UK Forum on
Haemoglobin
Disorders

WM QRS West Midlands
Quality Review Service

Services for Children with Sickle Cell Disease or Thalassaemia
at
Lewisham Hospital NHS Trust, University Hospital Lewisham

Quality Review Visit Report
Visit date: May 12th 2010

Report finalised: January 27th 2011

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INTRODUCTION

This report presents the findings of the peer review visit to services for children with sickle cell disease or thalassaemia at Lewisham Hospital NHS Trust, University Hospital Lewisham [UHL] which took place on May 12th 2010. The purpose of the visit was to review compliance with the '*Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies', 2009*. The visit was organised by the West Midlands Quality Review Service.

ACKNOWLEDGEMENTS

We would like to thank the staff of Lewisham Hospital NHS Trust for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks too to the parents who took time to 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.

SICKLE CELL AND THALASSAEMIA SERVICES AT LEWISHAM HOSPITAL NHS TRUST

Service (as at 2010)	Patient numbers sickle cell disease	Sickle cell children on long term red cell transfusions	Patient numbers thalassaemia
Lewisham Hospital	244	7	<5

The children's sickle cell and thalassaemia service at UHL was large, and growing. There was some uncertainty before the visit about its status as a specialist or local service, partly because it was suggested that it might be a Centre in the original draft list, based on its very large patient numbers. It anyway justified a visit separate from the specialist hospital teams with which it linked because of the number of children it managed. Based on the findings of the visit, the review team considered that it functioned as a busy local service. The lead paediatrician was responsible for service development and delivery but the red cell service constitutes only a part of her commitments. She was supported by a Consultant in Emergency Paediatrics who provided basic cover for emergency queries in her absence, and by other general paediatric colleagues. Efforts had been made to recruit to a staff grade post to support the lead paediatrician, but these had been unsuccessful. A clinical nurse specialist had been in post covering children's and adult services but left some years ago and funding was transferred to adult services. The ward sister had a role in education and leadership but could not provide clinical continuity, attend clinic or see children in A&E. The adult haematology

team were not routinely involved in children's care, and the transition of patients from paediatric to adult services had not been the subject of much focus to date.

Accident and Emergency

Children presenting to A&E arrived at a shared adult and paediatric area and it was intended they should be 'fast triaged' once it was known they had sickle cell disease. User families indicated to the review team that this did not always happen. Some families bypassed the booking-in area and presented straight to the children's area. Standard analgesia was usually intravenous morphine. Staff said that this can be given as quickly as within 10 minutes, although the parents of children using the service were concerned that sometimes there could be delay of up to an hour before analgesia was given. Those who had been given a protocol letter to present in A&E reported that this was useful, and helped to secure faster access to pain relief. Users reported that the doctors in A&E 'did not always appear to be listening to them'. A&E staff were familiar with the management of sickle cell children, and guidelines were in place there. A small book recorded when affected children attend and / or are admitted, so that the acute and community teams were kept informed. Older children could continue to use the paediatric pathway until they felt comfortable to transfer over to adult services, up to the age of 19. They could carry a small 'credit card' indicating this to admitting teams.

Outpatient Clinics

Out patient clinic facilities were soon to be relocated. At the time of the visit they were currently in an older part of the hospital but were pleasant, light and user-friendly with a large and well-stocked play area. The lead paediatrician ran the clinics alone, seeing new patients in a separate monthly clinic with 40 minutes appointment intervals. There was also a monthly clinic for children on hydroxycarbamide, or with transfusional iron overload and receiving iron chelation therapy. Other children attended a clinic which was held weekly. Out of hours clinic appointments are not offered. When the lead paediatrician was on leave, the clinics were either rescheduled or cancelled. Service users reported that, if the lead paediatrician was away, they were unsure who to contact.

For the last 6 months, members of the vascular team at King's College Hospital had offered trans-cranial Doppler screening scans at this clinic using mobile equipment.

