WM QRS West Midlands Quality Review Service

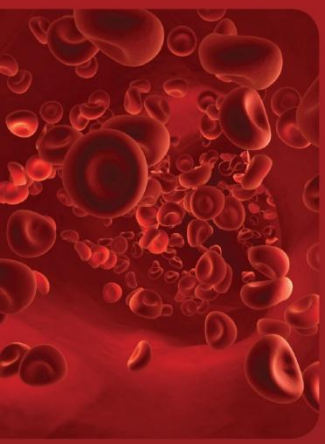
UK Forum on Haemoglobin Disorders

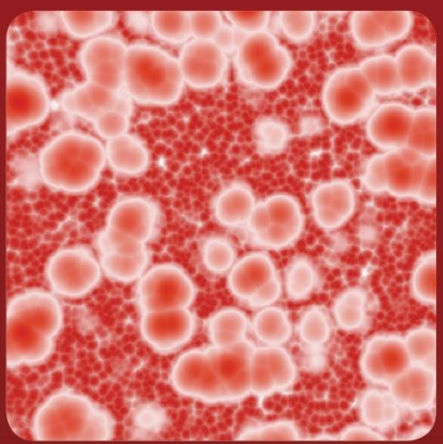
# Health Services Caring for Adults with Haemoglobin Disorders

## South West London

## St George's Healthcare NHS Trust

**Visit Date: October 10th 2012** **Report Date: April 2013**

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## INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia in the South West London Network, in particular St George's Healthcare NHS Trust, which took place on October 10th 2012. The purpose of the visit was to review compliance with the '*Quality Standards for Health Services Caring for Adults with Haemoglobinopathies',* 2011. The visit was organised by the West Midlands Quality Review Service and supported by the UK Forum on Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Programme.


## ACKNOWLEDGEMENTS

We would like to thank the staff of St George's Healthcare NHS Trust and Epsom and St Helier University Hospitals 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.


## ADULT HAEMOGLOBIN DISORDERS SERVICES IN SOUTH WEST LONDON SICKLE AND THALASSAEMIA NETWORK

| Trust | Reviewed as: | Hospital(s) |
|---|---|---|
| St George's Healthcare NHS Trust | Specialist Haemoglobinopathy Team (SHT) | St George's, University of London |
| Epsom and St Helier University Hospitals NHS Trust | Accredited Local Haemoglobinopathy Team (A-LHT) | St Helier Hospital<br>Epsom Hospital |
| Kingston Hospital NHS Trust | Linked Hospital | Kingston Hospital |
| Ashford and St Peter's Hospitals NHS Foundation Trust | Linked Hospital | St. Peter's Hospital, Chertsey |
| Surrey and Sussex Healthcare NHS Trust | Linked Hospital | East Surrey Hospital, Redhill |

| Trust | Reviewed as: | No. patients with sickle cell disease | No. patients with thalassaemia | No. patients on long term red cell transfusions |
|---|---|---|---|---|
| St George's Healthcare NHS Trust | SHT | 236 | 12 | 37 |
| Epsom & St Helier University Hospitals NHS Trust | A-LHT | 60 | - | - |

## NETWORK

St George's Healthcare NHS Trust was the specialist centre in South West London. The network included St Helier Hospital as an accredited centre and Kingston, St Peter's Hospital, Chertsey and East Surrey Hospital, Redhill as linked hospitals

In addition to the clinical network St George's was part of the broader South Thames Sickle Cell and Thalassaemia (STSCT) Network, which was formed in 2011 and covered educational, governance and research activities for the whole South Thames area. This Network was a collaboration led by the Consultant Haematologists and Paediatricians at King's College Hospital NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust, but including all the clinicians within both the South East and South West London clinical networks.

