WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

SERVICES FOR CHILDREN AND YOUNG PEOPLE WITH HAEMOGLOBIN DISORDERS

PEER REVIEW PROGRAMME 2010-2011: OVERVIEW REPORT

Version 1

September 2011

NHS

CONTENTS

KEY POINTS

1 This report summarises the findings of a programme of peer review visits to services for children and young people with haemoglobin disorders in England. Visits to 16 hospitals delivering specialist services for children and young people with sickle cell disease and / or thalassaemia and to three large linked hospitals took place during 2010 and 2011. The primary purpose of the programme was developmental, aiming to improve the quality of services for children and young people with the haemoglobin disorders sickle cell disease and thalassaemia.

2 About 360 babies with haemoglobin disorders and 9,000 carriers are born each year. About 800 people in England have major thalassaemias and over 15,000 have sickle cell disease, with an estimated 55% and 35% respectively being children and young people. Over 80% of children and young people with sickle cell disease and about 50% of those with thalassaemia are cared for by London-centred networks. Two London networks each include over 1,100 sickle cell children. Birmingham and one London hospital had the largest numbers of children with thalassaemia. Numbers of affected children were rising rapidly in some areas.

3 These conditions seriously affect the lives of affected children and young people. Those with sickle cell disease are at major risk from bacterial infection, severe bone and joint pain 'crises' and stroke. Children with thalassaemia need blood transfusions every three to four weeks from the age of about one for the rest of their lives. This leads to iron overload in the body which can be fatal by mid-teens unless appropriately managed. Good care prolongs the lives of affected individuals, improves quality of life, and can help prevent hospital admission and reduce complications, especially stroke in children with sickle cell disease.

4 National recommendations are that services should be provided by specialist haemoglobinopathy teams [SHT's] supported, especially in high prevalence areas, by local hospital teams [LHT's] providing much of the planned care. In practice, the organisation of specialist and local teams is based on proximity to the nearest large centre, historical referral patterns and clinical links, with few formalised clinical networks. In two areas it was not possible to identify a specialist centre, and there were no visits to these areas. In some others, referral was to several specialist centres. In high prevalence areas, especially in south and east London, local teams were caring for over 200 affected children – more than most specialist teams outside London.

5 In some areas 'fail-safe' arrangements to ensure children identified by the screening programme access appropriate care were not in place. No SHT could accurately enumerate all the children for which they had responsibility across the network and some were not sure about the exact number managed within their own centres. Responsibility for ensuring that all children and young people are reviewed regularly was unclear in some areas and, because of the lack of robust data, audit of compliance with key aspects of clinical care was often not available.

6 In every hospital visited there were key staff members who were remarkably committed to providing high quality care, often in very difficult circumstances. The number of consultant and specialist nurse sessions bore little relationship to the number of children cared for by the service. In some teams the workload of specialist staff was unreasonably high and the provision of consistently good quality care was not feasible. In several centres, the service was mainly provided by a single consultant working with one or more specialist nurses. Children admitted with acute complications often had their care managed by a consultant paediatrician with no specialist expertise in haemoglobin disorders, especially outside normal working hours. Doctors in training were often not involved in the routine or planned care of children with haemoglobin disorders. Collaboration with adult haematology services to improve the quality of care, reduce pressure on paediatric staff and smooth transition to adult care was in place in some but not all services.

7 Cooperation between acute and community nursing teams was sometimes very good but this was not universal. The availability of play specialist, social work and psychology support was variable despite the important contribution of these disciplines to the care of children with haemoglobin disorders. Many Specialist Teams had no access to a named social worker and had to explain the needs of children with haemoglobin disorders repeatedly to generic social workers. Psychology support is key to achieving adherence to treatment for children with thalassaemia. For children with sickle cell disease neurocognitive assessment may be the first indication of brain ischaemia needing further investigation and treatment, and detailed assessments of children who have cerebrovascular disease is necessary to provide appropriate learning support. Teams rarely included a psychologist on a regular basis and some teams were not able to access assessments other than for children with obvious impairments.

8 Several services had made strenuous efforts to make care responsive to the needs of children and young people with haemoglobin disorders with some examples of excellent practice. However, some problems were common, including delays in administration of analgesia for children presenting with acute pain crisis. Most services were not able to offer planned care outside school / college hours and so many children on monthly transfusions were missing about one and a half days of education every month.

9 Some services were provided from excellent facilities. Others were, however, based in premises which were dilapidated or unfit for purpose, with issues ranging from a lack of facilities to examine children through to broken toys and chairs and areas which could have been easily improved with a coat of paint and some good displays.

10 Transcranial Doppler (TCD) scanning can identify children who are at high risk of stroke who are then offered regular blood transfusions. This intervention significantly reduces their stroke risk. All Specialist Teams visited offered TCD scanning but arrangements for ensuring all children in the network were scanned were not usually robust.

11 Use of the National Haemoglobinopathy Register provides a means of monitoring the number of affected children in a clinical network and for demonstrating compliance with key standards of clinical care. None of the services reviewed had entered all of their patients onto the Register, although four were well advanced. Ten had not yet started entering data.

12 Only six of the nineteen services reviewed had completed all the expected audits of clinical care for the children managed at their Centre, and no Specialist Team could provide audit data covering the whole of their clinical network. Thresholds for attendance at A&E and for admission appeared variable and the proportion of children with sickle cell disease who were on regular transfusion ranged from 1:10 to 1:30. The reason for this variation was not clear.

13 Although a Specialised Services National Definition Set was agreed in 2010 for Specialised Haemoglobinopathy Services, most specialist services commissioners were not yet involved in commissioning these services.

14 This report makes several recommendations which, when implemented, will improve the quality of care for children and young people with haemoglobin disorders. Central to these recommendations is more active commissioning, including defining clinical networks and monitoring of key process and outcome metrics. Recommendations also cover improved links between screening services and Specialist Teams and a programme of national clinical audit of service delivery and outcomes. A peer review programme of services for adults with haemoglobin disorders is also recommended.

INTRODUCTION

HAEMOGLOBIN DISORDERS

15 Sickle cell disease and the thalassaemias are a group of recessively inherited haemoglobin disorders. Children with these disorders are usually born to two symptom-free 'carriers', inheriting an unusual or variant beta-globin gene from each parent. Parents who are themselves affected by a major haemoglobin disorder can have affected children if their partner is a carrier or another affected individual.

16 It is estimated that around 800 people in England have major thalassaemias and over 15,000 have sickle cell disease, with an estimated 55% and 35% respectively being children and young people[1]. The NHS Sickle Cell and Thalassaemia Screening Programme reports that approximately 360 affected babies are born each year. Affected babies are born in all regions of England but approximately 70% are in London. Data gathered by this peer review programme indicate that over 80% of children and young people with sickle cell disease and about 50% of those with thalassaemia are managed by the London-centred networks. Areas such as the north-east and south-west of England have much lower prevalence. Sickle cell disease is now more common than, for example, cystic fibrosis. In high prevalence areas the incidence is now higher than that of childhood cancer and, unlike those with most cancers, children with haemoglobin disorders need life-long treatment.

17 The sickle gene occurs in up to 25% of people whose family origins are in West Africa or the Caribbean. Between 12 and 15% of people from the Mediterranean area and up to 18% of those from south-east Asia are carriers of the beta thalassaemia gene. In England there are about 250,000 carriers of genes for haemoglobin disorders and about 9,000 carriers are born each year.

18 Children with sickle cell disease are at major risk from bacterial infection, many suffer severe bone and joint pain 'crises', and they have a greatly increased risk of stroke. Bacterial infection, especially with streptococcus pneumoniae, can result in early death. This can be prevented by appropriate immunisation, regular prophylactic antibiotics started in infancy and prompt management of febrile illnesses. Early death can also by caused by stroke or by acute sickling in the lungs or other organs. Significant anaemia and chronic fatigue also characterise the most common and severe subtype of the disorder, haemoglobin SS.

19 Children with thalassaemia major require blood transfusions every three to four weeks from infancy for the rest of their life. This results in an overload of iron in the body which is harmful, and usually fatal by mid-teens, unless appropriately managed.

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[1] These estimates were derived by dividing the numbers of children and young people identified during the peer review programme by the estimated total number (children and adults) taken from the National Specialised Services Definition Set No. 38.

20 Haemoglobin disorders are now an important issue for public health and for the NHS in England. They are common and sometimes life-threatening. They alter every aspect of the lives of affected people. Good care enables people with haemoglobin disorders to live longer and improves their quality of life. Good care can reduce complications, in particular stroke and hospital admissions. The main national guidance on the care of people with haemoblobin disorders is listed in Appendix 1.

NATIONAL CARE STANDARDS

21 '*Standards for the Clinical Care of Children and Adults with Thalassaemia*' were first published in 2005 (second edition 2008) by the UK Thalassaemia Society, written jointly with members of the UK Forum on Haemoglobin Disorders[2]. '*Standards for the Care of Children and Young People with Sickle Cell Disease*' were written by the UK Forum on Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Committee jointly with the Sickle Cell Society and published in 2006 (second edition 2010). These Standards were produced by groups of professional and service users who wanted to see access to high quality care for all those affected by haemoglobin disorders.

22 The NHS Sickle Cell and Thalassaemia Screening Programme was established in 2001 to improve infant health through prompt identification of affected babies and to ensure high quality care was available throughout England. The UK Forum on Haemoglobin Disorders, the Sickle Cell Society, the UK Thalassaemia Society and the NHS Sickle Cell and Thalassaemia Screening Programme agreed that a peer review programme would be useful - to help services work towards meeting the National Care Standards and to monitor the extent to which Standards were being implemented. Acceptance of the Specialised Services National Definition Set number 38 – Specialised Haemoglobinopathy Services (all ages) helped to support the process of peer review.

TERMINOLOGY

23 The following terms are used throughout this report:

Specialist Team or Specialist Haemoglobinopathy Team [SHT]: The multi-disciplinary team providing specialist care for children and young people with haemoglobinopathies, including annual review and specialist monitoring for patients from across the clinical network[3].

Specialist Centre: The hospital at which the specialist team is based.

Local Team or Local Hospital Team [LHT]: The team providing local care for children and young people with haemoglobinopathies under the guidance of the specialist team, including routine out-patient

[2] The UK Forum on Haemoglobin Disorders is an organisation which includes most of the senior professionals involved in planning and delivering services for people with haemoglobin disorders, together with representation from the Sickle Cell Society and UK Thalassaemia Society.

[3] Whether every child who has a milder form of sickle cell disease, haemoglobin SC or Sβ^+ thalassaemia needs specialist review every year is under discussion but remains recommended practice at this time.

management, regular blood transfusions, and the management of uncomplicated pain crises and other relatively straightforward complications.

Local or Linked Hospital: The hospital at which the local team is based.

Community Care or Community Services: Community-based education and support for service users and their families. In some areas this includes outreach nursing care in the home.

Clinical Network: A specialist team and its referring local teams and community care services who work together under a formal governance structure to improve pathways of care.

Appendix 2 gives more details of each level of care.

QUALITY REQUIREMENTS

24 The UK Forum on Haemoglobin Disorders developed a set of Quality Requirements which aimed to describe what should be in place in each service if the National Care Standards had been implemented. The *'Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies'* were published in 2007. These were written in a format suitable for use in peer review and were piloted in a peer review visit to the Royal London Hospital early in 2007.

25 The Quality Requirements covered Specialist and Local Teams caring for children and young people with haemoglobin disorders and commissioners of these services. The Quality Requirements for Specialist and Local Teams covered:

a. Information and support for patients and their carers
b. Staffing and support services
c. Clinical and referral guidelines
d. Service organisation and liaison with other services
e. Data collection and audit

26 The peer review programme also reviewed five standards from the newborn screening programme. These standards covered the period between identification of an affected baby by the screening laboratories and his or her entry onto an appropriate clinical care pathway.

PEER REVIEW PROGRAMME

27 The primary purpose of the peer review programme was developmental, aiming to improve the quality of services for children and young people with haemoglobin disorders. During 2010 and 2011, review visits took place to 16 hospitals which indicated that they were acting as Specialist Teams – or 'Centres' of a wider network of linked hospitals. These 16 networks care for the great majority of children and young people with haemoglobin disorders in England. It is probable that small numbers of affected children are cared for by paediatric services in hospitals which are not part of one of these networks.

28 Three large linked hospitals in south and south-east London were also visited at the request of their Specialist Team Clinical Lead. These visits were informative and important as each of the three linked hospitals was managing the care of over 200 children. Some similar sized linked hospitals in East London, particularly Newham University Hospital and the slightly smaller service at Whipp's Cross Hospital, were not visited.

29 Visiting teams were made up of service and carer user representatives, consultants (paediatricians, haematologists or paediatric haematologists), specialist nurses and, when possible, a non-clinical manager or a commissioner. Each team consisted of between six and eight reviewers. The programme's clinical lead Dr Anne Yardumian attended all visits except that to her own Specialist Centre (North Middlesex University Hospital) to ensure consistency of approach and interpretation between visits. The visit to North Middlesex University Hospital was led by a senior paediatric haematologist from the West Midlands.

