassaemia intermedia (QS HN-510) <p>Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHCs.</p> | Y | The clinical guidelines for adults and children with haemoglobin disorders produced by both SHCs within North West London Network had been reviewed and ratified by the protocol sub-group of the managed clinical network. | Y | All Imperial College Paediatric Red Cell Network guidelines were agreed and utilised by clinical teams at LHTs within the network. |
| HY-701 | <p>Ongoing Monitoring</p> <p>The network should monitor on a regular basis:</p> <ol style="list-style-type: none"> Submission of data on all patients to the National Haemoglobinopathy Registry (QS HN-701) Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year. | Y | | Y | |

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| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HY-702 | <p>Audit</p> <p>The network should have an agreed programme of audit and review covering network-wide achievement of Qs HN-703, HN-704, HN-705 and HN-707.</p> | Y | | Y | |
| HY-703 | <p>Research</p> <p>The network should have agreed:</p> <ol style="list-style-type: none"> A policy on access to research relating to the care of patients with haemoglobin disorders A list of research trials available to all patients within the network. | N | A network research policy was not yet in place. | N | A network research policy was not yet in place. |
| HY-798 | <p>Network Review and Learning</p> <p>The SHC should meet at least twice a year with its referring LHT teams to:</p> <ol style="list-style-type: none"> Identify any changes needed to network-wide policies, procedures and guidelines Review results of audits undertaken and agree action plans Review and agree learning from any positive feedback or complaints involving liaison between teams Review and agree learning from any critical incidents or 'near misses', including those involving liaison between teams Consider the content of future training and awareness programmes (QS HY-202) | Y | | Y | |

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COMMISSIONING

| Ref | Quality Standard | Adult Services | | Services for Children and Young People | |
|--------|---|----------------|---|--|---|
| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HZ-601 | <p>Commissioning of Services</p> <p>Commissioners should have agreed the configuration of clinical networks based on the expected referral pattern to each SHC and LHT and, within each network, the configuration and location of services for people with haemoglobin disorders across each network, taking into account the type of patient (sickle cell and/or thalassaemia) who will be treated by each team, in particular:</p> <ol style="list-style-type: none"> Designated SHC/s for the care of people with sickle cell disease Designated SHC/s for the care of adults with thalassaemia Any agreements for delegation of annual reviews to accredited LHTs for care of people with sickle cell disease or thalassaemia Other LHTs/Linked providers for care of adults with sickle cell disease or thalassaemia Community care providers | N | Documentation on the formal commissioning arrangement was not seen as this work had not yet been undertaken. | N | Documentation on the formal commissioning arrangement was not seen as this work had not yet been undertaken. |
| HZ-701 | <p>Clinical Quality Review Meetings</p> <p>Commissioners should regularly review the quality of care provided by:</p> <ol style="list-style-type: none"> Each service, in particular QS HN-703 Each network, in particular, achievement of QS HY-702 and QS HY-798. Service and network achievement of relevant QSS | N | Regular clinical quality review meetings for services for people with haemoglobin disorders were not yet in place. However commissioners were engaged with the service through regular commissioner-clinician meetings. | N | Regular clinical quality review meetings for services for people with haemoglobin disorders were not yet in place. However commissioners were engaged with the service through regular commissioner-clinician meetings. |

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|--------|--|----------------|-------------------|--|-------------------|
| | | Met? Y/N | Reviewer Comments | Met? Y/N | Reviewer Comments |
| HZ-798 | <p>Network Review and Learning</p> <p>Commissioners should attend a Network Review and Learning meeting (HY-798) at least once a year for each network in their area.</p> | Y | | Y | |

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