## SPECIALIST TEAM: ST GEORGES HEALTHCARE NHS TRUST

St George's Healthcare NHS Trust, South West London had a main hospital site with almost 1,000 beds and provided secondary and tertiary care to a population of approximately 400,000. All the major specialties were present on a single site. This was a large teaching hospital with a haematology department providing care for the whole range of malignant and non-malignant haematological disorders. The haemoglobinopathy service was led by a consultant appointed just over 12 months before the visit. The service catered for a population of around 300 to 400 patients with sickle cell disease who attend regularly and a small population with thalassaemia. At the time of the visit data for 48 adult patients had been entered onto the National Haemoglobinopathy Registry (NHR) which was approximately one third of those seen since recording on the NHR began. In 2011 to 2012 there had been 169 admissions.

**Accident and Emergency**

Approximately 200 patients per annum with complications of sickle cell disease accessed care via the Accident and Emergency Department (A&E) but were then admitted under the care of the haematology department. During working hours the patients were reviewed in A&E by the haematology team. Out of normal working hours there was a resident medical SHO-level doctor who reviewed patients for admission and discussed them with the on call (non-resident) haematology registrar or consultant. A lead A&E consultant and nursing sister for haemoglobinopathy patients worked closely with the haematology team and were responsible for the implementation of appropriate guidelines.

**Out-patient facilities**

Haemoglobinopathy clinics were held weekly in a dedicated haemato-oncology out-patient clinic. The specialist nurse and psychologist ran concurrent clinics with the lead clinician and a specialist registrar.

The haematology day case facility was adjacent to the main in-patient area which also housed the apheresis unit. There was a large population of patients on a regular red cell exchange programme. The apheresis unit was staffed on a 24 hour basis and had three apheresis machines. A Trust-wide venous access service was available for patients with poor venous access.

**In-Patient Facilities**

Haematology in-patients were accommodated in dedicated haematology wards.

**Community Services**

Community services were provided from Balham Health Centre. The staff there consisted of one clinical nurse specialist (CNS) for adults, one CNS for paediatrics and one Specialist Midwife Genetic Counsellor for Haemoglobinopathies.

**User Feedback**

The review team met with a group of service users.

## ACCREDITED LOCAL TEAM: EPSOM AND ST HELIER UNIVERSITY HOSPITALS NHS TRUST

St Helier Hospital, an accredited local team, provided care for approximately 60 patients with sickle cell disease. There were no thalassaemia patients at the time of the review although some were in the process of transition from children's services. The review team had a face-to-face meeting and detailed discussion with the lead consultant about the services offered at St Helier but did not visit facilities or talk to other staff at the hospital.

# REVIEW VISIT FINDINGS

## NETWORK

**General Comments**

The South West London Network was functioning, but not fully operational.

## SPECIALIST TEAM: ST GEORGE'S HEALTHCARE NHS TRUST

**General Comments and Achievements**

A highly effective and committed team operated at St George's. The reported improvements in care for patients were impressive and had been achieved in a remarkably short time. It was clear that the team had many plans for innovative service improvement and collaboration with colleagues in the community. Plans were in place to strengthen and formalise this relationship further. The peer review team was impressed by the strong multidisciplinary team ethos at St George's. Much had been achieved by the haemoglobinopathy team in the preceding year.

Regular educational sessions for all staff were held by the specialist team. Hard copies of individual pain protocols were kept in the A&E department. Changes to IT provision in the Trust meant that it was not possible to view the intranet versions of the guidelines at the time of the visit.

The apheresis unit was staffed on a 24 hour basis by an enthusiastic team. An excellent Trust-wide venous access service was available for patients with poor venous access.

Haemoglobinopathy patients were admitted to haematology beds wherever possible and outlier rates were low. Facilities for teenage / young adult patients were not available.

Community services were led by a highly motivated GP commissioner and public health consultant. Novel and exciting work was being undertaken with Wandsworth Clinical Commissioning Group (CCG) to integrate primary care, the community team and secondary care. This had led to the generation of service-specific Commissioning for Quality Innovations (CQUINs) and key performance indicators to drive further improvements in care. The work with the CCG enabled start of work on a specialist pain programme. Work between the CCG, the community team and the acute services to reduce admission rates and 'did not attend' rates was ongoing.

Users made it clear that there had been a radical improvement in patient experience over the last 12 months. The roles of the lead clinician, specialist nurse and psychologist in this change were all acknowledged.