30 Forty-five reviewers attended one day training and 42 reviewers took part in at least one visit. Attending training and acting as a reviewer was Continuing Professional Development for health care professionals and no reviewers received additional payment for undertaking this work.

31 Chief Executives of all Trusts to be visited agreed that their service could be included in the review programme. Specialist Teams were given at least three months notice of the date of their review visit. Each visit lasted one day and included a review of written documentation, including some sets of medical records, a meeting with families of service users, discussions with members of the professional team, local managers and commissioners, and a tour of clinical facilities. Members of the linked hospital teams talked to the reviewers in person or by telephone. Table 1 gives the dates of each review visit.

Table 1 Visit dates

Service	Visit date
Sheffield Children's NHS Foundation Trust	March 10th 2010
Imperial College Healthcare NHS Trust [at St Mary's Hospital]	March 12th 2010
Birmingham Children's Hospital	March 17th 2010
University College London Hospitals NHS Foundation Trust [UCLH] and Whittington Hospital NHS Trust	March 31st 2010
St George's Healthcare NHS Trust	April 22nd 2010
University Hospital Bristol NHS Foundation Trust: Bristol Royal Hospital for Children and the South West Region	April 28th 2010
North West London Hospitals NHS Trust	April 30th 2010
Barts and the London NHS Trust: Royal London Hospital	May 6th 2010
*Lewisham Hospital NHS Trust, University Hospital Lewisham	May 12th 2010
Guy's and St Thomas' NHS Foundation Trust; Evelina Children's Hospital	May 13th 2010
North Middlesex University Hospital NHS Trust	May 18th 2010
*Mayday Healthcare NHS Trust	May 19th 2010 [half day visit]
*Queen Elizabeth Hospital, Woolwich	May 19th 2010 [half day visit]

Service	Visit date
Kings College Hospital NHS Foundation Trust	May 20th 2010
Central Manchester University Hospital NHS Foundation Trust: Royal Manchester Children's Hospital	June 23rd 2010
Alder Hey Children's NHS Foundation Trust, Liverpool.	June 24th 2010
University Hospitals of Leicester NHS Trust: Leicester Children's Hospital	June 30th 2010
Nottingham University Hospitals NHS Trust: Nottingham Children's Hospital	January 26th 2011
Leeds Teaching Hospitals NHS Trust	January 28th 2011

Notes:

1 Full Trust titles are given here. Elsewhere in the report shortened versions are mostly used.
2 * indicates a linked hospital / Local Team

32 Reviewers and the service being reviewed both commented on the draft report. Final reports were circulated to the Trust concerned and the relevant commissioner. All final reports are available on the West Midlands Quality Review Service (WMQRS) website www.wmqi.westmidlands.nhs.uk/wmqrs .

33 The peer review programme was run under the governance of WMQRS and WMQRS provided administrative support, ran reviewer training sessions and provided guidance and support to the programme's clinical lead. Funding for the review programme was provided by the NHS Sickle Cell and Thalassaemia Screening Programme.

34 The focus for this round of peer review visits was services for children and young people, including transition to adult services. It is hoped that peer review visits to services for adults with haemoglobin disorders will take place in 2012.

ACKNOWLEDGEMENTS

35 This peer review programme could not have taken place without the support of many people and organisations: the UK Forum on Haemoglobin Disorders, the UK Thalassaemia Society, the Sickle Cell Society and the National Sickle Cell and Thalassaemia Screening Programme; the cooperation of the services which were reviewed; the willingness of reviewers to give their time and expertise; the agreement of reviewers' employing organisations to release them; funding from the NHS Sickle Cell and Thalassaemia Programme; the support of the West Midlands Quality Review Service and its Board; the commitment and dedication of the Programme's Clinical Lead, Dr Anne Yardumian and the willingness of North Middlesex University Hospital NHS Trust to release her for this work. The contribution of all to this programme is gratefully acknowledged.

FINDINGS

GEOGRAPHICAL DISTRIBUTION OF AFFECTED CHILDREN

36 The prevalence of people with haemoglobin disorders was known to vary across the country. The variation in numbers found by the peer review visits is, however, even more extreme than previously recognised. The 16 networks visited cared for approximately 5,230 children with sickle cell disease and 443 with thalassaemia. Over 4,260 (81%) of the sickle cell children were managed by the London-centred networks. The two largest networks, centred at Kings College Hospital and the Royal London Hospital, each managed the care of 1,100 to 1,200 children with sickle cell disease. Three networks managed large numbers of children with thalassaemia; Birmingham cared for over 100, the Royal London Hospital over 50, and UCLH / Whittington just under 50. Three networks, centred in Bristol, Liverpool, and Nottingham, each cared for fifty or fewer children in total with haemoglobin disorders (table 2).

Table 2 Number of Children Cared for by Each Network

	Children with sickle cell disease across network					
	<50	50-	100-	250-	500-750	> 1000
Number of networks	3	3	4 [3]	3 [2]	1 [1]	2 [2]
	Children with thalassaemia across network					
	<10	10-	20-		50-100	> 100
Number of networks	7 [3]	3 [2]	4 [2]		1 [1]	1

Notes:

1 The London-centred networks are shown in brackets [ ] after the total.

2 The large linked hospitals in London are included in the network with which they work most closely.

37 Some areas had seen a very rapid rise in the number of affected children. For example, Medway Hospital, linked with Evelina Children's Hospital, was caring for 50 children with sickle cell disease compared with none three or four years ago. Numbers attending Sidcup Hospital had increased from 10 to about 100 over the last five years. Twenty babies with sickle cell disease identified through the NHS Screening Programme had been referred to Queen Elizabeth Hospital, Woolwich in 2009, and a further 14 in the first five months of 2010. Outer east London and south-west Essex were also seeing rapid growth. Basildon Hospital's caseload had increased from five to 60 children over the last five years. In the year before their peer review visit the hospital had taken on the care of 20 new cases, of which half were newborn and half had moved into the area.

SERVICE ORGANISATION AND LIAISON – THE STATE OF CLINICAL NETWORKS

38 Most networks visited had grown up on an *ad hoc* basis, with smaller local teams requesting advice from their nearest specialist centre and referring children as necessary. In some places referral had become more systematic and in some networks outreach models had developed, with staff from the specialist centre visiting linked hospitals regularly to see out-patients and offer TCD scanning. Examples of services with outreach are Kings College Hospitals, Imperial College Healthcare (St Mary's), North Middlesex Hospital and Birmingham Children's Hospital.

39 The networks did not follow any SHA, sector or PCT cluster boundaries: London centres cared for children from as far away as the south coast, Southend, Norwich, Cambridge, Stevenage and Milton Keynes. In East of England and the South East there were no established Specialist Centres and children were mostly referred to London-based teams. Two regions had small or medium-sized specialist centres operating more or less independently with their own networks, Manchester and Liverpool, and Nottingham and Leicester. Specialist commissioners in these areas were, however, working with their providers to establish joint working between the specialist centres which should help with training, guidelines, audit and review of difficult cases. A large paediatric thalassaemia service in Bradford, previously linked with Leeds, was operating autonomously and a supplementary visit to this service is planned. No functioning specialist centre was identified for the North-East or for the South Central SHAs.

40 In some high prevalence areas, especially in south London, children living in the same areas were accessing different local hospitals and different Specialist Centres, and some local hospitals linked with more than one Specialist Centre. Pathways of care were varied and sometimes complex. This can cause confusion at all levels as community and local teams have to remember, for each individual child, whom to contact for advice. Where Specialist Teams have different clinical guidelines, local and community teams may find themselves trying to comply with different guidance for different children.

41 Some of the unusual pathways of care were appropriate. For example, families who moved house sometimes chose to remain under the care of a familiar but more distant hospital. Some children were appropriately referred to specific sub-specialty expertise, for example, many south London children were referred to the Evelina Children's Hospital at St Thomas' for cardiac, renal, neurological and urological complications, and to King's College Hospital for neurovascular expertise, orthopaedics or laparoscopic abdominal surgery.

42 In the highest prevalence areas of south and east London, some of the Local Teams in linked hospitals were caring for very large numbers of affected children. For example, Queen's Hospital (Barking, Havering and Redbridge NHS Trust), Queen Elizabeth Hospital Woolwich, Lewisham Hospital and Mayday Hospital each cared for over 200 children with sickle cell disease - more than most of the Specialist Teams outside London.

43 Many of the smaller networks, for example, Bristol, Liverpool, Leicester, Nottingham and Sheffield, were highly organised and provided good care for children with haemoglobin disorders. These services each cared for less than 100 children and collaboration with another larger centre may be helpful, for example, for guideline development, training, audit, review of difficult cases, and possibly secondment of staff from the smaller centre to ensure ongoing familiarity with the range of clinical problems and their management. Smaller centres sometimes already had established routine outreach clinics and network meetings for the care of children with cancer and it may be possible to include children with haemoglobin disorders in these arrangements as the same staff are usually caring for both groups of patients.

44 **Recommendation 1: Specialised Services Commissioners [and the National Commissioning Board when it takes over these responsibilities] should require providers to establish formal clinical networks of services for children and young people with haemoglobin disorders. In determining the configuration of networks, commissioners should consider:**

a. **The number of children and young people with haemoglobin disorders, and the rapid increase in numbers in some areas. Further investigation is needed in the North-East and South Central regions.**

b. **The existing clinical relationships and referral patterns. Disruption of these relationships may be detrimental to patient care, especially in the short to medium-term.**

c. **The views of children with haemoglobin disorders and their families.**

d. **Links with tertiary paediatric networks (where applicable).**

e. **Although there is no nationally recommended minimum size for a specialist team, commissioners should consider whether services caring for less than 100 children and young people with haemoglobin disorders provide sufficient opportunity for staff to maintain their competence and confidence and whether a collaborative arrangement with another specialist team should be formally established (as described in section 43).**

f. **Although there is no nationally recommended maximum size for a specialist team, commissioners of services caring for over 1,000 children with haemoglobin disorders should consider whether the development of an additional specialist centre would improve access to services.**

g. **Commissioners of Local Teams caring for over 200 children and young people with haemoglobin disorders should, in discussion with the network's Specialist Team, consider whether Local Teams could be commissioned to undertake annual reviews of less complex children, and to manage some more complex acute presentations. This should be agreed only when staffing and expertise of the Local Team is appropriate for this level of care.**

45 **Recommendation 2: Trusts and Specialist Teams caring for less than 100 children and young people with haemoglobin disorders should review their arrangements for ensuring staff are maintaining confidence and competence in managing the range of clinical problems experienced by children with haemoglobin disorders and should consider whether establishing links with another Specialist Team would be beneficial.**[4]

RESPONSIBILITY FOR ENSURING AFFECTED BABIES IDENTIFIED BY SCREENING ACCESS CARE

46 In most of the larger networks, the results of the newborn screening programme were communicated only to the community nursing team. The community nurse specialists were responsible for visiting the family at home to give the result and referring the baby to the hospital considered the most suitable for care, depending on geography and parent choice. In some areas there was also direct communication between the newborn screening laboratory and the specialist team and in most areas there were arrangements for checking that all identified babies had attended an appropriate paediatric clinic. Because of the lack of robust 'fail-safe' arrangements at all sites, it is possible that some children identified by the screening programme are not receiving appropriate care.

47 Table 3 gives compliance with the five Screening Standards reviewed during the peer review visits. At a number of sites, no data were available at the time of the visit, and some community teams appeared surprised to be asked for them. For some, data were submitted later and were taken into account in the visit report. In others, it was not possible to access sufficient data to assess compliance – these were included in the 'not met' group. In a small number of centres there was discrepancy in the data submitted by community teams to whom the newborn screening results were communicated and that held by the acute paediatric team to whom children were referred.

Table 3 Compliance with NHS Screening Programme standards reviewed

	Standard	Met	Not met
P3	Timeliness of communication of a positive screening result to families: minimum 90% by 4 weeks	7	12
P4	Timeliness of referral into an appropriate clinic, and of first attendance at that clinic: Minimum 90% by 8 weeks and 90% by 3 months respectively.	12	7
P5	Time to confirmation of the positive screening result on a repeat sample – minimum 90% by 6 months.	11	8
S1i	Assurance of a failsafe mechanism to ensure ongoing care	17	2
S1ii	Maintenance of an up to date register* for all babies for which units were responsible	16	3

* for S1ii, 'maintenance of an up to date register for all babies for which the units were responsible' – the compliance was for a register of locally treated children, not for all children across the network for which the Specialist Team had responsibility. No Specialist Team held full data for all children in their linked hospitals.

[4] This recommendation duplicates 1d but places the emphasis on Trusts as well as commissioners considering this issue.

