WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Health Services Caring for Adults with Haemoglobin Disorders

North Central London

University College London Hospitals NHS Foundation Trust

Whittington Health NHS

Visit date: November 13th 2012 Report Date: April 2013

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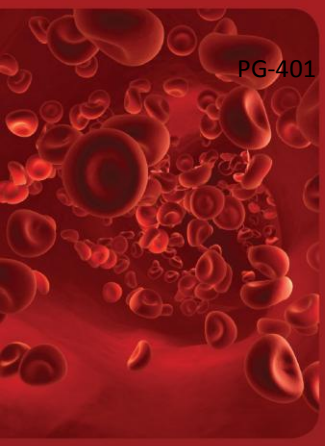

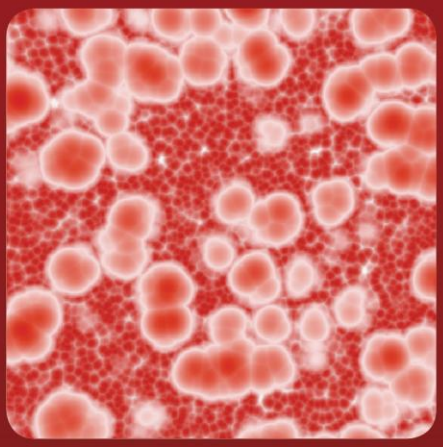

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INTRODUCTION

This report presents the findings of the peer review visit to services for adults with sickle cell disease and thalassaemia in the North Central London Network, in particular University College London Hospitals NHS Foundation Trust and Whittington Health NHS, which took place on November 13th 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 Midland 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 University College London Hospitals NHS Foundation Trust and Whittington Health NHS, 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 NORTH CENTRAL LONDON SICKLE CELL AND THALASSAEMIA NETWORK

Trust Name	Abbre-viation	Reviewed as:	Hospital
University College London Hospitals NHS Foundation Trust	UCLH	Specialist Haemoglobinopathy Team (SHT)	University College Hospital
Whittington Health NHS	WH	Specialist Haemoglobinopathy Team (SHT)	Whittington Hospital
Royal Free London NHS Foundation Trust	RFH	Local Haemoglobinopathy Team (LHT)	Royal Free Hospital
The Luton & Dunstable Hospital NHS Foundation Trust	LDH	Local Haemoglobinopathy Team (LHT)	Luton and Dunstable Hospital

Trust	Reviewed as:	No. patients with sickle cell disease	No. patients with thalassaemia*	No. patients on long term red cell transfusions*
University College London Hospitals NHS Foundation Trust	SHT	233	130	105 thalassaemia; 54 sickle cell disease on exchange blood transfusion.
Whittington Health NHS	SHT	205	140	140 thalassaemia and 15 sickle cell disease
Royal Free London NHS Foundation Trust	LHT	-	5	5
The Luton & Dunstable Hospital NHS Foundation Trust	LHT	100	6	<5

These figures were a significant underestimation of the total number of thalassaemia patients using the services as the patients who were seen for annual review or as tertiary referrals were not included.

NETWORK

A haemoglobinopathy network existed but it was not configured along formal hub-and-spoke lines. In 2004, the haemoglobinopathy services at University College London Hospital and Whittington Hospital entered into a formal agreement to pool their resources and expertise to form the Joint Red Cell Disorders Unit (JRCU). The Unit provided comprehensive care for adults and children with haemoglobin disorders for North Central London. In addition many patients were seen as tertiary and quaternary referrals from London and throughout the UK, predominantly for specialist out-patient care. Due to the expertise and the complexity of the work undertaken each hospital was designated as a specialist haemoglobinopathy centre and continued to look after its own patients. Considerable progress had been made on joint management of patients, cross-site working, development of joint clinical protocols and patient information. An active research programme existed at both sites.

Consultants worked across both sites. Two of the Whittington Consultants had UCLH funded PAs and attended clinics on a weekly basis at UCLH. Some of the consultants had honorary contracts with the linked hospital teams at the Royal Free (RFH) and the Luton & Dunstable Hospitals (LDH). One of the Whittington consultants visited LDH monthly to undertake a clinic with the local haematologist and was cross covered by one of the UCLH consultants. Patients requiring specialist renal or liver support were managed at the RFH.

Network meetings were held on a bi-monthly basis with representation from across the network and included different professional groups. Plans were in place for a bi-monthly, multi-disciplinary meeting via video-

conference to discuss morbidity and mortality.

SPECIALIST TEAM: UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST

UCLH consists of seven hospitals, including University College Hospital (UCLH), which had a busy Accident and Emergency Department (A&E) and over 700 in-patient beds. Haemoglobinopathy in-patients were admitted via A&E. The haemoglobinopathy day service and out-patient services were based in the UCLH Macmillan Cancer Centre, which was a two minute walk away from the main hospital, and was incorporated within UCLH. The red cell team at UCLH provided both a secondary level service for local patients and a very large transfusion practice. A tertiary level service cared for large numbers of patients with red cell disorders, primarily patients with sickle cell disease, thalassaemia and other iron overload conditions. These patients were referred from all over the UK and internationally.

At the time of the visit UCLH had 233 patients with sickle cell disorders registered with them, of whom 54 were on regular red cell apheresis. The number of patients with thalassaemia major was 130, those transfused at the UCLH site and who were all on long term transfusion numbered 105. Together with the Whittington Hospital this represented the largest thalassaemia service in the UK. Patients travelled from all over London to receive their care from these services, including transfusions.

In the previous 12 months there were 165 emergency admissions for haemoglobinopathy patients excluding A&E only attendances. These were mostly patients with sickle cell disease. The mean length of stay for emergency admissions was just over seven days, with a median of four days. Elective day case attendances numbered 2,606. The majority of the latter were thalassaemic patients attending for top-up transfusions, but 450 apheresis procedures were included in this figure. It was noted that the numbers of in-patient admissions and length of stay had markedly decreased since the instigation of the apheresis programme. Accurate data on the number of patients attending for tertiary care and specialist opinions were not available but 129 new patients had attended out-patients in the previous year and there had been 1,723 follow-up attendances.