**Good Practice**

The educational programme, provided to staff at all levels and all grades in primary and secondary care, was excellent. It was supported by readily usable guidelines. The in-house nurse education programme was reinforced by standardised RCN competence assessments. It was a significant achievement that these competences were being implemented into clinical nursing practice. The apheresis service was of high quality and was provided on a 24 hour basis.

**Immediate Risk:** No immediate risks were identified.

**Concerns**

1 The day unit and out-patient facilities appeared cramped for the number of patients using the department. Out of hours transfusion was not yet available.

2 Data management and administration support was insufficient, limiting the number of patients registered on the National Haemoglobinopathy Registry (NHR).

3 Staffing levels were insufficient. There was no effective cover for the lead consultant and clinics were not held when the lead consultant was absent. There was only one clinical nurse specialist (CNS) with cover only from the Day Unit Sister. Community Staff attended multidisciplinary team meetings but did not see patients on the ward. These staffing levels were of particular concern given the number of patients cared for by the service.

**Further Consideration**

1 Improvements in patient information could be easily achieved by cooperation with other South Thames Network partners.

2 Considering the size of the patient population there was little evidence of non-specialist nursing staff attending National Sickle Cell and Thalassaemia courses.

3 Although the guidelines were user-friendly the arrangements for finding these on the Trust intranet were not clear.

4 Many of the individualised pain protocols were out of date and may benefit from review.

5 There was a disparity in pain management between paediatric and adult services with intravenous infusions of morphine being used in paediatrics and regular morphine injections being used predominantly in adult patients. This might cause additional problems for patients during transition and

should be addressed. The team at St Helier had considerable experience in patient-controlled analgesia. The development of joint protocols and training across the network may be helpful.

6 Data on annual reviews were not yet being entered onto the National Haemoglobinopathy Register.

7 Although a number of audits into various aspects of patient care had been undertaken the action plans to address deficiencies were not always clear.

8 The service may benefit from having appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'.

## ACCREDITED LOCAL TEAM: EPSOM AND ST HELIER UNIVERSITY HOSPITALS NHS TRUST

**General Comments and Achievements**

The team at St Helier provided a good service with minimal resources. Its relationship with the team at St George's was strong and productive. The planned development of multi-disciplinary teams and combined protocols will improve services further. A visit to St Helier Hospital was not scheduled as part of the review visit. The conclusions reached here were therefore made on the basis of the evidence provided and discussion with the lead consultant, specialist nurse and service users.

Much had been achieved by the haemoglobinopathy team over the last year. A committed team operated cooperatively on the two sites.

The presentation of some of the information by the St Helier team made it difficult to match the evidence with the Quality Standards. The review team recognised that some aspects may have been clearer if a site visit had been undertaken.

The users interviewed reported high levels of confidence in the staff and the services provided.

**Immediate Risk:** No immediate risks were identified.

**Concerns**

1 Details of patients and annual reviews were not being entered on the National Haemoglobinopathy Registry.

2 The absence of data management support made submissions to the National Haemoglobinopathy Registry difficult and consideration should be given to providing this support.

3 The guidelines were incomplete and presented in a non-user friendly form. The team should consider adapting the St George's guidelines for use locally.

**Further Consideration**

1 Links between the two centres may benefit from a more formal arrangement, particularly with respect to common protocols and clarification of referral arrangements for specialist services, for example, ophthalmology where there was no local expertise.

2 As there was little experience in the case of patients with thalassaemia at St Helier, due to the small numbers of patients, it may be helpful for any thalassaemia patients transitioning from paediatrics to be seen at St George's Hospital for follow up.

3 Although there were cover arrangements for the lead consultant and nurse these were not robust and require further consideration.

## COMMISSIONING

**General Comments and Achievements**

The Lead Clinician for Haemoglobinopathy services had developed strong links with Wandsworth Clinical Commissioning Group (CCG) and, together, were making excellent progress in integrating all aspects of care. The review team felt that these developments were exemplary.

A large proportion of St George's patients came from Sutton and Merton and at the time of the visit links with commissioners were not yet achieving similar service integration.