Day Care

Children coming for booked blood transfusion attended the in-patient paediatric medical ward, usually at weekends. Cannulation was undertaken by medical staff. Delays in medical staff attending to see the child, cannulate and prescribe were not evident. Individual protocols for each regularly transfused child were held on the ward. A ward based play specialist was available 8 am – 6 pm Monday to Friday, and there was a large play area.

In-Patient Facilities

Children with sickle cell requiring admission were treated on the medical paediatric ward, which had 16 beds, including a 4 bedded area used predominantly for older children and adolescents. They were managed by the admitting paediatrician, with input from the service lead paediatrician as required. Older children were also sometimes seen by the adult sickle cell clinical nurse specialist. Analgesia on the ward was mainly with parenteral opiates, including patient controlled analgesia pumps. Full guidelines were located on the ward in a folder which included an introduction and explanation about the condition for nursing staff. Length of stay for children with sickle cell averaged 3 days.

Community Services

Specialist nursing input in the community was undertaken by a 10 - strong nursing team based in Lambeth, covering the large high prevalence areas of Lambeth Southwark and Lewisham [LSL]. There was a named nurse for Lewisham, who used to attend the weekly clinics but had been finding this increasingly difficult. Nurses felt the newborn screening programme now took much of their time, at the expense of individual and family support for older children. Families of children using the service reported that this was a problem for them. Users also reported that, although telephone contact with the community specialist nurses was available in theory, in practice this did not always work. The community team received the results of the newborn screening programme and visited families at home to explain the condition to the family, referring in to paediatric clinic. Lewisham families had the choice of attending UHL, Kings College Hospital or St Thomas'. Support group activity had been led by the community team and recently there had been renewed efforts to re-establish the groups and increase participation. The families who met the review team were knowledgeable and were keen on becoming involved. The community team were active in health promotion and education.

LINKED HOSPITALS

There were no hospitals referring children in to UHL for specialist aspects of care for these conditions.

COMMISSIONING ARRANGEMENTS

The review team did not meet any of the local team responsible for commissioning acute services. Commissioning had been undertaken by the Lambeth, Southwark and Lewisham Commissioning Alliance, but was now integrated into a new South East London acute commissioning unit. The community services were commissioned by Lambeth PCT for LSL. It was reported that these might merge managerially with Guy's and St Thomas'. A consultant in public health and a consultant midwife working with Lewisham PCT met members of the visiting team.

REVIEW VISIT FINDINGS

ACHIEVEMENTS

1 The energy and commitment of the lead paediatrician was evident. She was holding together a large clinical service and her service was much appreciated by users. The support of her general paediatric medical and nursing colleagues was acknowledged.

2 There was a well staffed and highly experienced community team, playing a positive role in health promotion, training and education.

3 Bringing a trans-cranial Doppler service, for assessing stroke risk in children with sickle cell disease, on site was a significant improvement for local families, leading to increased numbers of children accessing this key assessment.

4 The public health consultant who met the team stressed the commitment by UHL staff towards meeting national targets for screening, and their willingness to engage in a process for improvement where necessary.

CONCERNS

1 This service did not have the staffing needed for the number of patients receiving care. The acute service was delivered essentially by a single paediatric consultant without specialist colleagues or specialist nursing support, although efforts had been made to appoint additional medical staff. The review team was seriously concerned that appropriate quality care, particularly for in-patients, could not always be given in these circumstances and that the pressure being placed on the lead consultant was unreasonable. What specialist support was available, particularly input from the adult haematology team, did not appear to be utilised in delivering the service.

2 Some of the written guidelines and protocols were not sufficiently clear or detailed to be used by non-specialist staff or junior doctors, in the absence of the lead paediatrician. Others relating to out-patient or planned care were not documented. The lead paediatrician was the only consultant involved and the lack of documented guidelines and protocols would present significant problems if she were unavailable.

3 In-patient care of children with sickle cell disease who have complex acute problems could not appropriately be provided because services are staffed by general paediatric and A&E medical staff. It was considered that these children should be receiving care from a more fully resourced, specialist team.