48 **Recommendation 3: The NHS Sickle Cell and Thalassaemia Screening Programme should ensure that newborn screening laboratories communicate details of affected newborn babies to the named lead of the Specialist Team as well as to community nursing teams. Close liaison between the Screening Programme and commissioners on the precise configuration of clinical networks [recommendation 1] will be needed to achieve this.**

49 **Recommendation 4: All Specialist Teams should establish robust 'fail-safe' arrangements with relevant newborn screening laboratories, community nursing teams, and local hospital teams to ensure that all affected newborn babies identified through the screening programme access appropriate care. A multi-disciplinary meeting of Specialist Teams, newborn screening laboratories and community services should regularly review compliance with screening standards.**

RESPONSIBILITY FOR ALL CHILDREN IN THE NETWORK

50 In general, data collection on children and young people with haemoglobin disorders was poor. No Specialist Team could accurately enumerate all the children for which they had responsibility across the network and some were not sure about the exact number cared for within the specialist centre. This has obvious implications for audit of standards of clinical care. The National Haemoglobinopathy register could provide the vehicle for recording the number of children within a clinical network but is not yet fully utilised (see section 95).

51 **Recommendation 5: Specialised Services Commissioners / National Commissioning Board should ensure that responsibility for collecting data on all children and young people with haemoglobin disorders within each clinical network is clarified, included in service specifications and contracts and monitored. This includes both entering data to the National Haemoglobinopathy Register and submitting anonymous data to the screening programmes[5]. Commissioners should incentivise completeness of data entry and use contractual levers where this is not achieved.**

52 **Recommendation 6: Specialist Teams, working with Local Teams, should establish formal protocols for a) ensuring all babies identified through the newborn screening programme enter clinical care appropriately, b) sharing data on any other newly diagnosed children c) follow-up of children who do not attend and d) discussion with families of children who move outside of the clinical network's usual catchment area and formal handover of care to the Specialist Team closer to their new home.**

[5] The requirement for data for screening programmes is given in Appendix Seven of Sickle Cell Disease in Childhood Standards and Guidelines for Clinical Care http://sct.screening.nhs.uk/standardsandguidelines .

INFORMATION AND SUPPORT FOR PATIENTS AND THEIR FAMILIES

INFORMATION

53 The Quality Requirements detailed a range of information expected to be available for patients and families. Most of this could be met through standard booklets and documents supplemented by local information giving a description of the services available, how to access care out of hours, names of core team members and details of how to contact them. This information was available in most services although it was not clear how systematically it was given to families. Some excellent additional information had been developed. Examples are listed in Appendix 3 and will be made accessible on the UK Forum website: http://www.haemoglobin.org.uk .

54 **Recommendation 7: Specialist and Local Teams should ensure a full range of information is available for patients and families.**

USER INVOLVEMENT

55 Some services had made particular efforts to engage with their service users when planning services, and to try and improve the user experience in response to feedback. Examples included services at Bristol, Nottingham, Imperial, Mayday and North Middlesex Hospitals. In some other services, user involvement had been less successful.

56 **Recommendation 8: All clinical networks should develop mechanisms for receiving feedback from service users and their families and for involving them in planning and improving services.**

STAFFING

57 In every hospital visited there were key staff members who were remarkably committed to providing high quality services, often in very difficult circumstances. In some Trusts senior management were well informed about the service for children and young people with haemoglobin disorders and the issues it faced. In a few, senior management appeared to have little or no involvement and awareness.[6]

CORE TEAM STAFFING

58 The number of consultant and specialist nurse sessions bore very little relationship to the number of children cared for by the service. It proved impossible to quantify the consultant PA's dedicated to caring for children with haemoglobin disorders. The range of resources available can be illustrated: in one centre managing large numbers of children with sickle cell disease and thalassaemia and providing outreach to

[6] NB. Reports did not always identify where staffing levels were good – at one visit the level of play therapist provision was commended and one post was then removed.

five linked hospitals there was a weekly half-day clinic for children with haemoglobin disorders where two consultants saw about 50 children. In another centre managing slightly more children with sickle cell disease and a few with thalassaemia, the weekly clinic lasted most of the day. It was run by a lead consultant and specialist nurse and attended by two Specialist Registrars, a transition nurse and /or psychologist, and a member of the community nursing team. About 20 children were seen who could access different members of the multi-disciplinary team and TCD scans were undertaken at the same visit. In some teams the workload of specialist staff was unreasonably high and the provision of consistently good quality care was not feasible.

59 **Recommendation 9: The UK Forum on Haemoglobin Disorders should produce guidance on appropriate staffing levels for Specialist and Local Teams, taking account of the number of children cared for by the service and the need for support to Local Teams within the network.**

60 In several centres, service delivery was mostly by a single consultant paediatrician or paediatric haematologist in conjunction with one of more specialist nurses. This was seen as an advantage locally because experienced and knowledgeable staff were managing the children's care. The visiting teams were concerned because:

a. Children may not have access to staff with appropriate expertise out of hours or when key staff were on leave.
b. Medical staff in training and other consultants did not take part in the routine management of children with haemoglobin disorders which impacted on their ability to deliver care at other times.
c. In some services, the lead consultant had been in post for many years and involving a more junior colleague could be useful succession planning.
d. Doctors in training were not being encouraged to develop an interest in managing the growing numbers of children with haemoglobin disorders. This is particularly important because consultant recruitment in these services is currently difficult.

61 **Recommendation 10: Specialist and Local Teams should ensure that, under the supervision of core team members, doctors and nurses in training are actively involved in all aspects of care for children with sickle cell and thalassaemia.**

NURSING ROLES

62 Specialist nurses and nursing teams in several hospital services were making an outstanding contribution to the care of children and young people with haemoglobin disorders. Some teams worked flexibly across different clinical areas of the hospital and so got to know the children and young people very well. This was highly appreciated by families. For example, at King's College Hospital a single team ran the in-patient and day care areas. At North West London / Central Middlesex Hospital the same team covered in-patient, day care and the paediatric A&E department. The range of duties undertaken by hospital nurse specialists was

wide. Some were highly clinically skilled in assessing and managing children and, for example, undertaking exchange red cell transfusions. Others offered more general support and health promotional advice. The publication of RCN Nursing Competency Framework (Appendix 1) should help teams to ensure nursing staff have appropriate competences.

63 Some acute and community teams cooperated very well, for example, those in Manchester, Bristol, Leeds, North West London and UCLH / Whittington. In Croydon / Mayday and Nottingham a community nurse 'in-reached' to cover gaps in acute nursing. In some places, for example Bristol, Manchester and Whittington, the hospital nurse specialist did outreach work in homes and schools, for example, taking pre-transfusion blood samples or school visits. In others, for example, Leicester and Sheffield, the interface between acute and community services was less well developed.

64 Community nursing roles included genetic counselling for pregnant women who carry haemoglobin disorders, and their partners, identifying couples at risk of having an affected baby and offering referral for pre-natal diagnosis. Most received and managed the results of the NHS Sickle Cell and Thalassaemia Screening Programme. Work also included some individual client education, support and care at home. These roles were not always clearly defined, and it was reported that individual clinical support work was sometimes compromised by the increased demands of managing the results of the newborn screening programme. As with core hospital team staff, the number of community nurses bore little relationship to the size of their service. Some small, hard-pressed teams, for example in Woolwich and Croydon, provided a highly organised, good quality service. Service level agreements covering the work of community services were rarely evident and acute Trusts were not always clear what they could expect from community services. Services seemed to work best where community nursing teams were part of the same organisation as acute services. In a few areas it appeared that some of the work of community nursing teams might more appropriately be undertaken by active local voluntary groups. The Manchester community team had good recording of activity and clearly monitored targets. This was, however, exceptional and most community nursing teams lacked readily available data on their activities including compliance with the NHS Screening Programme targets for timeliness of visiting families and ensuring first clinic attendance for affected newborn babies (see section 47).

65 **Recommendation 11: Members of all community nursing teams should be clear about their roles (genetic counselling, work with couples at risk of having an affected baby, managing the results of the NHS Screening Programme, and / or individual client education, support and care), the competences needed for these roles and the time spent on each aspect of their work. Teams should systematically record activity data for the different aspects of their work, including reporting on performance against relevant Screening Standards.**

COLLABORATION WITH ADULT HAEMATOLOGY SERVICES

66 Services for children with sickle cell disease and thalassaemia are best managed by paediatricians and haematologists and, ideally, by paediatric haematologists. Paediatricians with an interest in haemoglobin disorders bring to the service all their training and expertise in caring for long term illness in children and families and in managing acutely ill children. Haematologists bring their understanding of laboratory investigations and blood transfusion practice and, sometimes, extensive clinical expertise in managing the care of adults with sickle cell and thalassaemia. Paediatric medical staff with expertise in haemoglobin disorders are not abundant and, in some centres, they were carrying a very high workload. Some services had established good collaboration with adult haematologists, for example, Royal London Hospital, Nottingham, Leicester, North West London, UCLH / Whittington and the North Middlesex Hospital. This arrangement also smoothed the transition to adult services. In Queen Elizabeth Woolwich, close collaborative working between paediatric and adult haematology consultants was helping to reduce pressure on a very stretched service. Others, for example, Lewisham Hospital, Mayday Hospital and the Leeds Hospitals, had minimal input from adult haematologists. Lewisham and Mayday Hospitals had few paediatric specialist staff and input from adult haematology could have improved clinical cover by appropriately skilled staff.

67 **Recommendation 12: All Specialist and Local Teams caring for children and young people with haemoglobin disorders should review their arrangements for collaboration with adult haematology services to ensure that full advantage is being taken of the potential for a) improving services through collaborative working and b) improving transition arrangements. This is particularly important where the children's service lead is a paediatrician and not a dually trained paediatric haematologist.**

OTHER TEAM MEMBERS

68 Input from play specialists can make a great difference to a child's experience of care but the availability of play specialists was highly variable. Many Specialist Teams had no access to a named social worker and teams said they had to explain to each new 'generic' social worker about the needs of children with haemoglobin disorders. This is particularly important because complex care packages may need to be put in place for children with haemoglobin disorders. Social work team members can also 'signpost' families to benefits and housing advice. Poor housing has a direct impact on health and wellbeing, especially for sickle cell children. Cold, damp conditions exacerbate respiratory problems and can cause pain crises.

69 Access to an appropriately experienced psychologist is essential in managing haemoglobin disorders in children. For those with thalassaemia, a psychologist is key to addressing difficulties with acceptance and adherence to treatment. In both conditions there may be family difficulties or behavioural issues relating to long term illness or frequent pain. In children with sickle cell disease cerebrovascular problems can give rise to sometimes subtle learning disabilities. Identification of these by careful neurocognitive assessment may be the first indication of brain ischaemia needing further investigation and treatment. Understanding a

child's limitations is also important for families and for schools, where extra learning support may be needed. In practice, teams rarely included a psychologist on a regular basis. Some teams were not able to access a neurocognitive assessment other than for children with obvious difficulties or impairments.

70 The lack of availability of play specialists, and appropriately experienced social workers and psychologist support at some sites was particularly disturbing as these services should be an integral part of all paediatric care.

71 **Recommendation 13: Specialist Services Commissioners / National Commissioning Board should ensure that service specifications for services for children and young people with haemoglobin disorders include the need for play specialist, social work and psychology services.**

72 **Recommendation 14: All Trusts providing services for children and young people with haemoglobin disorders should review their arrangements for play specialist, social work and psychology support to ensure these are sufficient for the needs of children and young people with haemoglobin disorders.**

FACILITIES

73 Review teams visited Accident and Emergency Departments, out-patients, and day care and in-patient wards at each site. The quality of the premises, the adequacy of space available, and the attention to up-keep was extremely variable. Some centres had outstanding and beautiful facilities, including some large teaching hospital sites such as Royal Manchester Children's Hospital, the Evelina Children's Hospital at St Thomas' and University College London Hospital. At two other large London teaching hospitals, however, facilities fell short of appropriate standards. Refurbishment was in progress in one, so disruption was understandable, but play equipment in ward and clinic areas was old and broken. In another, the out-patient clinic rooms were positively dilapidated. In a large out of London teaching hospital, a busy day treatment area was too small for purpose and outpatient facilities were inadequate so that, some weeks, clinic sessions were held in the staff tea room with no facilities to examine children.

74 Varying degrees of consideration had been given to the needs of children of different ages. Facilities for young children were mostly appropriate. The needs of older children and teenagers were less consistently taken into account. At some sites, however, including some of the smaller centres such as Bristol and Nottingham, specific attention had been given to provision of separate relaxation rooms and other facilities for this age group. On two sites, Teenage Cancer Trust ward areas of a very high standard had recently been established and it was planned that teenagers with red cell disorders could use these, space allowing.