In-patient and iron chelation elements of the service had been commissioned through the London Specialised Commissioning Group since April 2012. As a tertiary centre the service had a plan in place to be fully commissioned by the NHS Commissioning Board from April 2013. Initial commissioning initiatives were in place including commissioner and clinician meetings and review of morbidity and mortality data.

**Immediate Risk**

No immediate risks were identified.

**Concern**

1 Within the South West London Network several other small hospitals appeared to have a relationship with St George's as a Specialist Haemoglobinopathy Centre. In reality formal links did not exist. It was not clear whether there were any patients currently receiving local care but without specialist input.

## APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

| | | |
|---|---|---|
| Dr Josh Wright | Lead Consultant | Sheffield Teaching Hospitals NHS Foundation Trust |
| Dr Nick Jackson | Consultant Haematologist | University Hospitals Coventry and Warwickshire NHS Trust |
| Natasha Lewis | Specialist Nurse | East London NHS Foundation Trust |
| Neill Westerdale | Advanced Nurse Practitioner Haemoglobinopathies | Dept of Haemotology, Guy's & St Thomas' NHS Foundation Trust |
| Teresa Warr | Head of Service Development | South Central Specialised Services Commissioning Group |
| Elaine Miller | Voluntary Sector Representative | UK Thalassaemia Society |
| Pip Maskell | Quality Manager | Haemoglobin Disorders Review on behalf of WMQRS |

# APPENDIX 2: COMPLIANCE WITH QUALITY STANDARDS

**The Quality Standards are in the following sections:**

**HN - Services for Adults with Haemoglobin Disorders**

**HY - Haemoglobin Disorders Network (Adults):**
Quality Standards for Haemoglobin Disorders Clinical Networks are given separately from those for Specialist Haemoglobinopathy Teams. These Standards are the responsibility of Specialist Haemoglobinopathy Teams but, by agreement, the functions may be delegated to other organisations or coordinating groups.

**HZ - Haemoglobin Disorders – Commissioning**
These Quality Standards are the responsibility of commissioners.

Each section covers the following topics:

100 - Support for Service Users and their Carers
200 - Staffing
300 - Support Services
400 - Facilities and Equipment
500 - Guidelines and Protocols
600 - Service Organisation and Liaison with Other Services
700 - Governance

NOTE. Different Quality Standards (QSs) are not comparable in terms of their importance or likely impact on the quality or outcomes of the service, and a figure summarising the number of QS's met cannot be used to assess the overall standard of the services provided or to compare this Trust's services with others.