4 More clarity was needed in written guidance on the management of acutely unwell children to ensure discussion with, or if necessary, transfer to the care of, a full specialist team.

5 Some written guidelines were duplicated with slight differences, for example, guidelines on red cell exchange. This had the potential to cause confusion and error.

6 Transition materials were sparse and, in practice, this period did not seem to receive the focus required. Some of the families who met the team report that their older teenagers have concerns about coming to the adult ward.

7 No audits against the key standards were available. Data collection was starting, but with the personnel in post at the time of the visit, it would be difficult to enter data onto the planned local database and national registry.

8 The degree to which the standards for the newborn screening programme were met was not clear. A small audit undertaken by the hospital team suggested only a small proportion of

families were being informed that their baby was affected by 4 weeks, and being seen in clinic by 3 months. The community team indicated that this was not representative data. They acknowledged that there could be delays, sometimes outside their control, and a fuller audit was planned. Hospital and community staff agreed that there had been recent improvements in processes. [Note: detailed figures regarding compliance with the screening standards were received after the visit, and these are included in Appendix 2].

FURTHER CONSIDERATION

1 Consideration needs to be given to future of this service, to ensure that staffing levels are adequate to provide the range and depth of services expected from a large unit with high local population need. In the meantime, close working links with a more fully staffed team are essential. The expected loss of high dependency beds from the UHL site, as in-patient surgery moves off site, was likely to lead to early referral out for more acutely ill children.

2 Individualised care plans or protocols for patients presenting with sickle cell crisis to A&E might be useful. Users reported that the 'fast triage' system did not always work for them, and consideration might also be given to using alternative regimens for these children – for example intra-nasal diamorphine which was used for other children in this A&E – which can be administered quickly and may reduce waiting time to first analgesia.

3 As the community team are involved with an increasing number of newborn and young children, older children may no longer have the access to, and support from, that team which they would like.

4 Some regular meetings between the lead paediatrician and the community nursing team are needed for case management discussion and to ensure continuity of care of children.

5 As only a very small number of children with thalassaemia attend UHL, the families might be made aware that there are other hospitals treating larger patient numbers locally, and that they could choose to transfer care to one of these for reasons of peer and family support.

6 Some social work, and especially benefits advice, input would be valuable.

GOOD PRACTICE

1 The lead paediatrician's practice of writing clinical letters to the parents, copied to the GP, was considered to be an excellent way of ensuring that families are fully involved and that language used is comprehensible.

2 Booked blood transfusions were available at weekends.

3 The flexibility around age of transfer of patients from paediatric to adult services was commendable, as was the small card carried by children over 16 years indicating their preference to remain under paediatrics so they are directed appropriately on presentation.

4 A 'communication book' was held in A&E to record sickle cell children's attendance or admission, for the information of acute and community teams.

5 The offer of a long clinic appointment slot for the first visit was excellent, so that initial discussions can be full and unhurried.

6 The DNA policy was comprehensive and appears to be used robustly in practice to try to avoid losing children from follow-up.

7 Some of the patient and family information was very strong, including leaflets on priapism, TCD / stroke, and dietary advice relevant for African Caribbean food choices.

8 There has been a detailed audit of the 'timeline' for children attending for regular transfusion, breaking down how time was spent between leaving home and returning there, as part of trying to minimise any delays in hospital.

9 Some very good nursing educational material was seen on the in-patient ward.

10 Especially given the small clinical team, the fact that the lead paediatrician's secretary was readily available and offers a familiar and friendly point of first phone contact was appreciated.

APPENDIX 1: MEMBERSHIP OF THE REVIEW TEAM

Dr Paul Telfer	Senior Lecturer (Honorary Consultant) in Haematology	Barts and The London NHS Trust
Dr Corrina McMahon	Consultant Haematologist	Our Lady's Children's Hospital, Dublin
Christine Williams	Service Director	Sickle Cell & Thalassaemia Centre, Hackney
Jon Currington	Senior Strategy & Planning Manager	East Midlands Specialised Commissioning Group
Elaine Miller	User Representative	UK Thalassaemia Society
Rajpal Singh	User Representative	
Dr Anne Yardumian	Clinical Lead for Peer Review Programme	

APPENDIX 2: COMPLIANCE WITH QUALITY REQUIREMENTS

Assessment was against those QR's relating to an LHT [local haemoglobinopathy team].