There were 151 patients with sickle cell disease and 105 patients with thalassaemia registered on the National Haemoglobinopathy Registry (NHR).

Accident and Emergency

Approximately 60% of the acute admissions were admitted via A&E, the others were admitted via the day unit. Initial triage was carried out by the A&E staff. In normal working hours the Red Cell Haematology Specialist Registrar was contacted for all A&E attendances and was involved in the decision to admit under the haematology team. Outside working hours patients were admitted by the haematology SHO. Any A&E attendances that did not result in admission were notified to the Red Cell Clinical Nurse Specialist (CNS) for follow-up.

The majority of patients, including those with thalassaemia, had a 'Patient Key Record' which was available via the electronic patient record. These had previously been available as paper copies but had recently moved to an electronic record.

Out-patient and Day Case Facilities

The out-patient clinics and day case facilities were situated on the fourth floor of the UCLH Macmillan Cancer Centre which had recently opened and had high quality facilities. Free television and free Wi-Fi was available for patients. A patient lounge and information suite was on the ground floor, and although run by Macmillan, extensive patient literature for haemoglobinopathy patients was available. The Cancer Centre was open from Monday to Friday 8.30am to 7pm and provided a 'rapid access service' for haemoglobinopathy patients between 9am and 4pm. Patients were asked to phone before attending the 'rapid access service' but would be seen if they turned up unannounced. A stand-alone apheresis service provided red cell apheresis, plasmapheresis and stem cell collection 24/7. This was an eight bedded unit with four permanent members of staff. Initially it was funded for 12 long term red cell apheresis patients, but in the last two years this had been increased to 50. At the time of the visit 20 further places had opened most of which were also filled. This service was provided for local patients and for patients from Whittington Health NHS, North Middlesex Hospital and further afield. The majority of patients were apheresed via peripheral access but a small number had vortex ports and about a third used femoral access. These were inserted by a nurse-led central access team located in the cancer centre. The apheresis service provided out of hours emergency care but routine apheresis could only be provided within working hours.

Red cell transfusions for haemoglobinopathy and malignant patients were given in the supportive care area of the day unit. Usually four to five patients with thalassaemia received transfusions daily. Patients who wished to have transfusions at the weekend or overnight were accommodated in the in-patient wards where there was a dedicated bed. Eighteen and nineteen year olds were also transfused any time of day or night on the teenage ward T12. Patients were able to attend for phlebotomy, in particular cross match sampling, at the weekend or in the evenings.

The out-patient department was adjacent to the Supportive Care and Apheresis Unit. Patients booked in on the ground floor and waited in the lounge area before being called electronically to the fourth floor. Red cell clinics were held on Wednesday morning and in the evening from 5pm to 8pm. The morning clinic was primarily for patients with sickle cell disease and other red cell disorders, and was staffed by three consultants and one specialist registrar as well as a clinical psychologist, clinical nurse specialist and a data manager. Phlebotomy was performed in the basement of the centre and near patient testing ensured that blood results were available within 10 minutes. The evening clinic was primarily for thalassaemia patients, although other patients attended if this was more convenient. The clinic was run by two haematology consultants and an endocrinology consultant, a clinical psychologist and a clinical nurse specialist providing multidisciplinary care. The psychologist ran a clinic on Wednesday alongside these clinics. Patients were seen by a data manager at

these clinics who filled in the annual review proforma, chased up annual review investigations and entered this information onto the database and the National Haemoglobinopathy Registry (NHR).

A weekly cardiology clinic took place on Tuesday afternoons. There were plans to move this to a Wednesday afternoon and co-locate to the Cancer Centre so patients could attend on the same day as their haematology review. This was a one-stop clinic where patients had electrocardiograms (ECG) and echo testing before seeing the cardiology consultant. Initially the service had started specifically for monitoring the thalassaemic patients, but all the patients with sickle cell disease were now referred to this service for pulmonary hypertension screening. Referrals were received from many centres outside UCLH. The clinic was supported by an administrator who booked cardiac MRI scans on the same day as the appointment if required.

Pregnant haemoglobinopathy patients were jointly managed in a high risk pregnancy clinic staffed by a consultant haematologist and consultant obstetrician.

In-Patient Facilities

The patients were admitted from A&E or from the day unit to one of the haematology wards T16 and T13, if a bed was available. If there was no haematology bed available they were admitted to the Acute Medical Ward pending the availability of a haematology bed. They were admitted by the red cell SHO or Specialist Registrar during normal working hours, or by the on call haem-oncology SHO out of normal working hours. Patients were reviewed daily by the red cell team and were seen by one of the red cell consultants on their ward rounds at least twice weekly or more frequently if required. It was noted that the two red cell consultants did a one in three attending rota with the third post being filled by an acute medical consultant with an interest in red cell disorders. The two haematology consultants were “attending” five months a year and the acute medical consultant two months a year. Facilities were available specifically for young people.

User Feedback

The review team met with a group of patients with sickle cell disease and thalassaemia.

SPECIALIST TEAM: WHITTINGTON HEALTH NHS

Whittington Health NHS was an integrated care organisation combining the hospital and community based services previously provided by Islington and Haringey PCTs for a population of 443,000.

In 2006, Whittington Health NHS took over the care of children and adults with sickle cell disease and thalassaemia at the Royal Free Hospital (RFH). All adult thalassaemia patients attended the specialist clinic at Whittington for out-patient care but a few continued to receive their regular transfusions at the Royal Free Hospital. Nearly all RFH adult patients with sickle cell disease had transferred to WH for out-patient and in-patient care. However, a small number of patients still presented acutely to the RFH. Patients requiring liver

and renal services were referred to the RFH specialist unit. One of the WH consultants was available to advise and, if necessary, see patients with sickle cell disease or thalassaemia at RFH. WH was nationally recognised for expertise in the care of thalassaemia patients and, as a result, had many referrals from other centres in London and the rest of the UK.