## SERVICES FOR ADULTS WITH HAEMOGLOBIN DISORDERS

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-101 All | **General Support for Service Users and Carers**<br>Service users and their carers should have easy access to the following services. Information about these services should be easily available:<br>a. Interpreter services, including access to British Sign Language<br>b. Independent advocacy services<br>c. PALS<br>d. Social workers<br>e. Benefits advice<br>f. Spiritual support<br>g. *HealthWatch* or equivalent organisation | Y | | Y | |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-102 All | **Haemoglobin Disorder Service Information**<br>Written information should be offered to patients and, where appropriate, their carerscovering at least:<br>a. Brief description of the service, including times of phlebotomy and transfusion services<br>b. Clinic times and how to change an appointment<br>c. Ward usually admitted to and its visiting times<br>d. How to contact the service for help and advice, including out of hours<br>e. Staff of the service<br>f. Community services and their contact numbers<br>h. Relevant support groups<br>g. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns<br>h. How to get involved in improving services (QS HN-199) | Y | | Y | However,'d'did not have adequate information. |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-103 All | **Information about Haemoglobin Disorders**<br>Written information should be offered to patients and, where appropriate, their carers covering at least:<br>a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment<br>b. Problems, symptoms and signs for which emergency advice should be sought<br>c. How to manage pain at home (SC only)<br>d. Where to go in an emergency<br>e. Health promotion, including:<br>i. Information on contraception and sexual health<br>ii. Travel advice<br>iii. Vaccination advice<br>iv. Staying well through a healthy diet, exercise and not smoking.<br>f. Where to go for further information, including useful websites and national voluntary organisations | N | There were plans to produce a leaflet for some areas.<br>Good information on sickle cell disease was reviewed, however, there was only awareness information for thalassaemia. | N | The information for 'e''i' and 'e' 'iii' was too general and there was no information for thalassaemia. Consideration should be given to using patient information that is produced in other centres in the network. |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-104 All | **Information for Primary Health Care Team**<br>Written information for the patient's primary health care team should be available covering their roles and responsibilities, including:<br>a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC)<br>b. Information covering side effects of medication, including chelator agents [SC and T]<br>c. Guidance for GPs on shared care for hydroxycarbamide and iron chelation therapy (if being prescribed by GPs). | N | Written information for the primary healthcare team was not available. Shared care arrangements were not applicable for 'c' as GPs were not prescribing hydroxycarbamide. | N | Written information for the primary healthcare team was not available. Shared care arrangements were not applicable for 'c' as GPs were not prescribing hydroxycarbamide. |
| HN-105 All | **Care Plan**<br>All patients should be offered:<br>a. An individual care plan or a written summary of their annual review<br>b. A permanent record of consultations at which changes to their care are discussed | Y | However, many of the individualised pain protocols were out of date. | Y | However, it was not clear how the evidence from the annual review was used to improve the service provided. |
| HN-106 SHT<br>A-LHT | **Transition Information**<br>Information should be available for young people covering arrangements for transition to adult care. This information should cover all aspects of QS HN-501. | Y | However, pain management between paediatric and adult services was different with Patient Controlled Analgesia (PCA) unavailable in adult services. | Y | There was an excellent 'Welcome Pack'. |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-199 All | **Involving Patients and Carers**<br>The service should have:<br>a. Mechanisms for receiving feedback from patients and carers<br>b. A rolling programme of audit of patients' and carers' experience<br>c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service. | Y | | Y | However, further arrangements for a rolling programme were needed. |
| HN-201 All | **Lead Consultant**<br>A nominated lead consultant haematologist with an interest in the care of patients with haemoglobin disorders should have responsibility for guidelines, protocols, training and audit relating to haemoglobin disorders, and overall responsibility for liaison with other services within the network. The lead consultant should undertake Continuing Professional Development of relevance to this role and should have session/s identified for this role within their job plan. | Y | | Y | |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-202 All | **Cover for Lead Consultant**<br>Cover for absences of the lead consultant should be available. In SHTs this should be a named deputywithin the SHT with regular experience caring for people with haemoglobin disorders or through agreed arrangements for cover from another SHT. In LHTs this should be a named deputy with regular experience caring for people with haemoglobin disorders with agreed arrangements for access to SHT advice and support. | N | A named cover was available, however the cover provided was emergency cover. There was no cover for ongoing work and routine clinics. Continuing Personal Development relating to haemoglobinopathy was not evident for the covering consultant. | N | However, emergency cover only was available. |
| HN-203 All | **Lead Nurse**<br>A lead nurse should have responsibility, with the lead consultant, for guidelines, protocols, training and audit relating to haemoglobin disorders, and responsibility for liaison with other services within the network. The lead nurse should have RCN competences in caring for people with haemoglobin disorders. | Y | However, there was some confusion regarding the definition of the role. | Y | |
| HN-204 All | **Cover for Lead Nurse**<br>Cover for absences of the lead nurse should be available. | N | No formal cover was available for the lead nurse. | N | No formal cover was available for the lead nurse. |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-205 All | **Staffing Levels and Competences**<br>The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including:<br>a. Medical staffing<br>b. Nurse staffing on the ward and day unit<br>c. Nurse specialist or counsellor who provides support for patients in the community.<br>Staffing levels should be appropriate for the number of patients cared for by the service and its role in the network (SHT / LHT). Cover for absences should be available. | N | Staffing levels were insufficient. There was no effective cover for the lead consultant and clinics were not held when the lead consultant was absent. There was only one CNS with cover only from the day unit Sister. Community staff attended MDT meetings but did not see patients on the ward. These staffing levels were of particular concern given the number of patients cared for by the service. | N | However, they planned to check that the competences were met. |
| HN-206 All | **Training Plan**<br>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-205). | Y | An excellent training programme was available which included competence assessment. | N | No training plan or records were available, but there was evidence of training materials being used. |
| HN-207 All | **Training Plan – Other Staff**<br>A programme of induction and training covering the care of patients with haemoglobin disorders should be run for:<br>a. Clinical staff in the Emergency Department<br>b. Non-consultant medical staff<br>c. Allied health professionals working with the SHT / LHT (QS HN-301). | Y | A programme of ongoing training for staff in all areas and at all levels was running. | N | However, there was evidence of informal training. |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-298 All | **Administrative and Clerical Support**<br>Administrative, clerical and data collection supportshould be appropriate for the number of patients cared for by the service. | N | The Quality Manager did not have sufficient time to meet all the requirements of the NHR. | N | Administrative support for data collection and analysis was not available. |
| HN-301 All | **Support Services**<br>Timely access to the following services should be available:<br>a. Dietetics<br>b. Physiotherapy<br>c. Occupational therapy<br>d. Leg ulcer service | Y | | N | No evidence was presented for this standard. |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-302 All | **Specialist Services**<br>Access to the following specialiststaff and services should be available:<br>a. Erythrocytopheresis or manual exchange transfusion (24/7)<br>b. Acute and chronic pain team<br>c. Pulmonary hypertension team<br>d. Consultant obstetrician<br>e. Fertility services<br>f. Consultant cardiologist<br>g. Consultant endocrinologist<br>h. Consultant hepatologist<br>i. Consultant ophthalmologist<br>j. Consultant nephrologist<br>k. Consultant urologist with expertise in managing priapism and erectile dysfunction<br>l. Orthopaedic service<br>m. Psychologist with an interest in haemoglobinopathies<br>n. Specialist imaging<br>o. DNA studies | Y | | N | Evidence for 'e', 'f', 'g', 'i', 'j', 'k' or 'l' was not seen by the review team. |
| HN-303 All | **Laboratory Services**<br>CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available. | Y | | Y | |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-401 All | **Facilities available**<br>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. | Y | However, the Day Unit was only adequate for the current patient population. | N/A | The facilities were not seen by the reviewers. |
| HN-402 All | **Facilities for Out of Hours Care**<br>Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. | N | An out of hours service was not provided. | N/A | The facilities were not seen by the reviewers. |
| HN-501 SHT<br>A-LHT | **Transition Guidelines**<br>Guidelines on transition to adult care should be in use covering at least:<br>a. Age guidelines for timing of the transfer<br>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<br>c. Allocation of a named coordinator for the transfer of care<br>d. Communication of clinical information from paediatric to adult services<br>e. Arrangements for monitoring during the time immediately after transfer to adult care<br>f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) | Y | | Y | |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-502<br>SHT<br><br>A-LHT | **Clinical Guidelines: Annual Review**<br><br>Clinical guidelines should be in use covering:<br>a. First out-patient appointment<br>b. Annual review for both sickle cell disease and thalassaemia | Y | | N | A clinical guideline for first appointments was planned. Thalassaemia patients were sent to St George's, so 'b' was not applicable. |
| HN-503<br>All | **Clinical Guidelines: Routine Monitoring**<br><br>Clinical guidelines on routine out-patient monitoring and management between annual reviews should be in use. Local Haemoglobinopathy Team guidelines should specify the indications for early referral to the Specialist Haemoglobinopathy Team. | Y | | N | There were plans to establish clear guidelines for referral to specialist teams. |
| HN-504<br>All | **Transfusion Guidelines**<br><br>Transfusion guidelines should be in use covering:<br>a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion<br>b. Protocol for carrying out an exchange transfusion<br>c. Hospital transfusion policy | Y | The transfusion guidelines were well written and easy to follow. | N | Evidence of transfusion guidelines were not seen as they were on the Trust's intranet and the reviewers were unable to view this. |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
|---|---|---|---|---|---|
| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-505 All | **Chelation Therapy**<br>Clinical guidelines on chelation therapy should be in use covering:<br>a. Indications for chelation therapy<br>b. Dosage and dosage adjustment<br>c. Monitoring of haemoglobin levels prior to transfusion<br>d. Management and monitoring of iron overload, including management of chelator side effects<br>e. Use of non-invasive estimation of organ-specific iron overloading heart and liver by T2*/R2<br>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 / SHT. | Y | | Y | These were based on the SHT guidelines. |