Ref	Quality Requirement	Met?	Comment
INFORMATION AND SUPPORT FOR PATIENTS AND THEIR CARERS			
1	Written information should be offered to patients and their families covering at least: 1 A simple explanation and description of the condition, how it might affect the individual, possible complications and treatment. For sickle cell disease this information should include: a Problems, symptoms and signs for which emergency advice should be sought b How to manage pain at home, including how to avoid pain, and non-pharmacological interventions c Importance of adequate fluid intake d Use of antipyretics for fever e Importance of regular antibiotics and full immunisation f How to feel the spleen and its significance. For thalassaemia this information should include: a Problems, symptoms and signs for which emergency advice should be sought b The importance of maintaining good haemoglobin levels by transfusion c Potential problems of iron load and how it can be managed. 2 Details of the services available locally including: a Clinic times and how to change an appointment b Key contact name and number c Alternative contact if key contact away d Who to contact for advice out of hours e How to use emergency services f Ward usually admitted to and its visiting times g Community services and their contact numbers h Details of support groups available. 3 Health promotional material including a Inheritance and implications for other family members b The importance of a good diet and regular exercise c Implications for travel d Age appropriate information on avoiding smoking and excess alcohol consumption e Age appropriate information on contraception and sexual health f Where to go for further information, including useful websites and national voluntary organisations.	N	*Information for families of sickle cell children was comprehensive, there was none relating to thalassaemia. Key contact information was not seen.*

Ref	Quality Requirement	Met?	Comment
2	Written information for the patient's primary health care team should be available covering at least: a All aspects of QR1 b The need for regular prescriptions, penicillin and analgesia (SC)	Y	
3	Information should be available on transition to adult care. This information should cover all aspects of the transition (QR43).	N	*But the 'young person's alert' card was noted as good practice.*
5	The locally agreed patient-held record (QR4) should be in regular use within the LHT / SHT.	N	
6	Services should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	Y	*Clinical areas were pleasant and child-friendly.*
STAFFING and SUPPORT SERVICES			
7	The LHT should have a nominated lead paediatrician / paediatric haematologist consultant with an interest in the care of patients with haemoglobinopathies who should have responsibility for guidelines, protocols, training, audit relating to haemoglobinopathies and overall responsibility for liaison with referring LHTs. The lead consultant should undertake CME activity of relevance to care of children and young people with haemoglobinopathies.	Y	*Although the documented relevant CME activity presented was slight for the lead clinical provider of such a service.*
8	There should be agreed cover arrangements for cover for absences of the lead paediatrician.	Y	*This was by general paediatricians and with input from one of the A&E Consultants.*
11	The LHT should have a lead haemoglobinopathy nurse with responsibility, with the lead consultant (QR7), for guidelines, protocols, training, audit relating to haemoglobinopathies, liaison with community nurses and liaison with the SHT. The lead nurse should have specific training in the care of patients with haemoglobinopathies.	N	*And this was an important lack at present.*
17	The following support services should be available: a Interpreters b Social work c Play specialist d Hospital teacher (in-patient care only) e Child psychologist f Dietician	Y	*Although social work input was felt to be insufficient.*
18	A service agreement for support from community services should be in place. This service agreement should cover, at least: a Guidelines for involvement of community paediatric services in the care of patients with haemoglobinopathies b Role of community services c Exchange of information between hospital and community services and vice versa d Arrangements for liaison with schools.	N	*A service specification provided was labelled 'draft', gave staff banding in pre-agenda for change terms [G and H], and mentioned service milestones / key objectives for 2004/5, so was felt not to be current.*
19	A nurse with competency in cannulation, starting and supervising a transfusion should be available at all times at which children are attending for transfusion.	N	