75 **Recommendation 15: All Trusts should review their facilities for the care of children and young people with haemoglobin disorders to ensure high quality, age-appropriate facilities are available for the number of children and young people being cared for by the service.**

ORGANISATION OF SERVICES

76 Some services had worked hard to make their care 'patient-centred'. For example, at Birmingham Children's Hospital the large group of regularly transfused children were age-cohorted with the same children attending together each month. Children and families therefore built up an increasingly familiar peer group who provided mutual support. At North Middlesex Hospital a quarterly 'family clinic', held by the adult haematologist in the children's outpatient department, offered the opportunity for all affected members of the same family to attend at the same time. This saved multiple visits as siblings, parents and sometimes grandparents attended together. Some hospitals, for example Bristol and Whittington, offered an outreach blood testing service where a nurse visited the school or home to take pre-transfusion or hydroxycarbamide monitoring samples. This minimised hospital visits and loss of school time.

ACCESS TO EMERGENCY CARE

77 Children presenting with acute complications, most frequently sickle cell pain crisis or infection, were advised either to attend a paediatric A&E Department or had direct access to a paediatric assessment or ward area. Either model can work well and time to first analgesia is a measurable indicator of service quality. For example, the busy Royal London Hospital A&E Department achieved prompt care and high levels of patient satisfaction through urgent triage, highly visible management guidance and use of intra-nasal diamorphine. Families more often reported difficulties and delays in A&E, for example, at Mayday Hospital, Nottingham Children's Hospital, Lewisham Hospital and Queen Elizabeth Hospital, Woolwich. Direct access to the paediatric assessment area or ward was usually highly valued by families and the speed and perceived quality of care tended to be better. Direct access did not necessarily result in more prompt care, however. For example, at St George's Hospital families reported delays in receiving analgesia for a child with pain crisis despite direct access to the in-patient ward.

78 **Recommendation 16: All Trusts providing urgent care for children with haemoglobin disorders should audit time from presentation to first analgesia, against a standard of 30 minutes, and adequacy of analgesia after one and two hours. This measure of quality should be included in Version 2 of the Quality Requirements.**

OUT OF HOURS FACILITIES FOR PLANNED CARE

79 Many services tried to enable children to come for blood tests before or after school and a few services were able to offer transfusions outside of school / college hours. Access to routine out-patient appointments outside school / college hours was a rarity. As a result, many children having monthly transfusions missed up to one and a half school days each month. As well as being detrimental to their education, these routine absences made their condition obvious to friends and teachers and some children and families were uncomfortable with this.

80 **Recommendation 17: All services should offer planned care outside of school / college hours, especially for older children.**

81 Children and young people admitted with complications of haemoglobin disorders were usually admitted under the care of the on call paediatrician. Access to a consultant with specialist expertise in the care of children with haemoglobin disorders was variable. In some centres, careful arrangements were in place to ensure that care was supervised at all times by consultants who regularly worked in the haemoglobin disorders service. In others, especially where specialist staff numbers were small, this did not happen. Continuity and quality of in-patient care was better in services with an in-patient specialist nurse who regularly saw all children with haemoglobin disorders who had been admitted, for example at Manchester, Whittington, King's and Evelina, St Thomas'. Collaboration between paediatricians and adult haematologists (see section 66) could improve the availability of specialist expertise, even in hospitals with smaller teams. Collaboration between services may be needed to achieve 24/7 access to an appropriately skilled and experienced consultant.

82 **Recommendation 18: Specialist Teams, and Local Teams admitting children as emergencies, should ensure that appropriately skilled clinical staff are available at all times, including nights and weekends, to manage the care of children admitted with acute complications. This should be an early area for the attention of clinical networks. Where collaborative arrangements include telephone advice, these should be supported by formalised indications for referral, the implementation of which should be audited regularly.**

83 The time when young people move from paediatric to adult services can be a frightening and difficult time for young people and their families. These difficulties can be greatly reduced by adequate preparation, careful handover and early involvement of the adult haematologist who will take responsibility for their care. Some Specialist Teams had put considerable effort into achieving robust and sensitive transition arrangements, for example the Evelina Children's Hospital / Guy's and St Thomas', Nottingham and Birmingham. Lewisham Hospital had a flexible transition policy so that young people were not admitted to an adult ward until they felt ready to make this change. In others, little attention had been given to managing the transition process, although most acknowledged that this was an area needing further work. There were many examples of good practice and some excellent materials to guide the transition process (Appendix 3). Some will be available on the UK Forum website: http://www.haemoglobin.org.uk/

84 **Recommendation 19: Where robust transition arrangements have not yet been implemented, paediatric and adults teams caring for young people with haemoglobin disorders should work together and with young people themselves to develop and implement appropriate arrangements for transition to adult care.**

LONDON-SPECIFIC PROBLEMS

85 Some concerns were raised repeatedly during visits to London-centred networks. These included difficulties with prompt access to paediatric intensive care for children who were deteriorating, especially for hospitals which did not have a paediatric intensive care unit on site. Concerns were also raised about urgent access to specialist opinion for urology (priapism) and neurology.

86 **Recommendation 20: Specialist Teams in London should work together and with providers of highly specialist services to agree clear guidelines and pathways which will result in timely access to highly specialist services.**

TRANSCRANIAL DOPPLER SCANNING COVERAGE

87 Increased flow rates in the large cerebral vessels, as measured by non-invasive transcranial Doppler (TCD) scanning indicates a high stroke risk in children with sickle cell disease, and screening should be offered to all children with HbSS and $S\beta^0$ thalassaemia from at least age two. Until recently this was not routinely available in all areas. Each Specialist Centre visited had established TCD scanning. This was undertaken by a variety of healthcare staff, sometimes in regular clinics to save multiple attendances. Four Specialist Teams also took a TCD machine plus operator to outreach clinics and three more had plans to do this. Where this was not available, children from linked hospitals were invited to attend the Specialist Centre for TCD scanning. At the time of the visits, however, there was no way of ascertaining the proportion of children who had been scanned at least once. The Quality Requirements asked for an audit of eligible children who had been scanned in the previous year but most centres were not able to give data on this.

88 **Recommendation 21: Specialist Services Commissioners / National Commissioning Board and all Specialist Teams should monitor the proportion of eligible children who have had transcranial Doppler scans. (NB. This will require implementation of recommendations 1 and 5 to give an accurate denominator of the number of affected children in each clinical network.)**

89 **Recommendation 22: Specialist Teams should audit the proportion of eligible children who have had TCD scans, the proportion started on regular transfusion and the number of further neurological events, and should take part in the TCD quality assurance scheme as it is developed.**

CLINICAL GUIDELINES

AVAILABILITY OF GUIDELINES AND DOCUMENT CONTROL

90 The document review part of the peer review visit looked in detail at clinical and referral guidelines in use in each service. The Quality Requirements were clear about the guidelines which should be available. These were considered necessary in order to reduce variation within clinical teams and give guidance to

more junior members of the multi-disciplinary team and to staff providing out of hours cover. Many excellent, comprehensive, user-friendly clinical guidelines were seen. Examples are listed in Appendix 4 and will be made available on the UK Forum website: *http://www.haemoglobin.org.uk/* . Some guidelines appeared to have been drawn up, or revised, just in time for the visit but reviewers were satisfied that the guidelines would help to improve the standard of care as long as relevant staff were familiar with their contents. Some services, especially those with few staff, did not have the expected clinical guidelines. This was of particular concern as specialist staff were not available to give advice at all times.

91 Some guidelines were in use after their review date and, more commonly, guidelines had no clear authorship, formal ratification or review date. Sometimes more than one guideline was found for a particular clinical problem, with contradictory contents, giving potential for confusion and error.

92 **Recommendation 23: Specialist and Local Teams should ensure that clinical and referral guidelines expected by the *Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies* are developed and implemented as soon as possible. Robust arrangements for document control of clinical guidelines should be in place.**

93 It is expected that guidelines in use across a clinical network of Specialist and Local Teams will be the same or, at least, consistent. The review visits found that sharing of clinical guidelines was an aspiration for most networks and already in place in some, for example, Imperial. The major linked hospitals in London which were visited did not all use the Specialist Team guidelines and two of the three had not been able to produce their own guidelines due to pressure on staffing.

94 **Recommendation 24: Clinical and referral guidelines should be common across a clinical network or, at least, should be approved by the network's Specialist Team. Where Local Teams do not yet have a comprehensive set of guidelines, they should adopt, with local adaptation where necessary, those of their Specialist Team. This is urgent for those services where small numbers of specialist staff cannot always be available for advice and guidance.**

Data Collection and Clinical Audit

95 The National Haemoglobinopathy Register provides a means for monitoring the number of affected children in a clinical network, for demonstrating compliance with key standards of clinical care, and can give a denominator for clinical audits. The Register must be kept up to date as new babies are identified by the screening programme and additional children move into each network's catchment area. Full entry of data into the National Haemoglobinopathy Register was not in place in any of the services visited. Nine services had started entering children and four of these were well advanced. Time to gain consent, rather than refusal of families to give consent, and time to enter data were cited by others as reasons why they had not yet started entering data. All saw the value of the Register and were intending to use it. One large

centre, the Royal London Hospital, had a comprehensive and well-established local database which was updated at every attendance and efforts were being made to allow direct communication with the National Haemoglobinopathy Register to avoid duplicate data entry. (Recommendation 5 addresses this issue.)

96 The Quality Requirements expect regular audits of compliance with key clinical standards:

a. For children with sickle cell disease: proportion taking regular penicillin, proportion fully immunised against pneumococcus, proportion of those with HbSS or Sβ^0 thalassaemia who had had TCD scan within last year, proportion of patients who had had annual review within the last year[7].

b. For children with thalassaemia: proportion receiving chelation, proportion who had had annual review in the last year, and adequacy of recording of some clinical and laboratory measures.

c. For both: effectiveness of action to contact families who had not attended for follow up, and review of the care of any patients who had died.

97 No Specialist Team could provide audit data for all children in the network they served. Only six of the nineteen services reviewed, five Specialist Teams (Liverpool, Kings College Hospital, North Middlesex University Hospital, St George's Hospital and UCLH / Whittington) and one of the three large linked hospitals (Mayday Hospital) were able to present full audit data for their own, locally-managed children.

98 **Recommendation 25: Specialist and Local Teams should ensure a robust programme of audit against key clinical standards is in place covering all children and young people within the clinical network.**

99 **Recommendation 26: Specialised services commissioners / National Commissioning Board should ensure key process and outcome metrics from all clinical networks are shared with all commissioners and providers so that comparative performance can be easily seen.**

100 **Recommendation 27: The UK Forum on Haemoglobin Disorders should regularly review comparative data on key process and outcome metrics and, if necessary, advise commissioners and providers on actions required.**

[7] Recommendation 15 adds that time from presentation to first analgesia for children presenting with acute sickle cell pain crisis, and adequacy of analgesia at one and two hours, should be included in the next edition of the Quality Requirements.

CLINICAL THRESHOLDS

101 The peer review visits did not set out to compare activity levels at different services. The impression was, however, that the variation in the number of A&E attendances, hospital admission rates, average length of stay, frequency of out-patient review and number of children with sickle cell disease on a regular transfusion programme was greater than could be explained by case mix variations. It appeared that different services may be giving different messages about when to attend A&E and when home care, supported by a telephone consultation or visit by a community nurse, is appropriate. There is no 'right answer' on when a child needs A&E assessment or admission, as much depends on the capability, knowledge and experience of the family, but the extent of variation was surprising. Similarly, the proportion of children with sickle cell disease who were on regular transfusion varied from 1:10 to 1:30. This degree of variation suggests that children in different centres may be started on regular transfusion according to different criteria or that uptake rates vary. The variation may also be explained by the proportion of children who have had TCD screening and been found to have a high stroke risk.

102 **Recommendation 28: The UK Forum on Haemoglobin Disorders should develop guidance on indications for A&E attendance and on indications for regular transfusion. The UK Forum on Haemoglobin Disorders, working with the Healthcare Quality Improvement Partnership, should implement national audits of key activity and clinical indicators in order to understand variation in current clinical practice and the relationship with clinical outcomes. (NB. This will require implementation of recommendations 1 and 5 on establishing an accurate denominator of the number of affected children in each clinical network and entry of data into the National Haemoglobinopathy Register.)**

COMMISSIONING OF SERVICES

103 A Specialised Services National Definition Set for Specialised Haemoglobinopathy Services was published in 2010 although, at the time of the peer review visits, most Specialised Commissioning Groups / Teams were not yet actively engaged in commissioning these services. Services for children and young people with haemoglobin disorders were usually part of the acute general paediatric block contract. Local commissioners attended many of the review visits and some were knowledgeable about the services. Commissioners of the service at St George's Hospital were planning to include a CQUIN on the quality of in-patient care in the service contract. Most commissioners had little information about haemoglobin disorder services and some acknowledged that they were only aware that the service existed. All said they would like more information. Specialist commissioners were actively involved in planning services in the North West (Liverpool and Manchester) and East Midlands (Leicester and Nottingham).