| | | St. George's Healthcare NHS Trust | | Epsom and St Helier University Hospitals NHS Trust | |
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| **Ref** | **Quality Standard** | **Met Y/N** | **Comment Specialist Haemoglobin Team** | **Met Y/N** | **Comment Accredited Haemoglobin Team** |
| HN-506 All | **Clinical Guidelines: Acute Complications**<br>Clinical guidelines on the management of acute complications should be in use covering at least:<br>**For patients with sickle cell disease:**<br>a. Acute pain<br>b. Fever, infection and overwhelming sepsis<br>c. Acute chest syndrome<br>d. Abdominal pain and jaundice<br>e. Acute anaemia<br>f. Stroke and other acute neurological events<br>g. Priapism<br>h. Acute renal failure<br>i. Haematuria<br>j. Acute changes in vision<br>**For patients with thalassaemia:**<br>k. Fever, infection and overwhelming sepsis<br>l. Cardiac, hepatic or endocrine decompensation<br>Guidelines should include the indications for referral to specialist services (QS HN-302). | Y | The guidelines were covered extensively. | N | The guidelines lacked clarity. |
| HN-507 All | **Emergency Department Guidelines**<br>Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department. | Y | General emergency department guidelines for haemoglobinopathy were very good and included in the *Grey Book* – for medical emergencies available to all medical staff. Individualised pain protocols were also available but only in hard copy form. | Y | |