The adult haemoglobinopathy team was led by two consultants, a senior specialist thalassaemia nurse and a community matron. There were two haematology trainees from the London Deanery rotation.

Emergency admission with a primary diagnosis of sickle cell crisis, excluding A&E only attendances, numbered 212 patients and the average length of stay was 4.79 days. There were 1,842 (thalassaemia 1,634; sickle cell – 208) elective day cases. In 2010/2011 the clinic attendances, including nurse-led clinics, numbered 2,029.

There were 164 patients with sickle cell disease and 125 patients with thalassaemia registered on the National Haemoglobinopathy Registry (NHR).

Accident and Emergency

Acutely ill patients with sickle cell disease and thalassaemia were advised to attend A&E. All A&E attendances were immediately notified to all three haematology consultants, both haematology specialist registrars and the community matron via an automatic e-mail alert system when the patient was triaged. Patients with uncomplicated sickle cell crises were usually looked after by the on-call medical team until handed over to the haematology team after the post-take ward round the following day. However, the haematology team saw known high-risk patients with uncomplicated crises or sicker patients during normal working hours.

Many patients with sickle cell disease had individualised pain protocols, which were available in A&E and the haematology ward (Mercers). Those without a pain protocol were treated using a generic protocol, or wherever possible, their individualised protocol was requested from their base hospital.

Thalassaemia patients requiring emergency care were seen by the haematology team during normal working hours.

The haematology service as a whole had a 24 hour on-call rota so that a consultant haematologist was always available to provide on-call advice and support for all haematology patients including those with sickle cell disease and thalassaemia disorders.

Out-patient and Day Case Facilities

Elective day care of patients with sickle cell disease and thalassemia was based in the refurbished Thalassaemia Unit. The unit had a thalassaemia specialist nurse and one to two other nurses (including a senior sister). It was open Monday to Friday 9am to 5pm. Out of hours transfusion was available until 8pm Monday to Friday, and 9am-5pm Saturday and Sunday. This unit undertook all the transfusion management of patients with thalassemia and with sickle cell disease, including the review of routine blood results. The specialist nurse

carried out annual reviews. The nursing staff were trained to perform manual red cell exchange but patients requiring automated exchange were referred to the apheresis service at UCLH.

Both consultants each saw haemoglobinopathy patients in twice weekly clinics. In the Tuesday clinics patients were seen alongside other haematology patients. A dedicated specialist clinic was held on Thursdays with extended times into the evening.

In addition to scheduled clinics both consultants saw patients on an ad hoc basis in the haematology offices. Appointments were arranged in advance for complex cases and for patients who were unable to attend the regular clinics.

The Friday clinic for thalassaemia patients was held in the Thalassaemia Unit where patients had a nurse led consultation, although a consultant was available if needed. The clinic was held in-between consultant led clinics and was for any outstanding clinical issue and for annual reviews.

A number of combined specialist clinics were also held:

- a joint diabetes/endocrine clinic for thalassaemia patients every three months
- a paediatric thalassaemia clinic every two months
- a paediatric sickle cell disease clinic every week

Patients were referred to the one stop cardiology clinic at UCLH for specialist cardiac investigations.

Pregnant sickle cell disease and thalassaemia patients were managed by the haemoglobinopathy team in conjunction with two consultant obstetricians with expertise in haemoglobinopathies. Patients were seen in separate clinics by the haematologists and obstetricians but there was close liaison between members of the team. A designated consultant provided fertility services for patients.

In-Patient Facilities

Acutely ill sickle cell and thalassaemia patients requiring in-patient care were usually admitted initially to the Medical Assessment Unit (MAU) from where they were usually admitted to the haematology ward. If no beds were available on the haematology ward, then the patient either spent their entire admission on MAU if a short admission, or were moved to another medical ward with transfer to the haematology ward when a bed subsequently became available. If a bed was available at the time of presentation to A&E, the patient was admitted directly to the haematology ward. All haemoglobinopathy patients were reviewed at least once daily by the haematology team or as frequently as their clinical needs dictated.

Community Services

The community team was based at the Camden and Islington Sickle Cell and Thalassaemia (SCAT) Centre and provided care for patients from both UCLH and Whittington Hospital who were resident in Camden and Islington. Whittington Health NHS hosted the service. Patients who lived outside these areas were seen in the centre, but were not offered home visits. Staff included a community matron for haemoglobinopathy who provided home support primarily for patients with complex needs resident in Islington with a few from Camden. She saw some in-patients dependent on their clinical need. However, in-patients from other boroughs were seen at the request of the clinicians or they were part of her community workload. Plans were in place to expand the service to cover Camden as part of an initiative to prevent hospital admissions. Nurse counsellors supported patients at both the Whittington Hospital and UCLH though the community nurse did not attend the multi-disciplinary team meetings at UCLH. Patients were able to self-refer to the psychologist based in the SCAT Centre. Active support groups were available at the centre. Community clinics were discontinued with the retirement of a consultant but were under review. Patients from other London Boroughs were referred on to their local service.

The community services were organised with a high level of patient engagement and a support group had been continuously in operation at the centre since 1989. Adult patients and carers met on the first Friday of every month and the 'Post Transition' and 'Mother and Baby' groups met at other times arranged by service users.

User Feedback

The review team met with a group of patients with sickle cell disease and thalassaemia.

REVIEW VISIT FINDINGS

NETWORK

General Comments

Considerable progress had been made towards a network with the development of common clinical protocols and cross-site working. There appeared to be good working relationship between the teams on both sites. Network arrangements were not, however, formalised and robust support for administration was not available. Although each hospital had undertaken a considerable number of audits, there was no evidence of any network wide audits.