104 **Recommendation 29: Specialist services commissioners / National Commissioning Board should actively commission services for children and young people with haemoglobin disorders including agreeing the configuration of clinical networks for their population (recommendation 1); ensuring data collection on all children cared for within each network (recommendations 5 and 25); ensuring service specifications require compliance with the *Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies,* including play specialist, social work and psychologist support; monitor key process measures, outcome metrics (recommendation 21 and 26) and user experience measures.**

COMPLIANCE WITH QUALITY REQUIREMENTS

105 Comparisons of percentage compliance with Quality Requirements have not been produced for this round of peer review visits especially because the relative importance of different Quality Requirements is not taken into account in crude percentage comparisons. Percentage compliance also takes no account of 'working towards' a particular Quality Requirements. Reviewers often comment that it is better to have a 'No but', where there is real commitment to achieving a particular standard, than a 'Yes but' – where a 'box has been ticked' but the commitment to implementation is lacking. Appendix 5 details compliance with each of the Quality Requirements and can be used by services to look at their position compared with others.

106 Further work is taking place on a risk-based approach to summarising the findings of each peer review visit. It is hoped that this will produce a more robust overall assessment than percentage compliance which can also be used to look at progress over time.

EVALUATION AND RECOMMENDATIONS FOR FUTURE PROGRAMMES

107 This was the first peer review programme of services for children and young people with haemoglobin disorders and much was learnt through the process. Almost all the services reviewed volunteered that, although the preparation for the visit had been arduous, the process of preparation and reflection on the issues raised during the visits had been useful and would help them continue to develop and improve their services. The programme additionally offered useful 'continuous professional development' for reviewers.

108 Future review programmes should ensure that comparative data on activity and outcomes are available to the visiting teams before the visit.

109 Some Trusts entered into lengthy dialogue about the contents of their draft report and submitted additional written material and data after the visit. This lengthened the review process and delayed the

publication of reports. For any future peer review programmes, services should be made aware that material submitted after the visit will not be taken into account.

110 Quality Requirements for services for adults with haemoglobin disorders are being developed and the findings and recommendations of this Overview Report will be taken into account in finalising these. Revisions to the *Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies* will also be needed prior to future peer review visits. The revised Quality Requirements should include a requirement to audit time to first analgesia, and adequacy of analgesia at one and two hours after presentation for people presenting with acute sickle pain crisis, and the need for guidance on prescribing and monitoring hydroxycarbamide treatment.

111 Appendix 6 summarises the evaluation of this peer review programme. Overall, the evaluation shows that the peer review process was a catalyst for improving services for children and young people with haemoglobin disorders. Several examples of changes made before and after the visits were given. Reviewers clearly appreciated the opportunity to visit and learn from other services. Respondents were generally happy with the organisation of the programme, with some suggestions for improvement and the input of the programme's clinical lead was highly appreciated. Some respondents were not confident that progress would continue, especially where additional resources were needed. Compared with other peer review programmes, the reviews of services for children and young people with haemoglobin disorders scored well on the visiting process and the report. The proportion of immediate risks and concerns that had been addressed was, however, lower than other programmes.

112 This peer review programme undoubtedly led to improvements to services for children and young people with haemoglobin disorders. Adult services have not yet been reviewed in the same way.

113 **Recommendation 30: A peer review programme looking at the standards of care for adults with haemoglobin disorders should be run in 2012. Peer review of services for children and young people with haemoglobin disorders should be repeated in 2013 or 2014 in order to assess progress with meeting the expected Quality Requirements and implementing the recommendations of this report.**

SUMMARY OF RECOMMENDATIONS

Rec. No.	Section	Recommendation
FOR SPECIALISED SERVICES COMMISSIONERS / NATIONAL COMMISSIONING BOARD:		
1	44	Specialised Services Commissioners [and the National Commissioning Board when it takes over these responsibilities] should require providers to establish formal clinical networks of services for children and young people with haemoglobin disorders. In determining the configuration of networks, commissioners should consider: a. The number of children and young people with haemoglobin disorders, and the rapid increase in numbers in some areas. Further investigation is needed in the North-East and South Central regions. b. The existing clinical relationships and referral patterns. Disruption of these relationships may be detrimental to patient care, especially in the short to medium-term. c. The views of children with haemoglobin disorders and their families. d. Links with tertiary paediatric networks (where applicable). e. Although there is no nationally recommended minimum size for a specialist team, commissioners should consider whether services caring for less than 100 children and young people with haemoglobin disorders provide sufficient opportunity for staff to maintain their competence and confidence and whether a collaborative arrangement with another specialist team should be formally established (as described in section 43). f. Although there is no nationally recommended maximum size for a specialist team, commissioners of services caring for over 1,000 children with haemoglobin disorders should consider whether the development of an additional specialist centre would improve access to services. g. Commissioners of Local Teams caring for over 200 children and young people with haemoglobin disorders should, in discussion with the network's Specialist Team, consider whether Local Teams could be commissioned to undertake annual reviews of less complex children, and to manage some more complex acute presentations. This should be agreed only when staffing and expertise of the Local Team is appropriate for this level of care.
5	51	Specialised Services Commissioners / National Commissioning Board should ensure that responsibility for collecting data on all children and young people with haemoglobin disorders within each clinical network is clarified, included in service specifications and contracts and monitored. This includes both entering data to the National Haemoglobinopathy Register and submitting anonymous data to the screening programmes[8]. Commissioners should incentivise completeness of data entry and use contractual levers where this is not achieved.
13	71	Specialist Services Commissioners / National Commissioning Board should ensure that service specifications for services for children and young people with haemoglobin disorders include the need for play specialist, social work and psychology services.

[8] The requirement for data for screening programmes is given in Appendix Seven of Sickle Cell Disease in Childhood Standards and Guidelines for Clinical Care http://sct.screening.nhs.uk/standardsandguidelines .

21	88	Specialist Services Commissioners / National Commissioning Board and all Specialist Teams should monitor the proportion of eligible children who have had transcranial Doppler scans. (NB. This will require implementation of recommendations 1 and 5 to give an accurate denominator of the number of affected children in each clinical network.)
26	99	Specialised services commissioners / National Commissioning Board should ensure key process and outcome metrics from all clinical networks are shared with all commissioners and providers so that comparative performance can be easily seen.
29	104	Specialist services commissioners / National Commissioning Board should actively commission services for children and young people with haemoglobin disorders including agreeing the configuration of clinical networks for their population (recommendation 1); ensuring data collection on all children cared for within each network (recommendations 5 and 24); ensuring service specifications require compliance with the *Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies,* including play specialist, social work and psychologist support; monitor key process measures, outcome metrics (recommendation 21 and 26) and user experience measures.
FOR PROVIDERS OF SERVICES FOR CHILDREN AND YOUNG PEOPLE WITH HAEMOGLOBIN DISORDERS:		
2	45	Trusts and Specialist Teams caring for less than 100 children and young people with haemoglobin disorders should review their arrangements for ensuring staff are maintaining confidence and competence in managing the range of clinical problems experienced by children with haemoglobin disorders and should consider whether establishing links with another Specialist Team would be beneficial. (This recommendation duplicates 1d but places the emphasis on Trusts as well as commissioners considering this issue.)
4	49	All Specialist Teams should establish robust 'fail-safe' arrangements with relevant newborn screening laboratories, community nursing teams, and local hospital teams to ensure that all affected newborn babies identified through the screening programme access appropriate care. A multi-disciplinary meeting of Specialist Teams, newborn screening laboratories and community services should regularly review compliance with screening standards.
6	52	Specialist Teams, working with Local Teams, should establish formal protocols for a) ensuring all babies identified through the newborn screening programme enter clinical care appropriately, b) sharing data on any other newly diagnosed children c) follow-up of children who do not attend and d) discussion with families of children who move outside of the clinical network's usual catchment area and formal handover of care to the Specialist Team closer to their new home.
7	54	Specialist and Local Teams should ensure a full range of information is available for patients and families.
8	56	All clinical networks should develop mechanisms for receiving feedback from service users and their families and for involving them in planning and improving services.
10	61	Specialist and Local Teams should ensure that, under the supervision of core team members, doctors and nurses in training are actively involved in all aspects of care for children with sickle cell and thalassaemia.

11	65	Members of all community nursing teams should be clear about their roles (genetic counselling, work with couples at risk of having an affected baby, managing the results of the NHS Screening Programme, and / or individual client education, support and care), the competences needed for these roles and the time spent on each aspect of their work. Teams should systematically record activity data for the different aspects of their work, including reporting on performance against relevant Screening Standards.
12	67	All Specialist and Local Teams caring for children and young people with haemoglobin disorders should review their arrangements for collaboration with adult haematology services to ensure that full advantage is being taken of the potential for a) improving services through collaborative working and b) improving transition arrangements. This is particularly important where the children's service lead is a paediatrician and not a dually trained paediatric haematologist.
14	72	All Trusts providing services for children and young people with haemoglobin disorders should review their arrangements for play specialist, social work and psychology support to ensure these are sufficient for the needs of children and young people with haemoglobin disorders.
15	75	All Trusts should review their facilities for the care of children and young people with haemoglobin disorders to ensure high quality, age-appropriate facilities are available for the number of children and young people being cared for by the service.
16	78	All Trusts providing urgent care for children with haemoglobin disorders should audit time from presentation to first analgesia, against a standard of 30 minutes, and adequacy of analgesia after one and two hours. This measure of quality should be included in Version 2 of the Quality Requirements.
17	80	All services should offer planned care outside of school / college hours, especially for older children.
18	82	Specialist Teams, and any Local Teams admitting children as emergencies, should ensure that appropriately skilled clinical staff are available at all times, including nights and weekends, to manage the care of children admitted with acute complications. This should be an early area for the attention of clinical networks. Where collaborative arrangements include telephone advice, these should be supported by formalised indications for referral, the implementation of which should be audited regularly.
19	84	Where robust transition arrangements have not yet been implemented, paediatric and adults teams caring for young people with haemoglobin disorders should work together and with young people themselves to develop and implement appropriate arrangements for transition to adult care.
20	86	Specialist Teams in London should work together and with providers of highly specialist services to agree clear guidelines and pathways which will result in timely access to highly specialist services.
22	89	Specialist Teams should audit the proportion of eligible children who have had TCD scans, the proportion started on regular transfusion and the number of further neurological events, and should take part in the TCD quality assurance scheme as it is developed.
23	92	Specialist and Local Teams should ensure that clinical and referral guidelines expected by the *Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies* are developed and implemented as soon as possible. Robust arrangements for document control of clinical guidelines should be in place.

24	94	Clinical and referral guidelines should be common across a clinical network or, at least, should be approved by the network's Specialist Team. Where Local Teams do not yet have a comprehensive set of guidelines, they should adopt, with local adaptation where necessary, those of their Specialist Team. This is urgent for those services where small numbers of specialist staff cannot always be available for advice and guidance.
25	98	Specialist and Local Teams should ensure a robust programme of audit against key clinical standards is in place covering all children and young people within the clinical network.
FOR OTHERS:		
3	48	The NHS Sickle Cell and Thalassaemia Screening Programme should ensure that newborn screening laboratories communicate details of affected newborn babies to the named lead of the Specialist Team as well as to community nursing teams. Close liaison between the Screening Programme and commissioners on the precise configuration of clinical networks [recommendation 1] will be needed to achieve this.
9	59	The UK Forum on Haemoglobin Disorders should produce guidance on appropriate staffing levels for Specialist and Local Teams, taking account of the number of children cared for by the service and the need for support to Local Teams within the network.
27	100	The UK Forum on Haemoglobin Disorders should regularly review comparative data on key process and outcome metrics and, if necessary, advise commissioners and providers on actions required.
28	102	The UK Forum on Haemoglobin Disorders should develop guidance on indications for A&E attendance and on indications for regular transfusion. The UK Forum on Haemoglobin Disorders, working with the Healthcare Quality Improvement Partnership, should implement national audits of key activity and clinical indicators in order to understand variation in current clinical practice and the relationship with clinical outcomes. (NB. This will require implementation of recommendations 1 and 5 on establishing an accurate denominator of the number of affected children in each clinical network and entry of data into the National Haemoglobinopathy Register.)
FOR ALL ORGANISATIONS INVOLVED WITH THE CARE OF PEOPLE WITH HAEMOGLOBIN DISORDERS:		
30	113	A peer review programme looking at the standards of care for adults with haemoglobin disorders should be run in 2012. Peer review of services for children and young people with haemoglobin disorders should be repeated in 2013 or 2014 in order to assess progress with meeting the expected Quality Requirements and implementing the recommendations of this report.

APPENDIX 1 NATIONAL GUIDANCE ON THE CARE OF PEOPLE WITH HAEMOGLOBIN DISORDERS

National Service Framework for Children, Young People and Maternity Services. Department of Health. 2004.

Standards for the linked Antenatal and Newborn Screening Programme. NHS Sickle Cell and Thalassaemia Screening Programme, 2006.

Sickle Cell Disease in Childhood: standards and guidelines for clinical care. Dick M et al, UK Forum on Haemoglobin Disorders, and NHS Sickle Cell and Thalassaemia Screening Programme, 2006.