Ref	Quality Requirement	Met?	Comment
20	All staff involved in the care of children and young people with haemoglobinopathies should undertake regular child protection training.	N	*Details of level and date of child protection training for staff involved in the service were requested at the visit, and subsequently, but were not supplied.*
CLINICAL and REFERRAL GUIDELINES			
21	Guidelines should be in use covering a How to establish and confirm diagnosis b Parent and sibling testing	N	*No written guidance about confirming diagnosis, or family testing.*
22	Clinical guidelines should be in use covering: a Recommended immunisations b Immunisations, other prophylaxis and travel advice prior to travel abroad. c Penicillin prophylaxis while awaiting clarification of diagnosis (sickle cell disease only)	Y	*Appropriate guidance was in place.*
23	Clinical guidelines should be in use covering possible acute presentations including, at least: **For patients with sickle cell disease:** a Fever and infection including major sepsis b Acute pain c Acute anaemia d Stroke and other acute ischaemic events e Acute chest syndrome f Acute splenic sequestration g Abdominal pain / jaundice h Priapism i Changes in vision, including urgent referral for an ophthalmologic opinion j Indications for 'top-up' and for exchange transfusion and practical protocol for undertaking exchange transfusion **For patients with thalassaemia:** a Fever and infection including major sepsis b Unexpected cardiac, hepatic, endocrine decompensation. These guidelines should ensure that patients are transferred to the paediatric ward for assessment as quickly as possible	N	*Although many guidelines are in place, hard copy and on the 'Lewinet', several were felt to be unclear, lacking practical guidance and hard to follow if a user was unfamiliar with the subjects. There was no specific guidance about acute management of stroke. Two forms of guideline were seen for red cell exchange which differed in some content.*

Ref	Quality Requirement	Met?	Comment
24	Clinical guidelines should be in use covering routine out-patient monitoring and management between formal annual progress review visits, including: **All patients:** a General assessment of well-being including school attendance b Any difficulties adhering to treatment or other difficulties with care c Monitoring growth and development d Checking for palpable spleen **Patients with sickle cell disease:** a Discussion to ensure analgesics available for home use understood and effective b Informal assessment of cognitive function, learning and behavioural difficulties, including referral if needed c Checking for history of priapism in boys d Checking for and management of nocturnal enuresis e Checking all necessary immunisations up to date f Penicillin therapy and alternative therapy for children who are allergic to penicillin g Monitoring of oxygen saturation by pulse oximeter h demonstrating to parents / carers how to check for splenic enlargement i Monitoring of Hb levels, renal function tests, liver function tests j Indications for early referral to specialist haemoglobinopathy team (LHT only) **Patients with thalassaemia and regularly transfused sickle cell:** a Checking adherence specifically to chelation therapy and any difficulties b Monitoring Hb levels, iron levels, liver function and other biochemistry c Indications for early referral to specialist haemoglobinopathy team	N	*In the sickle cell guideline there was no mention of enuresis, adherence to medication, growth, assessment of spleen size.* *No thalassaemia guidelines.*
26	Guidelines should be in use for referral of patients and their families to a clinical psychologist with experience in the care of patients with haemoglobinopathies (including the option for self-referral)	N	*No written guidance was seen.*
27	Guidelines for referral for consideration of bone marrow transplantation should be in use.	N	*No written guidance was seen.*
28	Clinical guidelines should be in use covering: a Indications for regular transfusions b Investigations and vaccinations prior to first transfusion c Monitoring of haemoglobin levels	Y	
29	Clinical guidelines should be in use covering review by a specialist nurse or doctor prior to transfusion to ensure that each transfusion is appropriate.	Y	