Further Consideration

1. The clinical and academic expertise together with the patient case mix presented this network with unique opportunities for research which should be actively encouraged and adequately resourced.

SPECIALIST TEAM: UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST

General Comments / Achievements

This was an excellent service providing 'world-class' care, particularly for patients with thalassaemia. The team was working as a national and international resource providing support for hospitals and patients across the UK and beyond via tertiary consultations as well as through e-mail and phone advice. The patient feedback about medical and nursing support was very positive, and the facilities were of very high quality. The transition to the new facilities had been managed well with good patient input. The day care unit provided an excellent service both for transfused patients and for patients needing acute pain relief. Despite the very high numbers of thalassaemia patients attending for transfusion it offered a service that was both efficient and personal.

Good links were in place with all necessary specialist services and the psychology provision was integrated into the service. Comprehensive thalassaemia and sickle cell patient leaflets were available. A comprehensive work plan included innovative suggestions such as a video to support training for manual exchanges which potentially could be a useful national resource.

Whilst senior A&E staff were aware of how to access the 'Patient Key Record', patient feedback suggested that junior A&E staff, especially out of hours, were not able to access them in a timely fashion. A plan was in place to provide laminated guides for accessing the 'Patient Key Record' but this was not yet displayed in A&E. A generic protocol was available for the treatment of patients without a 'Patient Key Record', and although it could be found on the hospital intranet it was not easily accessible.

An audit of A&E attendances had shown that fewer than 30% of patients had received analgesia within 30 minutes and patients had experienced delays. The audit findings had been acted on and there had been extensive recent educational input into A&E.

Some patients expressed concerns that the haemoglobinopathy out-patient facility was within a centre called 'The Cancer Centre' and they felt excluded by the name. However, the lead clinician had written to all patients to explain the name when they had re-located. Patient feedback about this service was very positive and they reported easy accessibility. Despite the extremely high workload, transfusions were done in a highly efficient manner. Patients reported that it was easy to book when they wanted transfusions and that they were started almost as soon as they arrived in the department. A recent initiative of giving a unit of blood over one hour in suitable patients was in place, which was particularly rapid and was popular with the patients. Weekend or

overnight transfusions were accommodated and patients reported that this service was easy to access. However, patients reported that they sometimes had long waits to see a doctor in the out-patient clinics.

Patients commented that the haematology wards were well staffed and the staff had good knowledge about haemoglobinopathies. They valued the SCAT Centre services highly and thought that they decreased hospital admissions.

There was very positive feedback about the medical and nursing teams and patients stated that they felt confident in their care and had good relationships with staff. Both sickle cell disease and thalassaemia patients valued the service, in particular, the day service, in both its role in transfusion and in acute pain management.

Despite the excellent research reputation of this department, the research programme was all externally funded. No formal research infrastructure or research support, either medical, nursing or administrative, was provided by the Trust.

Good Practice

1 The cardiology clinic was unique and offered a high quality service for patients. The integrated 'one stop' approach was supported by dedicated staff. This was a model which could be adopted by other services.

2 The care of thalassaemia patients was exemplary and the patient protocols and care pathways were comprehensive. The management of iron overload in this centre guided UK practice and offered support to other services across the UK.

3 Research was an integral part of the service and there was evidence of an extensive research output.

4 The annual review process was integrated into clinic attendance and there was a clear proforma. The availability of a data manager in clinic enabled data to be collected and uploaded in 'real time'.

5 The introduction of a comprehensive red cell apheresis service had led to significant service improvements. The model of care, using a specific service co-ordinator, could be shared with other services and provided an efficient service which received good patient feedback.

Immediate Risk: No immediate risks were identified.

Concerns

1 Consultant staffing was insufficient for the service providing only 12 PAs of consultant time (five plus three plus three across the other two consultants and one other) was allocated to the care of patients with haemoglobin disorders. The consultants worked far beyond their contracted hours and the long term sustainability of the service was of concern. Whilst the appointment of a second red cell

consultant had provided some support to the lead consultant, this second consultant also supported the paediatric haemoglobinopathy practice. The extent of tertiary work, e-mail and telephone advice provided was not recognised in the consultants' job plans or in workload assessment. The role of the lead consultant in providing a national lead in this field was not recognised in their job plan. Urgent consideration should be given to a review of the consultant workload.

2 The multi-disciplinary team data manager was a temporary appointment. The post had resulted in a marked improvement in data collection. The work was concentrated on data collection about local patients, but could be expanded to collect data on annual review of tertiary referrals which might more accurately reflect the workload of the service.

Further Consideration

1 The acute pain pathway was embedded within the large sickle cell disease protocol and was not easily accessible. Creation of a simple algorithm or patient pathway may be helpful for staff working in A&E. Audit of the acute pain pathway had shown poor results and, whilst the issues raised were being addressed, a re-audit following these changes would be of benefit to show the impact on quality.

2 Transition care was primarily being provided by one of the consultants. A good patient pathway had been developed but did not have sufficient support from a paediatric/transition nurse. A business case for this was being developed at the time of the visit.

SPECIALIST TEAM: WHITTINGTON HEALTH NHS

General Comments / Achievements

Whittington Health delivered an excellent service for a large cohort of patients with complex haemoglobinopathy disorders on a par with UCL. The team had built up considerable expertise in the care of thalassaemia patients and, together with UCLH, had gained a national and international reputation. The team was led by two highly committed and dedicated consultants with an experienced specialist thalassaemia nurse. Together they delivered high levels of activity very efficiently.

Patients who met the visiting team gave universal praise for the care delivered by the team, in particular the approachability of the consultants and the thalassaemia CNS. Positive feedback was received for the support from the community matron. They were happy with the arrangements for transfusion and said they felt "very safe" within this service.