Standards for the care of children and adults with thalassaemia in the UK. ISBN 978-1-900254-19-9. United Kingdom Thalassaemia Society, (1st edition 2005, 2nd edition 2008)

Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care. NHS Sickle Cell and Thalassaemia Screening Programme, 2010.

Specialised Services National Definition Set Definition No. 38 Specialised Haemoglobinopathy Services (all ages) (3rd Edition). NHS Specialised Services. 2010.

RCN Competences: Caring for people with sickle cell disease and thalassaemia syndromes - A framework for nursing staff. Anionwu, E., Tankayi,S., Westerdale, N., 2011.

APPENDIX 2 LEVELS OF CARE FOR SICKLE CELL DISEASE AND THALASSAEMIA

Taken from Specialised Services National Definition Set Definition No. 38 Specialised Haemoglobinopathy Services (all ages) (3rd Edition)

Care of sickle cell disease and thalassaemia patients usually takes place within a clinical network and can be divided into three levels of care:

Specialist team care includes:

- Institution and supervision of blood transfusion management (SCD and thalassaemia)
- Institution and supervision of iron chelation management, prescribing of iron chelating drugs, monitoring adverse event management and optimization of compliance (SCD and thalassaemia)
- Prevention and management of neurological complications of SCD including Transcranial Doppler screening in childhood, specialised neuroradiology, neurology and neuropsychology services (SCD)
- Management of severe and life-threatening acute complications (SCD and thalassaemia)
- Management of chronic complications (SCD and thalassaemia)
- Surgical management (SCD and thalassaemia)
- Management of pregnancy (SCD and thalassaemia)
- Bone marrow transplantation (SCD and thalassaemia)
- Annual out-patient review (SCD and thalassaemia)
- Out-reach clinics in local hospitals (SCD and thalassaemia)

Local team care includes:

- Management of acute, uncomplicated crises (SCD)
- Routine monthly day case transfusions (thalassaemia major and transfusion-requiring SCD)
- Routine out-patient monitoring (SCD and thalassaemia)
- Agreed shared care arrangements for specific therapies (SCD and thalassaemia)
  (including support with adherence to iron chelation regimes, monitoring of hydroxycarbamide, care following stem cell transplantation)

These functions are generally undertaken by hospital-based haematology or Haemoglobinopathy nurse specialists and a designated paediatrician / haematologist.

Community care includes:

- Education of and support to patients and carers in self-management of these long-term conditions
- Support to patients and carers in home management of milder sickle cell crises and supervision after discharge from hospital

- Education of and support to patients and carers in adherence with home medication (oral penicillin prophylaxis for SCD, regular iron chelating therapy for patients with thalassaemia major and for patients with SCD on regular transfusion)
- Liaison with and facilitation of access to community health services, social services, educational services, welfare benefits etc
- Support for local users' groups.

These functions may be undertaken by specialist Haemoglobinopathy nurses. They may be based in a local community setting (eg Community Sickle Cell and Thalassaemia Centres already exist in some high prevalence areas, especially in London) and liaise with local hospital or specialist centre clinics. Alternatively, in some areas hospital-based specialist nurses provide outreach services to the community from the local hospital or specialist centre clinic. In both scenarios there is close collaboration with the hospital-based paediatrician / haematologist how is responsible for SCD and thalassaemia care.

APPENDIX 3 EXAMPLES OF GOOD INFORMATION FOR PATIENTS AND FAMILIES

Information resources available through the NHS Sickle Cell and Thalassaemia Screening Programme include:

- A parent's guide - Care and management of your child with Sickle Cell Disease. 2007.
- Information for mums and dads - Your baby carries a gene for sickle cell. 2010.
- Information for mums and dads - Your baby carries a gene for unusual haemoglobin. 2010,

Other booklets and materials are available through the UK Thalassaemia Society and Sickle Cell Society.

Examples of good information for patients and families identified through the peer review programme include:

- Alder Hey Children's NHS Foundation Trust, Liverpool: age appropriate leaflets for children in hospital and undergoing procedures, information about thalassaemia.
- Royal Manchester Children's Hospital: locally developed packs for the parents of affected newborn, parent's teaching material for using desferrioxamine infusions and intravenous 'port' devices.
- Leeds Teaching Hospitals NHS Trust: information booklet about exchange transfusion.
- Leicester Children's Hospital: guidance for management after discharge from A&E for sickle cell children, home pain score and management sheet, TCD leaflet for parents.
- Nottingham Children's Hospital: 'red amber green' alert sheet to guide families of children with sickle cell disease what they might manage at home vs seek urgent assessment in hospital, a 'thermometer card' for use in a baby's cot, which included the community nurse team contact numbers, information leaflets for parents, teachers and carers for sickle cell disease and for thalassaemia, a 'survival pack' for teenagers.
- Sheffield Children's NHS Foundation Trust: leaflet 'what to do in an emergency', leaflet about starting deferasirox treatment.

London centres:

- Guy's and St Thomas' NHS Foundation Trust: much information for families of children with sickle cell disease.
- North West London Hospital's NHS Trust: comprehensive patient information, much available through Brent Sickle Cell and Thalassaemia website.
- St George's Healthcare NHS Trust: pack for family of affected newborn, pack for schools, pack for transition aged children.

London linked hospitals visited:

- Mayday Healthcare NHS Trust: full range of material for families with sickle cell disease and thalassaemia, personalised 'school packs' for communication between health services and schools.
- Lewisham Hospital NHS Trust: leaflets on priapism, TCD / stroke, dietary advice relevant for African Caribbean food choices.

APPENDIX 4 EXAMPLES OF GOOD CLINICAL GUIDELINES AND OTHER MATERIAL

- Alder Hey Children's NHS Foundation Trust, Liverpool: outpatient guidance, colour coded proformas for use at clinic visits, sickle cell annual review proforma.
- Birmingham Children's Hospital: 'early years and young person's protocol'.
- Royal Manchester Children's Hospital: comprehensive local service description, 'chelation folder'.
- Leeds Teaching Hospitals NHS Trust: flow chart for the management of actue presentations, protocol for anti-thrombotic treatment, presentation of the analgesic ladder, transfusion prescription chart.
- Leicester Children's Hospital: service description leaflet, information for use during transition management to adult services.
- Nottingham Children's Hospital: haemoglobinopathy service 'operational policy'.
- Sheffield Children's NHS Foundation Trust: overall clinical guidelines.

London centres:

- Guy's and St Thomas' NHS Foundation Trust: 'sickle cell care plan' for complex children or those who cannot communicate easily, 'cannulation plan' guiding co-operation between child and staff during this procedure.
- Imperial College Healthcare NHS Trust: overall clinical guidelines.
- North West London Hospital's NHS Trust: 'contact sheet' including all support team contacts, standard letter templates, 'out of area' transfer sheet, 'specialist nurses paediatric contact' checklist, transition materials.
- Kings College Hospital NHS Foundation Trust: guidelines for exchange transfusion, management of chest syndrome, shared care guidelines including list of key contacts for network professionals, cannulation competency document.
- Barts and the London NHS Trust, the Royal London Hospital: A&E clerking / admission proforma, containing a copy of the analgesia pathway.
- St George's Healthcare NHS Trust: checklist for use by nurse counsellor visiting family to give diagnosis, DNA letter with reminder guidance on reverse for if the child becomes ill before the next appointment, 'paediatric cannulation and venepuncture assessment' document.
- University College Hospital London and Whittington Hospital NHS Foundation Trusts: operating procedures and service descriptions.

London linked hospitals visited:

- Mayday Healthcare NHS Trust: many of the guidelines, including nursing guidelines for care, A&E assessment sheet, pain management flowchart.
- Lewisham Hospital NHS Trust: DNA policy, nursing education material held on in-patient ward.
- Queen Elizabeth Hospital, Woolwich: A&E guideline for management of pain in children over 1 year old.

APPENDIX 5 COMPLIANCE WITH QUALITY REQUIREMENTS

Ref No	Short Title	Quality Requirement Met	Not Met
Services for Children and Young People with Sickle Cell Disease and Thalassaemia			
1 LHT SHT	Written information should be offered to patients and their families.	16	3
2 LHT SHT	Written information for the patient's primary health care team should be available.	10	9
3 LHT SHT	Information should be available on transition to adult care. This information should cover all aspects of the transition (QR43).	9	10
4 SHT	The SHT and its linked LHTs should have agreed a patient-held record for recording.	5	11
5 LHT SHT	The locally agreed patient-held record (QR4) should be in regular use within the LHT / SHT.	2	17
6 LHT SHT	Services should be provided in a child friendly environment, including toys and books / magazines for children and young people of all ages.	19	0
7 LHT	The LHT should have a nominated lead paediatrician / paediatric haematologist with responsibility.	3	0
8 LHT	There should be agreed arrangements for cover for absences of the lead paediatrician.	2	1
9 SHT	The SHT should have a nominated lead paediatrician / paediatric haematologist consultant.	15	1
10 SHT	The lead consultant (QR9) should have a named deputy who will provide cover for absences.	13	3
11 LHT	The LHT should have a lead nurse who has responsibility, with the lead consultant.	1	2
12 SHT	The SHT should have a lead haemoglobinopathy nurse with responsibility, with the lead consultant.	11	5
13 SHT	The SHT should have a nurse specialist or counsellor who provides outreach support for patients in the community.	15	1
14 SHT	There should be agreed cover arrangements for the outreach nurse specialist / counsellor.	13	3
15 SHT	Access to the following staff and services should be available: a MRI and CT scanning b Transcranial Doppler ultrasonography (SC) c Hospital dental services d Genetics services e Bone marrow transplantation services f Contraception and sexual health services g Consultant cardiologist h Consultant endocrinologist i Consultant hepatologist j Consultant neurologist k Consultant ophthalmologist l Consultant orthopaedic surgeon m Consultant obstetrician n Child and adolescent mental health services	16	0

16 SHT	The following services should be available a Paediatric high dependency care b Paediatric intensive care There should be agreed criteria for admission to each level of care.	15	1
17 SHT LHT	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	18	1
18 SHT LHT	A service agreement for support from community services should be in place.	5	14
19 SHT LHT	A nurse with competency in cannulation, starting and supervising a transfusion should be available at all times at which children are attending for transfusion.	11	8
20 SHT LHT	All staff involved in the care of children and young people with haemoglobinopathies should undertake regular child protection training.	15	4
21 SHT	Guidelines should be in use covering a How to establish and confirm diagnosis b Parent and sibling testing	15	1
22 SHT LHT	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)	19	0
23 LHT SHT	Clinical guidelines should be in use covering possible acute presentations including, at least: For patients with sickle cell disease:	13	6
24 LHT SHT	Clinical guidelines should be in use covering routine out-patient monitoring and management between formal annual progress review visits.	18	1
25 SHT	Clinical guidelines should be in use covering annual specialist review visits.	14	2
26 LHT SHT	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)	10	9
27 LHT SHT	Guidelines for referral for consideration of bone marrow transplantation should be in use.	14	5
28 LHT SHT	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	15	4
29 LHT SHT	Clinical guidelines should be in use covering review by a specialist nurse or doctor prior to transfusion to ensure that each transfusion is appropriate.	15	4
30 LHT SHT	A Transfusion Policy should be in use.	16	3
31 LHT SHT	Clinical guidelines for chelation therapy and monitoring iron load should be in use.	15	4
32 LHT SHT	Clinical guidelines for the management of thalassaemia intermedia should be in use.	14	5
33 LHT SHT	Clinical guidelines should be in use covering: a Indications for exchange transfusion b Arrangements for carrying out an exchange transfusion.	15	4

34 LHT SHT	Clinical guidelines for acute and out-patient monitoring and management (QR23and QR24) should be available and in use in appropriate areas including A&E, clinic and ward areas.	18	1
35 LHT SHT	A protocol should be in use covering the initial clinic visit for patients with haemoglobinopathies.	14	5
36 LHT SHT	A protocol should be in use covering the initial clinic visit for patients previously treated outside the UK.	13	6
37 SHT	A protocol should be in use covering arrangements for care between SHT and LHT for ongoing care.	2	14
38 LHT SHT	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	4	15
39 SHT	The SHT and its linked LHTs should have agreed a policy on the communication of clinical information.	5	11
40 LHT SHT	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	10	9
41 LHT SHT	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	3	16
42 LHT SHT	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	18	1
43 SHT	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.	12	4
44 LHT SHT	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.	16	3
45 SHT	The SHT should run a programme of training and awareness of the management of patients with haemoglobinopathy for its main referring LHTs.	7	9
46 LHT	Staff from the LHT should participate in the training and awareness programme run by the SHT to which patients are usually referred.	3	0
47 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)	8	8
48 LHT	A representative of the LHT should attend each review meeting with the SHT to which patients are usually referred (QR47).	3	0
49 SHT	The SHT should meet at least annually with representatives of the neonatal screening programme to review progress, identify issues of mutual concern and agree action.	14	2
50 LHT SHT	The LHT / SHT should have audited compliance with key standards.	5	14

51 SHT LHT	Data should be systematically entered on all patients, following patient / parental consent, onto the National Haemoglobinopathy Registry.	8	11
Commissioners of Services			
52	Each Specialist Commissioning Group should have agreed the location of services for its population.	3	16
53	Each Specialist Commissioning Group should have: a Compared the staffing, support services and facilities of each SHT and LHT located within its area (QR 52) with the levels expected in QRs 7 to 19. 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.	2	17
Screening Standards			
P3	Timely communication of positive screening results (sickle cell disorder) – including a review of parental results	7	12
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 work)	12	7
P5	Timely confirmation of diagnosis for infants with a positive screening result**	11	8
S1i	Failsafe to ensure ongoing care	17	2
S1ii	Up-to-date registers maintained of babies (cases) for which units are responsible	16	3

APPENDIX 6 EVALUATION OF THE PEER REVIEW PROGRAMME

Evaluation of the peer review programme was undertaken in two phases. Firstly, all reviewers and staff at Trusts that were visited were asked to complete evaluation forms at the end of the visit. Secondly, 'overall evaluation' questionnaires were sent out to all reviewers and Trust lead contacts approximately two months after the final report of the visit was sent out. Comments received are duplicated in full so that the full 'flavour' of the responses can be appreciated.