Ref	Quality Requirement	Met?	Comment
30	A Transfusion Policy should be in use covering: a Area/s where transfusions will usually be given b Procedures for checking blood c Staff allowed to undertake cannulation d Recommended number of cannulation attempts e Maximum rate and volume of transfusion according to size of child f Monitoring the transfusions g Management of transfusion reactions h Arrangements for medical cover during transfusion i Arrangements for ensuring that a nurse with appropriate competences is in attendance throughout the transfusion.	N	*A transfusion policy was seen but it did not cover parts c, d, g.*
31	Clinical guidelines for chelation therapy and monitoring iron load should be in use including: a Indications for starting chelation b Choice of regime c Dosage and dosage adjustment d Clinical assessment of tissue damage e Monitoring of serum ferritin f Use of non-invasive estimation of organ-specific iron loading heart and liver by T2*/R2 g Management of side effects of chelators.	N	*Only a document guiding checks for children on deferasirox was presented.*
32	Clinical guidelines for the management of thalassaemia intermedia should be in use including: a Indications for transfusion b Monitoring iron loading c Indications for splenectomy.	N	
33	Clinical guidelines should be in use covering: a Indications for exchange transfusion b Arrangements for carrying out an exchange transfusion.	Y	*But the two sets included differ slightly and could be confusing to users.*
SERVICE ORGANISATION and LIAISON WITH OTHER SERVICES			
34	Clinical guidelines for acute and out-patient monitoring and management (QR23 and QR24) should be available and in use in appropriate areas including A&E, clinic and ward areas.	Y	
35	A protocol should be in use covering the initial clinic visit for patients with haemoglobinopathies covering, at least: a Giving each patient information relevant to their condition (QR1) b Giving each patient their patient-held record (QR4) c Allocation of a named contact for queries and advice to each patient. d Discussion of arrangements for future treatment and care e Sending the GP information relevant to their patient's condition (QR2)	N	*No written guidance [the lead paediatrician indicated that this was not felt to be necessary as it was only she who saw new patients – see report 'concern' 2].*
36	A protocol should be in use covering the initial clinic visit for patients previously treated outside the UK, including: a Full medical history and examination b Investigations c Referral to other specialist services (QR15) d All aspects of QR28	N	

Ref	Quality Requirement	Met?	Comment
38	A protocol should be in use covering: a Updating patient-held records b Offering patients a permanent record of consultations at which changes to their care plan are discussed. c Recording changes of key contact d Giving further information (QR1) as patients' and families' needs change	Y	*In practice this was covered by the systematic sending of clinic letters to families cc GP.*
40	An operational policy should be in use covering: a Teaching children, young people and their patients how to set up an administer subcutaneous desferrioxamine infusions b Encouraging children to participate in setting up and administering their own infusion c Regular assessment and updating administration techniques d Recording of assessments of administration techniques	N	*Although it was noted that no children currently receive desferrioxamine. All are on deferasirox, but written guidance on its use was also felt to be lacking.*
41	Patients and families should have choice of attending for blood tests, clinic appointments and blood transfusions 'out of hours' to minimise disruption to normal life	N	*Not for clinic appointments or for phlebotomy [8 a.m opening, but impractical for those having to get to school after]. Weekend transfusions mostly – commended.*
42	A protocol should be in use covering: a Follow up of children who do not attend b Communication and follow up of children who move to another area	Y	*DNA policy in place, but specific guidance on those who move to another area was not seen.*
43	A protocol should be in use covering transition to adult care. This should ensure: a Age guidelines for timing of the transfer. b Involvement of the young person in the decision about transfer. c Involvement of primary health care, social care and adult services in planning the transfer. d Allocation of a named coordinator for the transfer of care. e A preparation period and education programme relating to transfer to adult care. f Communication of clinical information to the adult services. g Arrangements for monitoring during the time immediately after transfer to adult care.	N	*No policy covering the areas outlined in this QR, and user families reported anxiety about the transfer of care.*
44	The team should have in place: a Mechanisms for receiving feedback from patients and carers about the treatment and care they receive. b Mechanisms for involving patients and carers in decisions about the organisation of the services. c Mechanisms for encouraging the development of local support groups.	N	*But some general user feedback mechanisms are in place across the hospital.* *Support groups are being re-established and publicised by community team.*