Arrangements for the care of thalassaemia patients were particularly effective given the large numbers of patients receiving regular transfusions. The refurbished unit was bright and clean and had been designed in conjunction with the patients. Audit showed minimal waiting times for regular blood transfusions and routine

and specialist monitoring investigations were done in an organised and timely manner. The thalassaemia clinical nurse specialist (CNS) was able to undertake annual reviews.

Overall there was strong evidence for a varied training programme, delivered by the lead consultants and specialist nurses that was tailored to the needs of different groups of staff. In particular, a large number of nurses, including A&E staff, had attended pain study days. A nursing strategy was in place for haemoglobinopathy nursing. Nurses were working toward the RCN competences. The nurses on the thalassaemia unit and the ward had undergone a training programme on manual exchange transfusions.

The level of documentation was good. An annual report was produced which detailed the number of completed audits, activity information, clinical trial participation and patient and carer involvement. A work plan was in place for the forthcoming year.

Good Practice

There were many examples of good practice. These included:

a. Thalassaemia protocols were comprehensive and clear

b. Communication of information to GPs and secondary care was comprehensive

c. Audit data showed the number of patients with increased myocardial iron had fallen from 60% to 20% over the last decade and survival data were the best reported in the world.

d. Automatic e-mail to medical and nursing staff when patients with sickle cell disease were admitted through A&E

e. Joint endocrine clinic and access to cardiac specialist clinics

f. Comprehensive arrangements for transition and management of young adults with thalassaemia and sickle cell disease

g. Community programme for patients with complex care needs

Immediate Risk: No immediate risks were identified.

Concerns

1 The consultant staff were working long hours in excess of their job plans and had a number of other responsibilities for the general haematology service. This situation was not sustainable in the long term and did not permit expansion of the research programme. Consideration should be given to a review of consultant job plans and additional medical support that might be needed to support the workload.

2 The service did not have permanent data collection support which raised concerns about the ability to collect data for annual reviews and the National Haemoglobinopathy Registry (NHR).

3 Patients who met the visiting team expressed concerns over the variable experience in the A&E department with delays in receiving analgesia on occasions and a perceived lack of experience and empathy in some of the staff.

4 There was no specialist nurse support for patients with sickle cell disease.

Further Consideration

1 Staffing levels for the service should be reviewed to ensure that sufficient staffing and high standards of care are sustained especially as patient numbers increase with transition of patients from paediatric care.

2 The re-admission rate was higher than would be expected and should be re-examined to determine the underlying reasons, for instance whether it might represent a number of "frequent attenders".

COMMISSIONING

General Comments

Members of the review team met with the Commissioner for London. Both UCLH and Whittington Hospital were designated as specialist providers of haemoglobinopathy services.

Concern

1 Patients requiring liver and renal support who were often very unwell were referred to the RFH which provided these regional services but had no local haemoglobinopathy specialist on site.

Further Consideration

1 A service-level agreement was not in place for the work undertaken by the Whittington Health NHS for Luton and Dunstable Hospital which had a moderately large population of adults with haemoglobinopathy disorders. Arrangements for Luton and Dunstable patients should be reviewed with consideration given for formal designation as a linked hospital to Whittington Health NHS.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Jo Howard	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Guy's & St Thomas' NHS Foundation Trust
Kate Ryan	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Central Manchester University Hospitals NHS Foundation Trust.
Joanne Bloomfield	Specialist Nurse & Manager	Sickle Cell and Thalassaemia Service Nottingham
Verna Davis	Nurse Manager	Central Manchester University Hospitals NHS Foundation Trust.
Joe Hayward	Service Manager- Clinical Haematology	Barts Health NHS Trust (Royal London Hospital)
Dorothy Zack-Williams	Nurse	Abercromby Health Centre, Liverpool
Elaine Miller	Voluntary Sector Representative	UK Thalassaemia Society
Sharon Ensor	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.

		University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
Ref	**Quality Standard**	**Met Y/N**	**Comment**	**Met Y/N**	**Comment**
HN-101 All	**General Support for Service Users and Carers** Service users and their carers should have easy access to the following services. Information about these services should be easily available: a. Interpreter services, including access to British Sign Language b. Independent advocacy services c. PALS d. Social workers e. Benefits advice f. Spiritual support g. *HealthWatch* or equivalent organisation	Y		Y	The operating policy indicated that patient leaflets were given to patients but they were not seen for 'e' and 'f' at the review visit although these were available for patients through sign-posting to internet links.
HN-102 All	**Haemoglobin Disorder Service Information** Written information should be offered to patients and, where appropriate, their carers covering at least: a. Brief description of the service, including times of phlebotomy and transfusion services b. Clinic times and how to change an appointment c. Ward usually admitted to and its visiting times d. How to contact the service for help and advice, including out of hours e. Staff of the service f. Community services and their contact numbers h. Relevant support groups g. How to give feedback on the service, including how to make a complaint and how to report adult safeguarding concerns h. How to get involved in improving services (QS HN-199)	Y		Y	

		University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
Ref	**Quality Standard**	**Met Y/N**	**Comment**	**Met Y/N**	**Comment**
HN-103 All	**Information about Haemoglobin Disorders** Written information should be offered to patients and, where appropriate, their carers covering at least: a. A description of the condition (SC or T), how it might affect the individual, possible complications and treatment b. Problems, symptoms and signs for which emergency advice should be sought c. How to manage pain at home (SC only) d. Where to go in an emergency e. Health promotion, including: i. Information on contraception and sexual health ii. Travel advice iii. Vaccination advice iv. Staying well through a healthy diet, exercise and not smoking. f. Where to go for further information, including useful websites and national voluntary organisations	Y	Information for thalassaemia was particularly good.	Y	Information for thalassaemia was particularly good.
HN-104 All	**Information for Primary Health Care Team** Written information for the patient's primary health care team should be available covering their roles and responsibilities, including: a. The need for regular prescriptions including penicillin or alternative (SC and splenectomised T) and analgesia (SC) b. Information covering side effects of medication, including chelator agents [SC and T] c. Guidance for GPs on shared care for hydroxycarbamide and iron chelation therapy (if being prescribed by GPs).	Y		Y	