Overall, the evaluation shows that the peer review process was a catalyst for improving services for children and young people with haemoglobin disorders. Several examples of changes made before and after the visits were given. Reviewers clearly appreciated the opportunity to visit and learn from other services. Respondents were generally happy with the organisation of the programme, with some suggestions for improvement and the input of the programme's clinical lead was highly appreciated. Some respondents were not confident that progress would continue, especially where additional resources were needed. Compared with other peer review programmes, the reviews of services for children and young people with haemoglobin disorders scored well on the visiting process and the report. The proportion of immediate risks and concerns that had been addressed was, however, lower than other programmes.

VISIT EVALUATION - REVIEWERS

Evaluation forms returned: 57

The information sent to me before the visit was:	Not helpful	Helpful	Very helpful	Total
Responses	0	9	48	57
	0%	16%	84%	100%

- The information I received before the visit was very helpful as it gave me a background knowledge of the hospitals, what they do and don't do.
- Information allowed me to get a good insight about services provided prior to visit.
- All info was clear.
- There was no indication where to meet at BCH.
- A nice level intro to the Trust, relevant without being overwhelming. Thanks for resending quality standards too as very useful.
- Having the background report ahead of time is useful.
- Useful background to service.
- Need to know more about staff make up of service. Organisational chart & WTE's.
- Very helpful with clear instruction on how to get to the hospital. Public consultation report was also very useful.
- Informative.
- The timetable did not print out correctly. So I was not sure of the plan for the day until I arrived.
- It would be useful to have times and venue longer than two weeks in advance (planning and getting cheaper fares organised especially for London).
- Useful to know details about service.
- Was very useful.
- Well organised & administered. Very friendly meeting & greeting.
  Very clearly laid out standards and guidance
- Clear vision of service provider.

Overall, I found the organisation of the visit:	Not helpful	Helpful	Very helpful	Total
Responses	0	12	45	57
	0%	21%	79%	100%

- Very accommodating.
- Despite being quite pushed for time, we managed to see everything and feel like we have seen everything.
- Staff very friendly and willing to ask questions.
- First visit so confusing to get head round evidence initially. Very useful to have lead, AY, to relate to evidence provided by other sites.
- Trust presented on adult services. Why?
- Not enough individual interviews for visit. Large group interviews not beneficial. AY lead was brilliant and a great chair.
- Very welcome team.
- Centre looked after us very well.
- Team very helpful & keen to chat/give info.
- Well organised, well thought out.
- Everyone knew where they were going/times/who visiting.

I found the recording form:	Not helpful	Helpful	Very helpful	Total
Responses	1	17	38	56
	2%	30%	68%	100%

- Limited space for our detailed assessment criteria overview. Generic comments very helpful.
- Certain aspects needed more space for comments.
- Sufficient space for comments - a notes page might have been useful.
- Not enough detail compared to the actual standards.
- Familiar with form but clear to use.
- Excellent method for recording comments.
- Well organised.
- It is quite complex however handling form, guidelines and info quite challenging. Extra paper for notes would be good.
- Very well laid out so clear to proceed.

What went well?

- The review in general went very well and everyone did what they had to do.
- Covered a lot of ground in a limited time. Well led.
- Information in files and presentation were clear. Staff very helpful on tour. Users and community team clear and informative.
- The peer review went smoothly in general. Good time keeping. Thanks for the hospitality and food.
- Although we started late, the day was well planned and all teams welcomed the reviews.
- It was all on time.
- Plenty of service users to meet the team.
- Time said to start the review. Even though late, flowed well. All information & staff available.
- Excellent leadership from AY. Discussion with team pulling together, evidence/conclusion.
- The visit in general went very well. It was a lovely environment and staff were very friendly.
- Overall, the whole day was well organised and went well.
- Meetings were flexible and ran smoothly.
- The timing & plan of the day.
- Very good catering.
- Access to staff & services to pad out folder evidence, plus double folder evidence, was very useful.
- The organisation - the structure and what we were expected to review them on was all logical. It ran smoothly.
- Travelling was easy. The team worked well together. Very tiring but productive day. Networking-thinking time.
- Able to meet many of the team members. Nice chance to see all the facilities of the hospital.
- The whole day was well organised by host institution and they have prepared for the visit well.

- Staff and staff on wards helpful.
- The whole visit. AY was an excellent lead and I learnt a lot.
- Trust team and documentation very well organised.
- Clear delegation of duties. Good focus. Good time keeping.
- Everything. Slightly difficult and confusing with 2 sites but copable with.
- Access to information. Visit to wards and clinical areas.
- I only attended visit at 10am. I would have liked to be there for full day.
- Overall, I think the whole day was well structured, with sufficient time to cover all areas. Meeting with user group very constructive and informative.
- Excellent food.
- A good team work.
- Coordination. We managed to get through a lot of information and flexibility of those being interviewed really help.
- Our group worked well together.
- Review was quite good. Lovely environment.
- Meeting with all involved - easily organised. Excellent ushering around.
- The timing
- Overall the day was well organised.
- The organisation of the timetable, flexibility of same and the use of the documentation provided. Meeting with user groups and general tour.
- Everything went smoothly, no hitches.
- Everyone was on time and generally the day ran on time.
- Ability to flex the timetable and visit more areas.
- Very helpful staff. Visits well planned. Documentation very well organised. Face to face discussions valuable.
- Lovely environment-parents had no negative comments on service.
- The operational policy provided by QMC very very helpful.
- A well organised day.
- Everything went well to the best of my knowledge.

What didn't go so well?

- Delay to start.
- No vegetarian sandwiches!
- Would have been nice to see more users.
- Timetable not clear, therefore required changes.
- Needed more patients for 'interview session' (only 2).
- Trying to stick to timetable!! But OK in the end.
- The interface with some of the specialities invited - was not taken up!
- Extra copies of clinical protocols would have been useful - only 1 provided. A brief summary of the case notes and what they illustrate would be better.
- Nothing. (x4)
- Time keeping on our part! No time to review notes. Joint visit with Whittington resulted in late start.
- Lunch didn't go well. Allow people to be free for lunch. They colour coded self assessment sheet rather than use Yes or No.
- Timing - very hard to control.
- Everything went very well.
- Time pressured. Food and drink not so good.
- A little unsure at times where to go and who to see but it sorted itself out.
- Time with CEO wasn't particularly fruitful, but appreciated that he did come to meet us.
- For me (a novice) could have had more time to review more thoroughly.
- Some groups were unable to attend or send representatives - (LHTS).
- Lack of evidence.

Suggestions to improve the process:

- If possible self assessment to be sent out in advance.
- Good briefing, organisation and information. I enjoyed being a part of the Review Team.
- Simplify quality standards. Broaden categories. Try to shorten the day to allow easier 'day' travelling : would increase availability of assessor.
- Room rather small for presentation
- Engagement by hierarchy (e.g. Medical Director)
- I think the visit was comprehensive in that Users, Community, SHT and LHT were all interviewed.
- I found this interesting and useful
- Good learning experience.

- An excellent well established process that work well.
- Enjoyable and informative.
- Friendly welcoming team.
- Some people had to wait outside until being interviewed. Could have found somewhere for the more comfortable for them to wait.
- Probably should have organised more rooms. Organised well but it was a long day.
- You really need to be fully prepared for the day. Really well-run and managed by AY.
- I have really enjoyed the opportunity to contribute to the peer review process and gaining insight into the work of other centres.

VISIT EVALUATION - TRUST

Evaluations Returned: 26

The pre-visit preparation was:	Not helpful	Helpful	Very helpful	Total
Responses	0	6	16	22
	0%	27%	73%	100%

- A great deal of work - but information which was necessary for us to have. Main points improvements in levels for uptake & a marathon, training and improvement of our intranet facility. Many of the standards we met but did not have the evidence until it was sought for the visit.
- The opportunity to meet with all involved was extremely useful. The document produced from that meeting was also a great help to ensure that everything could run smoothly on the day. All involved were extremely helpful.
- Useful to understand the wider process and what was expected of us on the day.
- Did not attend pre-visit preparation.
- A lot of hard work.
- Very helpful in terms of providing a good guideline.
- Unable to comment.
- Unable to give comment; was not available at time.
- Always helpful
- Very comprehensive pre-visit information. Good communication throughout.
- Thorough pre-visit document action was made available and clear expectations about the visit.
- The documentation and guidance sent was helpful to focussing on presentation.
- Very thorough. Caldicott Guardian issue possibly excessive.
- Unexpectedly so - made us appreciate what we have.

The visiting team was:	Not helpful	Helpful	Very helpful	Total
Responses	0	3	21	24
	0%	13%	88%	100%

- Did not meet.
- Everyone was extremely helpful.
- Friendly team who made the process non-threatening. Offered constructive ideas for improvement.
- Team did not really ask me anything for me to make comment.
- Very friendly and encouraging. Thank you for the good/excellent feedback.
- Polite, approachable and easy to relate to. Knowledgeable in their roles.
- Very collaborative approach and positive attitude.
- Friendly and accessible. Not intimidating.
- Friendly and non-intimidating.
- Very constructive.
- Courteous and generous with team.
- Remained cheerful through a long day. Visit encouraging.
- Enjoyable two way process.

- Very friendly positive team making the review process relaxed. Good structure throughout the day. Interested in seeing all aspects of service.
- Very experienced, helpful and thorough.
- Very sympathetically chaired in a focused and objective way.
- Very grounded review team, very helpful feedback. Very personable team- one of the most helpful peer review meetings I have been part of.
- Constructive comments throughout. Understanding and practical application of standards
- The knowledge and experience was evident and the team were able to advise on areas/concerns in a productive manner.
- Very easy going and clear.
- Highly organised, clear and constructive.

What went well?

- All visits on one day - incredibly hard work to organise but useful that it does not need repeating.
- We communicated prior to the visit with all staff, posters & standards placed in coffee room so that staff felt involved. Feedback email to all staff describing this which was gratefully received by all. Email sent by Trust Assistant Medical Director which was excellent and made staff have a good feeling about their work.
- The day ran smoothly and flowed well
- The whole process was good - no negative aspects.
- The interviews with various teams seemed to go well.
- The entire visit I believe.
- Communication about what was involved and reasons for process.
- All staff were available during tour for comment and to answer questions. Parents were available. Team gave very positive feedback.
- Small group discussions.
- All the members of the team being available and accessible.
- Feedback went very well.
- From feedback, day was successful. Enjoyed showing outpatients to visiting team and answering queries.
- Whole day fine.
- Overall visit arrangements. Clear feedback.
- Excellent concise feedback - positive even about concerns.
- Feedback.
- Everything. No negative comments.
- Hopefully a smooth day.
- Very constructive feedback given throughout the day. Good mixture of disciplines to look at all aspects of the service.
- Very thorough visit. No surprises. Very practical and grounded recommendations.
- No surprises and some useful suggestions shared to help on development.
- The timetable was followed.
- The whole day progressed well and the feedback from the review team was that they felt the organisation for the day was evident and appreciated.
- Going around ward and areas.

What didn't go so well?

- Rooms are a problems - sorry. Conference call at same time; not much equipment – can't do more than two simultaneously.
- The room changes for the review feedback caused a little confusion but was easily rectified.
- Timing! We were late starting.
- We acknowledge the need for more information for thalassaemia services as we have limited. We will definitely improve.
- Food was rubbish!
- The food was disastrous.
- Nothing. (x5)
- Food and coffee supplies.
- More time - but this could put more pressure on team.
- Too few user representatives.
- There were no adverse comments or issues that arose during the day.
- Timing was difficult especially with parents' time. I was worried about quality of notes.