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| HN-508 All | **Clinical Guidelines: Chronic complications**<br>Clinical guidelines on the management of chronic complications should be in use covering at least:<br>a. Renal disease<br>b. Orthopaedic problems<br>c. Retinopathy<br>d. Cardiological complications / pulmonary hypertension<br>e. Chronic respiratory disease<br>f. Endocrinopathies<br>g. Neurological complications<br>h. Chronic pain<br>Guidelines should include the indications for referral to specialist services (QS HN-302). Local Haemoglobinopathy Team guidelines should include indications for early referral to the Specialist Haemoglobinopathy Team. | Y | | N | However, it was recognised by the Trust that further development was needed in this area. |
| HN-509 LHT | **Transfer for Critical Care**<br>Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital. | N/A | | Y | However, these were available in the exchange transfusions guideline and should be separated out for clarity. |
| HN-510 SHT<br>A-LHT | **Specialist Management Guidelines**<br>Clinical guidelines should be in use covering:<br>a. Care of patients with haemoglobin disorder during anaesthesia and surgery<br>b. Care of patients with haemoglobin disorders who are pregnant<br>c. Hydroxycarbamide therapy | Y | | Y | Specialist management guidelines were shared with the SHT. |

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| HN-511 All | **Thalassaemia Intermedia**<br>Clinical guidelines for the management of thalassaemia intermedia should be in use, covering:<br>a. Indications for transfusion<br>b. Monitoring iron loading<br>c. Indications for splenectomy. | Y | | N | There was no evidence of clinical guidelines for the management of thalassaemia intermedia. |
| HN-601 All | **Operational Policy**<br>An operational policy should be in use covering:<br>a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602)<br>b. Arrangements for haematology input to the care of patients receiving critical care and for transfer to critical care at the SHTs main hospital (QS HN-509 – A-LHTs and LHTs only).<br>c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.<br>d. Notification of adverse events to the SHT(LHTs only)<br>e. Follow up of patients who do not attend<br>f. Arrangements for transfer of care of patients who move to another area, including communication with all SHT, LHTs and community services involved with their care before the move and communication and transfer of clinical information to the SHT, LHT and community services who will be taking over their care. | Y | However, the arrangements for 'b' were not documented, but discussion with the clinical team suggested that this happened.<br>There was also effective use of CQUINS and key performance indicators. | N | The Operational Policy was in development. |