		University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
Ref	Quality Standard	Met Y/N	Comment	Met Y/N	Comment
HN-105 All	**Care Plan** All patients should be offered: a. An individual care plan or a written summary of their annual review b. A permanent record of consultations at which changes to their care are discussed	Y		Y	There were individual care plans and copies of clinical letters.
HN-106 C SHT A-LHT	**Transition Information** 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		Y	Although information was available it might benefit from being more targeted to the age range of patients in transition to adult services.
HN-199 All	**Involving Patients and Carers** The service should have: a. Mechanisms for receiving feedback from patients and carers b. A rolling programme of audit of patients' and carers' experience c. Mechanisms for involving patients and, where appropriate, their carers in decisions about the organisation of the service.	Y	Patients were able to identify when their feedback had resulted in positive changes in service.	Y	
HN-201 All	**Lead Consultant** 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	The job plan was well laid out but there were only 5 PAs for the clinical red cell service.	Y	A detailed job plan was provided.

Ref	Quality Standard	University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
		Met Y/N	Comment	Met Y/N	Comment
HN-202 All	**Cover for Lead Consultant** Cover for absences of the lead consultant should be available. In SHTs this should be a named deputy within 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.	Y		Y	
HN-203 All	**Lead Nurse** 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	At the time of the visit the lead nurse was about to leave and there was a concern that a replacement would be needed quickly to maintain the quality of care provided. Recruitment was underway at the time of the visit and interviews held in January 2013 for the permanent replacement.	N	There was a lead nurse for thalassaemia but not for sickle cell disease.
HN-204 All	**Cover for Lead Nurse** Cover for absences of the lead nurse should be available.	N	One of the band 6 day care nurses was seconded to an “Acting CNS” role pending the appointment of the new CNS. This was successful to date and consideration was being given to maintaining this cover arrangement when the new CNS was in place.	N	There was a lead nurse for thalassaemia but not for sickle cell disease.

Ref	Quality Standard	University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
		Met Y/N	Comment	Met Y/N	Comment
HN-205 All	**Staffing Levels and Competences** The service should have sufficient staff with appropriate competences in the care of people with haemoglobin disorders, including: a. Medical staffing b. Nurse staffing on the ward and day unit c. Nurse specialist or counsellor who provides support for patients in the community. 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	Whilst the staff had high levels of competence the levels of staffing was not sufficient enough for the number of patients cared for by the service. The number of specialist registrars was insufficient for the complexity of the cases.	N	Whilst the staff had high levels of competence the levels of staffing was not sufficient for the number of patients cared for by the service. The number of specialist registrars was insufficient for the complexity of the cases.
HN-206 All	**Training Plan** 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	This was a highly skilled workforce. Clear training plans were in place with timeframes. The RCN competences were actively used as the structure for continuing professional development for nursing staff across all levels.	Y	This was a highly skilled workforce. Clear training plans were in place with timeframes. The RCN competences were actively used as the structure for continuing professional development for nursing staff across all levels.
HN-207 All	**Training Plan – Other Staff** A programme of induction and training covering the care of patients with haemoglobin disorders should be run for: a. Clinical staff in the Emergency Department b. Non-consultant medical staff c. Allied health professionals working with the SHT / LHT (QS HN-301).	Y		Y	

		University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
Ref	**Quality Standard**	**Met Y/N**	**Comment**	**Met Y/N**	**Comment**
HN-298 All	**Administrative and Clerical Support** Administrative, clerical and data collection support should be appropriate for the number of patients cared for by the service.	Y	A data manager had been in place for eight months but this was a temporary post.	N	Whilst medical secretaries produced excellent correspondence for patients, there was no support for data collection.
HN-301 All	**Support Services** Timely access to the following services should be available: a. Dietetics b. Physiotherapy c. Occupational therapy d. Leg ulcer service	Y		Y	

Ref	Quality Standard	University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
		Met Y/N	Comment	Met Y/N	Comment
HN-302 All	**Specialist Services** Access to the following specialist staff and services should be available: a. Erythrocytopheresis or manual exchange transfusion (24/7) b. Acute and chronic pain team c. Pulmonary hypertension team d. Consultant obstetrician e. Fertility services f. Consultant cardiologist g. Consultant endocrinologist h. Consultant hepatologist i. Consultant ophthalmologist j. Consultant nephrologist k. Consultant urologist with expertise in managing priapism and erectile dysfunction l. Orthopaedic service m. Psychologist with an interest in haemoglobinopathies n. Specialist imaging o. DNA studies	Y	Good practice was identified especially across specialist joint clinics for AHD patients in cardiology and endocrinology.	Y	Good practice was identified especially across specialist joint clinics for AHD patients in cardiology and endocrinology.
HN-303 All	**Laboratory Services** CPA accredited laboratory services with satisfactory performance in the NEQAS haemoglobinopathy scheme and MRHA compliance for transfusion should be available.	Y		Y	

Ref	Quality Standard	University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
		Met Y/N	Comment	Met Y/N	Comment
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.	Y	Excellent adolescent facilities were in place that supported patients through transition and up to age 20.	Y	In particular the facilities for thalassaemia patients were excellent and included a garden area.
HN-402 All	**Facilities for Out of Hours Care** Facilities should be available for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population.	Y	Although out of hours routine automated exchange was not available.	Y	
HN-501 SHT A-LHT	**Transition Guidelines** Guidelines on transition to adult care should be in use covering at least: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable)	Y	However the named coordinator for the transfer of care was currently the lead consultant. This role might be considered more appropriate for a paediatric CNS.	Y	The transition service worked with the patients for two to three years to support a smooth transition into adult services.
HN-502 SHT A-LHT	**Clinical Guidelines: Annual Review** Clinical guidelines should be in use covering: a. First out-patient appointment b. Annual review for both sickle cell disease and thalassaemia	Y		Y	