Ref	Quality Requirement	Met?	Comment
46,47 and 48	Staff from LHT participate in programme run by SHT. The SHT should meet at least annually with its referring LHT teams to: a Identify any changes needed to network-wide policies, procedures and guidelines b Review results of audits undertaken c Review any critical incidents including those involving liaison between teams d Consider the content of future training and awareness programmes (QR45)	All Y met as LHT	*The lead paediatrician attended the SKILS South London specialty group meetings.*
49	The team should meet at least annually with representatives of the neonatal screening programme to review progress, identify issues of mutual concern and agree action.	N	*No meetings were described or documented.*
DATA COLLECTION and AUDIT			
50	The LHT / SHT should have audited compliance with key standards including: **Patients with sickle cell disease:** a Proportion of patients taking regular penicillin b Proportion of patients fully immunised against pneumococcus c Proportion of patients (HbSS and HbSβ^0) who have had Transcranial Doppler ultrasonography undertaken within the last year d Proportion of patients who have had their annual multi-disciplinary review within the last year e Effectiveness of action to contact families who have not attended for follow up appointments. f Review of the care of any patients who have died. **Patients with thalassaemia:** a Proportion of patients on chelation therapy b Proportion of patients who have had their annual multi-disciplinary review within the last year c Adequacy of recording of: ▪ Pre-transfusion Hb levels ▪ Regular monitoring of iron level ▪ Complications of iron overload ▪ Height / weight progression ▪ Spleen size ▪ Support for home chelation programme (QR40) d Effectiveness of action to contact families who have not attended for follow up appointments. e Review of the care of any patients who have died.	N	*Much activity data had been collected and were presented here, but audits of the key standards await data input* to *the clinical database. Audit of timeline for children attending for booked red cell transfusion was noted.*
51	Data should be systematically entered on all patients, following patient / parental consent, onto the National Haemoglobinopathy Registry.	N	*Data entry had just started on local clinical database with intention to seek consent and enter to NHR in parallel.*

Commissioners of Services

Ref	Quality requirement	Met?	Comment
52	Each Specialist Commissioning Group should have agreed the location of services for its population: a Specialist Haemoglobinopathy Team/s for children and young people b Local Haemoglobinopathy Team/s for children and young people c The expected referral patterns to each SHT and LHT. d The type of patients (sickle cell and / or thalassaemia) who will be treated by each team.	N	
53	Each Specialist Commissioning Group should have: a Compared the staffing, support services and facilities of each SHT and LHT located within its area (QR52) with the levels expected in QRs 7 to19. b Agreed a plan for the development of SHTs and LHTs located within its area. c Monitored achievement of the agreed plan at least annually. The agreed development plan should ensure that QRs 7 to 19 are met within 2 to 5 years.	N	

Additional Requirement – Screening Services

Ref	Quality requirement	Met?	Comment
P3	Timely communication of positive screening results (sickle cell disorder) – including a review of parental results	N	*Figures received from community team after the visit, on 14 babies born between Jan and Oct 2009, indicated 31% visited and family informed by 4 weeks.*
P4	Effective follow-up of infants with positive screening results (sickle cell disorder) – all babies to be registered with a local clinic/centre (or clinic working as part of clinical network)	N	*Figures as above: 40% referred by 8 weeks and 33 % attending by 3 months.*
P5	Timely confirmation of diagnosis for infants with a positive screening result**	N	*No evidence provided.*
S1i	Failsafe to ensure ongoing care	Y	*Covered in DNA policy and community team described in practice*
S1ii	Up-to-date registers maintained of babies (cases) for which units are responsible	N	*A local clinical database was just being established at the time of the visit.*

** Specified conditions: Hb-SS, Hb-SC, $HbSD^{Punjab}$, Hb-SβThalassaemia (β^{+}, β^{0}, δβ, Lepore), $Hb\text{-}SO^{Arab}$, Hb-S/HPFHNOTE.

Different QR's 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 QR's met cannot be used to assess the overall standard of the services provided or to compare this Trust's services with others.