Comments to improve the process:

- Nothing your side. It ran well.
- Nothing to add. I believe this was a positive experience for all with a great outcome.
- We were pleased with the verbal feedback on the day. It was a very fair assessment of the situation we are in and the difficulties the service faces.
- Very flexible and helpful.
- I was happy to be able to be involved at such a process as a registrar.
- Let staff have more info about specific assessment areas.
- A long day for all. Good feedback. Well organised.
- User involvement on the panel.
- It would have been helpful to have had a user/parent on the visit.
- A very compact but comprehensive review. Well done. Excellent Chair.
- Avoiding school pick up. Notes problem in general.

OVERALL EVALUATION

Evaluation questionnaires were sent out by email approximately two months after a visit report had been finalised. Questionnaires were sent to reviewers (30), Trust lead contacts who were also reviewers (12), and Trust lead contacts who had not acted as reviewers (27). Despite reminders, only 10, 3 and 7 evaluation forms respectively were returned. The results should therefore be viewed with caution as the overall response rate was only 29%. Due to the low numbers of questionnaires returned, results of the three groups have been combined.

Did the preparation for the visit lead to changes in the services provided by the Trust?	1 No change	2	3	4	5 Significant improvement	Total
Responses	1	0	4	4	1	10
	10%	0%	40%	40%	10%	100%

Comments and examples

- The preparation was certainly helpful as far as getting our house in order and being able to evidence the work that we did. It supported us to develop the network links further and has provided us with additional peer support in delivering these services across sites. I am not sure that it affected real change in the way we delivered services however as clinical care on both sites is already good.
- Indirectly as the service was brought to the attention of the appropriate line management and identified gaps in the service
- It allowed us to expedite the trust-wide review of guidelines and patient information booklets.
- Improved the transition service
- Improved documentation
- We were able to look at service provision and development
- Improved data collection
- The preparation for the visit ensured that we thoroughly reviewed our current service and looked at areas that we could improve with current funding. We were also able to consider improvements that could be made if more funding was available. The preparation meant an operational policy was developed for the service and many new guidelines were formalised.

The pre- visit support available from West Midlands Quality Review Service was:	1 Not helpful	2	3	4	5 Very useful	Total
Responses	0	0	4	2	4	10
	0%	0%	40%	20%	40%	100%

- I found this support helpful when I needed to ask for assistance, however it was a new process and therefore some parts just need to be experienced first. Training was in Birmingham however and there was no compensation for travel expenses

Was the peer review visit to your own Trust a helpful or unhelpful experience?	1 Unhelpful	2	3	4	5 Very helpful	Total
Responses	0	0	0	2	5	7
	0%	0%	0%	29%	71%	100%

Comments:

- Highlighted areas of good and 'poor' practical as well as areas with poor resources.
- Although I do not work in the paediatric side it helped us both to focus on the service issues of transition and also brought it to attention of Managers.
- It has helped us ensure we have appropriate pathways of care for sickle and thalassaemia. It raised the trust management's awareness.
- I was not directly involved in the review visit to my Trust. However I was involved in pre-visit meetings and saw the benefit of the review process which I do belief was beneficial to the services provided and that the service became more patient-centred as a result of the process.
- Again really useful experience to see how a well-established process was delivered and provided useful ideas on how to apply locally
- From the peer review, we now have a database and a general increased awareness with senior managers of the work we do and income we generate.
- Yes - as they were able to give good recommendations.
- Managers and colleagues that attended the peer review understood the service better and what we provide.

Was the actual visit a helpful or unhelpful experience for staff within the Trust?	1 Unhelpful	2	3	4	5 Very helpful	Total
Responses	0	0	0	5	4	9
	0%	0%	0%	56%	44%	100%

Comments and examples:

- Apart from the stress that any visit like this is likely to put on the staff (who want to show they are performing well) I think the experience was positive. It allowed me in particular to focus on that part of the service that day and to share ideas with colleagues across different organisations.
- The preparation generated additional work but it was very helpful to see the range of work and achievements over the years. It was particularly pleasing to have the service acknowledged by external reviewers and service users.
- Allowed the trust at least to temporarily focus on the sickle cell/thalassaemia service.
- The haemoglobinopathy nurse specialist post, for which funding had been available for specialist commissioning for a few years, was all of a sudden being advertised at the time of the visit!

Did the report of the visit give a fair reflection of your services at your own Trust at the time of the visit?	1 Unfair	2	3	4	5 Very fair	Total
Responses	0	0	0	9	5	14
	0%	0%	0%	64%	36%	100%

- Yes it did, there were few that needed to be made after the draft report was sent out but these were negotiated well and the final report was a true reflection of our service. Our report was also presented shortly after the visit so the immediate results could be shared when we were still thinking about the peer review process.
- I thought the process for developing the reports was really good and the final reports were well written

If not, please give examples:

- Have not had a visit.
- I think so but as not directly involved I am not able to score this.
- Delay in report, still waiting after 2 months

Was the experience of being a reviewer useful in developing your own services?	1 Not helpful	2	3	4	5 Very useful	Total
Responses	1	0	0	6	6	13
	8%	0%	0%	46%	46%	100%

If so, please give examples:

- Protocols reviewed were very useful.
- Since the review we have upgraded care pathway and introduced transitional care clinic.
- It helped provide clarity for our own documentation. We are more focused on patient information.
- Nurturing a nascent patients group
- It was incredibly useful and informative to see the different conditions under which people work, the different facilities available to patients and to hear about the experiences of both staff and patients. I also gained much greater understanding of the experience of sickle patients than I had before.
- I am not directly involved in the paediatric services in my own Trust. However, it made me think about the differences in working practices and the potential improvements to adult services. The experience has developed my own ability to review services objectively and has, I think, provided me with improved skills by looking afresh at the way services are provided.
- It provided a really good basis for considering how we should evaluate other services and the tools we could develop
- For my own personal development I felt that the experience was good as I reviewed hospitals where thalassaemia was more frequent amongst the public.
- Yes, it was good to gain ideas from other units and be able to share this learning. It also helped to understand the review process and therefore helped prepare us for our own visit more effectively.

Has the peer review process overall been useful to your Trust in improving services?	1 Not helpful	2	3	4	5 Very helpful	Total
Responses	0	0	4	6	5	15
	0%	0%	27%	40%	33%	100%

Comments:

- We hope so in the future.
- It has helped focus on the management teams mind on haemoglobinopathy as a service and gelled the service at both sites.
- Very helpful in giving our team feedback on our service to help us in future projects.
- In the current financial climate, and with so many other competing issues, haemoglobinopathy is still “low profile”.

- Yes it is. It was very helpful in bringing the network closer together and for reviewing current practices and documentation as well as highlighting the importance of the service to senior management within the Trust. We have improved on a number of areas, most notably updating guidelines and sharing information across the two sites.
- I have given a '3' for this because although the intention of the trust would be to change things, there is simply no money or resources to do so it is practically out of our control.

If improvements have been achieved as a result, please give examples:

- Database
- Calculation of data and best practice into a national overview of services
- It would be helpful to send out a report of briefing that was grouped into areas eg. outpatients, inpatients, patient satisfaction etc. Outlining key things that reviewers highlighted as being good practice at their reviews. Perhaps contact details of the Trusts and key staff involved in delivering that good practice could also be added. Obviously it shouldn't be too long and should be easy to read to ensure that all staff are motivated to read and then act upon the ideas.
- It allowed the expedited review of guidelines policies/updating of procedures, patient information booklets.
- The peer review highlighted the need for review of pain management and as a result pain audits are underway. Patient experiences in the Accident and Emergency Department were noted and training sessions for the reception staff have taken place. The absence of locally accessible psychology service has been taken up by the local support group for sickle cell and thalassaemia and has raised their concerns accordingly.
- Improvement in 'out of hours' transfusion services.
- Improved relationship with link hospital.
- Better coordination of services and database.
- We have now appointed a 0.5 WTE paediatric haemoglobinopathy nurse who will start in September

Has the involvement of staff from your Trust in visits to other places been helpful in improving your own services?	1 Not helpful	2	3	4	5 Very helpful	Total
Responses	0	1	2	3	2	8
	0%	12%	25%	38%	25%	100%

Comments and examples:

- Useful opportunity and helped to see the services in operation.
- The sharing of information and materials from other Trusts at the recent UK forum meeting was invaluable examples of good practice will be incorporated accordingly.
- Good model for interaction between hospital and community. Always good to see how other people approach the same challenges.

Has your Trust been able to address the 'immediate risks' (if any) and 'concerns' identified in the report of its peer review visit?	1 Not addressed at all	2	3	4	5 Addressed in full	Total
Responses	3	1	6	1	2	13
	23%	8%	46%	8%	15%	100%

Examples of changes made as a result of the visit:

- Lack of resources.
- I have not seen the report.
- In the process of changing.
- Patient held records now available in A and E, previously not available.
- There were no risks identified. Areas of concerns were around staffing levels and this has not been addressed: Issues raised by parents around pain relief are being addressed.
- I don't think there were any immediate risks.
- Staff can now access all up to date information and guidelines through the Trust intranet.
- The main improvement is that we have now appointed a 0.5 WTE specialist nurse who will start in September which will make a vast difference to our service.

Areas that have proved very difficult to address:

- Trust has been very supportive on both sites so not really any issues.
- Even with the support contained within the report for the contribution of a nurse specialist post we have been unable to secure ongoing funding.
- Staffing levels and provision of psychology service.
- Those over which we had no control - the way results are given to parents in outlying areas.
- We have no continued funding or our haemoglobinopathy nurse so I fear progress that has been made will be lost.
- Psychology service and out of hours transfusions for children, no more manpower available to run what is a busy and increasing service.
- The need for another community nurse specialist has not been addressed but will be reviewed in the next service development meeting.
- We transferred the outstanding actions from the report and included our own learning experiences into a peer review plan which has now been subsumed into the Network Meetings. Some actions on here are still outstanding (improvement actions as opposed to those that are detrimental to the service) as they are longer term projects; however they are monitored regularly.

Do you have any suggestions how 'good practice' identified at the peer review visit could be disseminated? If so, please give examples:

- Policies and guidelines could be national.
- Internet website with examples of good practice so that the same type of work is not repeated at multiple sites and can simply be applied to local practice.
- Disseminated through the UK Forum, Sickle Cell Society, UKTS and other outlets especially ones accessed by service users to boost their confidence in the self-scrutiny of their doctors and nurses
- Perhaps a small, easy to read report on examples of good practice could be circulated via the UK Forum (separately from the main report). It could also be circulated via STAC, FASTN and the patient societies.
- It is important that good practice is feedback to all staff groups. There is always the tendency to disseminate feedback to Trust / Consultant level, from what I saw it was often the HCSW, junior nurses, play / teaching support, community staff who had introduced good practice and therefore feedback needs to go back in at 'grass roots' level.
- Would be really good to have a list of all lead nurses and consultants for all the centres visited so it is easier to contact people for help and advice.
- As demonstrated at the UK Forum meeting, a website with examples of good practice for sharing with networks, incorporated in standards and guidelines.
- Annual reviews being copied to parents.
- Housing officers providing a service in clinic.

Any other comments about the Quality Requirements or the peer review process?

- Well designed and organised project. Only need to emphasize next time round the importance of Trust meaningfully engaging with service users by actively seeking their feed-in to service design and delivery
- I only did one peer review visit, but I learnt from this, although I work in adult services we have started discussing issues at clinical governance and some things have changed e.g transitional care.
- Learning about service user experience is a vital part of the peer review process; however some hospitals (even very large ones) seemed to have made very little effort to get service users to be present. Perhaps it should be part of the requirements that service users should attend and be available to speak to the reviewers.
- An excellent process which I was delighted to be involved with. Having been involved with many formal 'accreditation / inspections' over recent years I felt that peer review allowed flexibility and encouraged learning rather than criticism and punishment encounter during some inspections.
- The use of praising good practice is used infrequently within the health services and it was obvious to all how delighted and motivated staff were when they were singled out for positive comments during the verbal feedback sessions.
- I found the whole experience really good for my personal development.
  It was really enjoyable experience, both being peer reviewed and being reviewer for other services. Please put my name down for the next round

Comparison with other evaluations

This table compares the results of the final evaluation with other review programmes run by the WMQRS team, including cancer, critically ill children (CIC) and renal peer review programmes:

Question	Response	%				
		CIC 2003	Cancer 2005	CIC 2006	Renal 2009	SC&T 2010/ 11
Did the preparation for the visit to your own organisation lead to changes in the services provided by the Trust?	Improvement or Significant Improvement	34	41	71	14	44
Was the peer review visit to your own Trust a helpful or unhelpful experience?	Helpful or Very Helpful	72	47	78	80	100
Did the report of the visit give a fair reflection of the services at your own Trust at the time of the visit?	Fair or Very Fair	83	58	65	66	100
Was the experience of being a reviewer useful in developing your own services?	Useful or Very Useful	81	74	89	91	92
Has the peer review process overall been useful to your Trust in improving services?	Useful or Very Useful	67	45	61	52	72
Has your Trust been able to address the 'immediate risks' (if any) and 'concerns' identified in the report of the visit to your services?			43		48	25