Ref	Quality Standard	University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
		Met Y/N	Comment	Met Y/N	Comment
HN-503 All	**Clinical Guidelines: Routine Monitoring** 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		Y	All staff demonstrated how they used the individualised care plan.
HN-504 All	**Transfusion Guidelines** Transfusion guidelines should be in use covering: a. Indications for regular transfusion, urgent 'top-up' transfusion and for exchange transfusion b. Protocol for carrying out an exchange transfusion c. Hospital transfusion policy	Y		Y	
HN-505 All	**Chelation Therapy** Clinical guidelines on chelation therapy should be in use covering: a. Indications for chelation therapy b. 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 / SHT.	Y		Y	Guidelines were clear and comprehensive.

		University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
Ref	**Quality Standard**	**Met Y/N**	**Comment**	**Met Y/N**	**Comment**
HN-506 All	**Clinical Guidelines: Acute Complications** Clinical guidelines on the management of acute complications should be in use covering at least: **For patients with sickle cell disease:** a. Acute pain b. Fever, infection and overwhelming sepsis c. Acute chest syndrome d. Abdominal pain and jaundice e. Acute anaemia f. Stroke and other acute neurological events g. Priapism h. Acute renal failure i. Haematuria j. Acute changes in vision **For patients with thalassaemia:** k. Fever, infection and overwhelming sepsis l. Cardiac, hepatic or endocrine decompensation Guidelines should include the indications for referral to specialist services (QS HN-302).	Y	The guidelines were particularly good for thalassaemia but 'b' would benefit from greater clarity.	Y	
HN-507 All	**Emergency Department Guidelines** Clinical guidelines on the management of acute complications (QS HN-506) should be in use in the Emergency Department.	Y	Whilst the guidelines were comprehensive a simplified diagram or algorithm would make it easier for users to access key information quickly.	Y	Whilst the guidelines were comprehensive a simplified diagram or algorithm would make it easier for users to access key information quickly.

Ref	Quality Standard	University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
		Met Y/N	Comment	Met Y/N	Comment
HN-508 All	**Clinical Guidelines: Chronic complications** Clinical guidelines on the management of chronic complications should be in use covering at least: a. Renal disease b. Orthopaedic problems c. Retinopathy d. Cardiological complications / pulmonary hypertension e. Chronic respiratory disease f. Endocrinopathies g. Neurological complications h. Chronic pain 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	The guidelines on chronic pain would benefit from more detailed information.	Y	The guidelines on chronic pain covered referral to the pain management team so would benefit from more detailed information.
HN-509 LHT	**Transfer for Critical Care** Guidelines should be in use covering the indications and arrangements for transfer to critical care services at the Specialist Haemoglobinopathy Team's main hospital.	Y		Y	
HN-510 SHT A-LHT	**Specialist Management Guidelines** Clinical guidelines should be in use covering: a. Care of patients with haemoglobin disorder during anaesthesia and surgery b. Care of patients with haemoglobin disorders who are pregnant c. Hydroxycarbamide therapy	Y		Y	

Ref	Quality Standard	University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
		Met Y/N	Comment	Met Y/N	Comment
HN-511 All	**Thalassaemia Intermedia** Clinical guidelines for the management of thalassaemia intermedia should be in use, covering: a. Indications for transfusion b. Monitoring iron loading c. Indications for splenectomy.	Y		Y	
HN-601 All	**Operational Policy** An operational policy should be in use covering: a. Indications for patient discussion at multi-disciplinary team meetings (QS HN-602) 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). c. Availability and arrangements for out of hours transfusion, phlebotomy and out-patient clinics appropriate to the needs of the local population. d. Notification of adverse events to the SHT(LHTs only) e. Follow up of patients who do not attend 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	Information followed patients at the point of transfer rather than before the move.	Y	

		University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
Ref	Quality Standard	Met Y/N	Comment	Met Y/N	Comment
HN-602 All	**Multi-Disciplinary Meetings** Multi-disciplinary team meetings should be held regularly involving at least the lead consultant, lead nurse, nurse specialist or counsellor who provides support for patients in the community (QS HN-205) and representatives of support services (QS HN-301).	N	Community and counsellor inputs were not evident in the minutes provided.	Y	A template had been developed and, if implemented, would support the multi-disciplinary team processes.
HN-603 All	**Service Level Agreement with Community Services** A service level agreement for support from community services should be in place covering, at least: a. Role of community service in the care of patients with haemoglobin disorders b. Two-way exchange of information between hospital and community services.	N	A service level agreement was not in place to cover community services.	Y	A full service specification was available for community services appropriate to an integrated organisation.
HN-701 SHT A-LHT	**Data Collection** Data on all patients should be entered into the National Haemoglobinopathy Registry. Data should include annual updates and serious adverse events.	Y	IT was well developed with e-alerts when a patient was admitted, e-alerts to GPs and e-annual reviews being used.	Y	Significant progress had been made as a result of the temporary appointment of a data manager. Data were entered in real time during clinics.