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| HN-602 All | **Multi-Disciplinary Meetings**<br>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 (QS HN-205) and representatives of support services (QS HN-301). | Y | | N | Multi-disciplinary meetings were not held, though informal discussions were a regular occurrence. |
| HN-603 All | **Service Level Agreement with Community Services**<br>A service level agreement for support from community services should be in place covering, at least:<br>a. Role of community service in the care of patients with haemoglobin disorders<br>b. Two-way exchange of information between hospital and community services. | N | The communication system with the community team was not clear, however, there were plans in place to address this issue. | N | No evidence was presented for this area. |
| HN-701 SHT<br>A-LHT | **Data Collection**<br>Data on all patients should be entered intothe National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events. | N | The data did not include annual review updates. Data entry was dependent upon the Clinical Lead. | N | The annual review data was not entered onto the register. |

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| HN-702 All | **Ongoing Monitoring**<br>The service should monitor on an ongoing basis:<br>a. Number of patients having acute admission, day unit admission or A&E attendances<br>b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year<br>c. Length of in-patient stays<br>d. Re-admission rate<br>e. DNA rate<br>f. Waiting times for transfusion | Y | | N | No evidence was presented for this area. |

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| HN-703 All | **Audit**<br>Clinical audits covering the following areas should have been undertaken within the last two years:<br>**For patients with sickle cell disease:**<br>a. Proportion of patients with recommended immunisations up to date<br>b. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required<br>c. 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. This audit should cover all hospitals where patients with sickle cell disease may attend.<br>**For patients with thalassaemia:**<br>d. Evidence of effective monitoring of iron overload, including imaging (QS HN-505)<br>e. Proportion of patients who have developed new iron-related complications in the preceding 12 months | Y | However, there was no clear plan for follow up actions. | Y | |
| HN-704 All | **Guidelines Audit**<br>The service should have a rolling programme of audit, including:<br>a. Audit of implementation of evidence based guidelines (QS HN-500s).<br>b. Participation in agreed network-wide audits. | N | However, participation in network audit was not formalised yet. | N | Plans were in place to begin an audit in the near future. |

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| HN-705 SHT | **Research**<br>The SHT should actively participate in research relating to the care of patients with haemoglobin disorders. | N | Plans were in place to participate in research activity. | Y | However this was limited and there was no research infrastructure. |
| HN-798 All | **Review and Learning**<br>The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include:<br>a. Review of any patient with a serious adverse event or who died in the last 12 months<br>b. Review of any patients requiring admission to a critical care facility within the last 12 months | N | No evidence was presented for this area. | N | No evidence was presented for this area. |
| HN-799 All | **Document Control**<br>All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures. | Y | | N | There were plans in place in this area. |

## COMMISSIONING

| Ref | Quality Standard | Met Y/N | Comments |
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| HZ-601 | **Commissioning of Services**<br><br>Commissioners should have agreed the configuration of clinical networks and, within each network, the configuration of services for people with haemoglobin disorders across each network, in particular:<br>a. Designated SHT/s for the care of adults with sickle cell disease<br>b. Designated SHT/s for the care of adults with thalassaemia<br>c. Accredited LHTs for care of adults with sickle cell disease or thalassaemia<br>d. Other LHTs/ Linked providers for care of adults with sickle cell disease or thalassaemia<br>e. Community care providers | N | The integrated service with Wandsworth CCG was an exemplar model. However the commissioning arrangements for other areas were unclear at the time of the visit.<br><br>The South West London haemoglobinopathy network was in development as part of the move to Specialist Commissioning. |
| HZ-701 | **Clinical Quality Review Meetings**<br><br>Commissioners should regularly review the quality of care provided by each network, in particular, achievement of QS HY-702 and HY-798. | N | Regular quality review meetings were not taking place yet across the network. However the South West London haemoglobinopathy network was in development as part of the move to Specialist Commissioning. |