		University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
Ref	**Quality Standard**	**Met Y/N**	**Comment**	**Met Y/N**	**Comment**
HN-702 All	**Ongoing Monitoring** The service should monitor on an ongoing basis: a. Number of patients having acute admission, day unit admission or A&E attendances b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year c. Length of in-patient stays d. Re-admission rate e. DNA rate f. Waiting times for transfusion	Y	Data for the last quarter were available	Y	Data for the last quarter were available

Ref	Quality Standard	University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
		Met Y/N	Comment	Met Y/N	Comment
HN-703 All	**Audit** Clinical audits covering the following areas should have been undertaken within the last two years: **For patients with sickle cell disease:** a. Proportion of patients with recommended immunisations up to date b. Proportion of patients on regular penicillin or equivalent or who have a supply for immediate use if required 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. **For patients with thalassaemia:** d. Evidence of effective monitoring of iron overload, including imaging (QS HN-505) e. Proportion of patients who have developed new iron-related complications in the preceding 12 months	Y	Whilst a good range of audits had been undertaken the numbers of patients included were low. Action had been taken as a result of audit outcomes.	Y	Audit demonstrated that there was no delay in receiving first analgesia for patients attending with acute pain. Action had been taken as a result of audit outcomes.
HN-704 All	**Guidelines Audit** The service should have a rolling programme of audit, including: a. Audit of implementation of evidence based guidelines (QS HN-500s). b. Participation in agreed network-wide audits.	N	Network-wide audits were not taking place. Consideration should be given by commissioners to encourage the development of the network for audit of guidelines.	N	Network-wide audits were not taking place. Consideration should be given by commissioners to encourage the development of the network for audit of guidelines.
HN-705 SHT	**Research** The SHT should actively participate in research relating to the care of patients with haemoglobin disorders.	Y	Excellent research was undertaken.	Y	

		University College London Hospitals NHS Foundation Trust		Whittington Health NHS	
Ref	**Quality Standard**	**Met Y/N**	**Comment**	**Met Y/N**	**Comment**
HN-798 All	**Review and Learning** The service should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses'. This should include: a. Review of any patient with a serious adverse event or who died in the last 12 months b. Review of any patients requiring admission to a critical care facility within the last 12 months	Y	Evidence over the last six months was provided.	Y	Evidence over the last six months was provided.
HN-799 All	**Document Control** All policies, procedures and guidelines should comply with Trust (or equivalent) document control procedures.	Y		Y	

HAEMOGLOBIN DISORDERS CLINICAL NETWORK

Ref	Quality Standard	Met Y/N	Comment
HY-199	**Involving Patients and Carers** The network should have mechanisms for involving patients and their carers from all services in the work of the network.	N	Network arrangements were not yet in place.
HY-201	**Network Leads** The network should have a nominated: a. Lead consultant and deputy b. Lead specialist nurse for acute care c. Lead specialist nurse for community services d. Lead manager e. Lead for service improvement f. Lead for audit g. Lead commissioner	N	Network arrangements were not in place yet.
HY-202	**Education and Training** The network should have agreed a programme of education and training to help services achieve compliance with QSs HN-205 and HN-206.	N	Network arrangements were not in place yet.
HY-501	**Transition Guidelines** Network guidelines on transition to adult care should have been agreed covering: a. Age guidelines for timing of the transfer b. Involvement of the young person, their carer, paediatric services, primary health care, social care and Local Haemoglobinopathy Team (if applicable) in planning the transfer c. Allocation of a named coordinator for the transfer of care d. Communication of clinical information from paediatric to adult services e. Arrangements for monitoring during the time immediately after transfer to adult care f. Arrangements for communication with Local Haemoglobinopathy Team (if applicable) Guidelines should be explicit about transition directly to any accredited LHTs.	N	Network arrangements were not in place yet.

Ref	Quality Standard	Met Y/N	Comment
HY-502	**Clinical Guidelines** Network guidelines should have been agreed covering: a. Annual review (QS HN-502) b. Routine monitoring (QS HN-503) c. Transfusion (QS HN-504) d. Chelation therapy, including guidelines for shared care with general practice (QS HN-505) e. Management of acute complications (QS HN-506), including indications for referral to specialist services (QS HN-302) f. Management of chronic complications (QS HN-508), including indications for referral to specialist services (QS HN-302) g. Transfer for critical care (QS HN-509) h. Specialist management (QS HN-510) i. Thalassaemia intermedia (QS HN-511) Guidelines should be explicit about any accredited LHTs which may take responsibility for annual reviews or any other aspect of care usually provided by SHTs.	N	Network arrangements were not in place yet.
HY-701	**Annual Meeting** The network should hold a meeting at least annually involving network leads (QS HY-201) and lead consultants and lead nurses for each LHT / SHT in the network (QSs HN-201 and HN-203) to review the network's progress towards achievement of Quality Standards and its implementation of agreed service development plans.	N	Network arrangements were not in place yet.
HY-702	**Ongoing Monitoring** The network should monitor on a regular basis: a. Submission of data on all patients to the National Haemoglobinopathy Register (QS HN-701) b. Proportion of patients who have had their comprehensive annual review undertaken and documented in the last year.	N	Network arrangements were not in place yet.
HY-703	**Audit** The network should have an agreed programme of audit and review covering, over the whole programme, network-wide achievement of QSs HN-702, HN-703 and HN-704.	N	Network arrangements were not in place yet.
HY-704	**Research** The network should have agreed: a. A policy on access to research relating to the care of patients with haemoglobin disorders b. A list of research trials available to all patients within the network.	N	Network arrangements were not in place yet.

Ref	Quality Standard	Met Y/N	Comment
HY-798	**Review and Learning** The network should have appropriate arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and 'near misses', especially those involving more than one service within the network.	N	Network arrangements were not in place yet.

COMMISSIONING

Ref	Quality Standard	Met Y/N	Comment
HZ-601	**Commissioning of Services** 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: a. Designated SHT/s for the care of adults with sickle cell disease b. Designated SHT/s for the care of adults with thalassaemia c. Accredited LHTs for care of adults with sickle cell disease or thalassaemia d. Other LHTs/ Linked providers for care of adults with sickle cell disease or thalassaemia e. Community care providers	N	Some progress had been made.
HZ-701	**Clinical Quality Review Meetings** Commissioners should regularly review the quality of care provided by each network, in particular, achievement of QS HY-702 and HY-798.	N	Clinical quality review meetings were not yet in place.