Services for People with Haemoglobin Disorders

Peer Review Programme 2014-16 Overview Report

Report Date: November 2016   Version 2

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<td>24.11.16</td>
<td>Page 15, paragraph 61: Hospital in London which looked after less than 50 children with sickle cell disease amended.</td>
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EXECUTIVE SUMMARY

1 This report summarises the findings of the peer review visits to 33 services for adults with haemoglobin disorders and 33 services for children and young people with these conditions. Services across England, Scotland, Wales and Ireland were reviewed between 2014 and 2016. The visits reviewed compliance with Quality Standards for Health Services for People with Haemoglobin Disorders, Version 2.3 (June 2014) and identified related issues. The findings presented are those identified at the time of the visit and, because the programme took place over a two year period, action may already have been taken to address the issues identified.

2 People with the haemoglobin disorders sickle cell disease (SCD) and thalassaemia require life-long care. People with sickle cell disease encounter problems during childhood including pain, acute stroke, recurrent infections and psychosocial issues. These problems continue into adulthood when chronic complications such as renal disease, chronic cardio-respiratory disease and bone and joint problems also arise. Most people with thalassaemia syndromes require blood transfusions every three to four weeks for life. This results in an overload of iron in the body that, if not appropriately managed, is harmful and usually fatal by mid-teens.

3 Patient numbers varied significantly in different parts of the UK and Ireland and some areas had seen rapid changes in patient numbers. Models of service provision are likely to vary depending on local patient numbers. NHS England specialised commissioning teams and Trusts should take account of predicted increases / decreases in patient numbers in future service planning.

4 The review programme found that availability of specialist services for people with haemoglobin disorders was not proportional to the local need for this care. Reviewers considered that some areas had more patients than could be cared for to an acceptable quality by the available specialist teams. As a result, pressure on staff was unreasonable and, in some areas, patient care was compromised. In other areas services had difficulty maintaining specialist expertise because of the low total number of patients. These services may benefit from the development of formal links with another centre. Some services had a low number of patients with thalassaemia. These patients may receive better care if they are referred to a centre with a larger number of thalassaemia patients.

5 With some notable exceptions, relatively little progress had been made with the development of clinical networks for the care of people with haemoglobin disorders. No networks had clinical time allocated for network development and very few had dedicated administrative or managerial support. Links with local hospitals were very variable and the expected standards for network-wide guidelines, training, data collection, audit and review and learning were mostly not yet being achieved. As a result, patients had variable access to, and received inconsistent quality of, both specialist and local care. Patients at some Trusts were still not being referred for specialist care which will have had a negative impact on their clinical outcomes. Access to community services was also highly variable as was the type of community service provided.

6 Information and support for patients and carers, including patient and carer involvement, had generally improved since the previous peer review visits with several examples of good practice. Ongoing work is needed on ensuring available information is actually given to patients and carers. More structured collection and use of patient feedback is also needed.

7 A significant shortfall in medical and nursing staff with specialist expertise in the care of people with haemoglobin disorders was identified in previous peer review programmes and the situation has deteriorated since then. Over 50% of review visits identified a shortage of medical staffing, high workload or a lack of cover. Many consultants were working far above their contracted hours and most job plans had insufficient time allocated for care of patients with haemoglobin disorders, no provision
for service development and no acknowledgement of network-wide roles and responsibilities. This issue poses a significant and urgent challenge to the provision of high quality care for people with haemoglobin disorders in the UK. The combination of the existing staffing pressures, growing number of patients and the expected retirement of 20 to 30% of consultants and specialist nurses over the next five years means that many services will be unsustainable. The number of doctors in training is likely to be insufficient to fill expected vacancies and training programmes often do not provide sufficient experience of caring for people with haemoglobin disorders.

Levels of specialist nurse staffing had also deteriorated since the previous peer review visits. In some services nurses were taking advanced roles, improving service quality and reducing pressure on medical staff, as well as providing training for ward and Emergency Department staff. In others, workload pressures, vacancies and recruitment difficulties were evident and appropriate specialist nursing support was not available.

Many services did not have a psychologist with time allocated for work with people with haemoglobin disorders and specialist expertise in their care. Where psychological support was available, the amount of time allocated was usually insufficient for the number of patients and the extent of their needs. Psychological support is particularly important for people with haemoglobin disorders because of the lifelong nature of the disease, the ongoing, frequent interactions with hospital services, the impact on all stages of development, including cognitive development, and the psychological consequences of a lifetime living with pain. These needs are additional to the underlying socio-economic challenges already faced by many people with haemoglobin disorders.

Only 40% services had sufficient administrative and data collection support. As a result, already overworked medical and nursing staff were often spending time on administrative and data collection duties which could have been undertaken by others.

Neuro-psychology, play specialists, social workers and benefits advisers all provided highly valued support for the care of people with haemoglobin disorders when they were available but access was inconsistent and was improved when these services had time allocated for work with the specialist haemoglobinopathy team.

Access to automated erythrocytopheresis was variable with some large services having no access. Several out of London services had worked closely with NHS Blood and Transplant to ensure good access. Several other services lacked robust arrangements for emergency manual exchange transfusion.

The quality of facilities and equipment available to patients with haemoglobin disorders was highly variable and the proportion of services with facilities which were appropriate for the number of patients had reduced.

Availability of 'out of hours' transfusion, phlebotomy and clinic services had improved for paediatric but not adult services. As a result, some patients were missing approximately one and a half days each month from school or work. This lack of improvement was disappointing as this was one of the most important issues (after pain management) highlighted by patients.

In general, the availability of clinical guidelines had improved but the detail and document control of these guidelines was highly variable. Robust arrangements for annual reviews of all patients with haemoglobin disorders were still not in place in some services with potentially serious implications for patient outcomes.

Significant variation in the proportion of patients with sickle cell disease on regular transfusion, the proportion of patients being treated with hydroxycarbamide and criteria for referral for stem cell transplantation for children were observed. This variation in clinical thresholds is likely to have significant impact on clinical outcomes.
Clinic ‘Did Not Attend’ rates were approximately 30% although this had been reduced in some Trusts through use of text reminders or through improved cooperation with community services. Some patients were lost to follow up because of Trusts’ DNA policies with potential serious implications for patient outcomes.

Data entry on to the National Haemoglobinopathy Registry (NHR) had improved but only 52% of paediatric and 55% of adult services were using the NHR to register patients and to record annual reviews and adverse incidents. Data collection had improved but was still incomplete, especially in networks where the specialist centre did not have strong links with local services.

Only 24% of adult and 35% of paediatric services had undertaken the audits of compliance with key clinical standards. Most services were unaware if they were achieving important clinical indicators.

Arrangements for Transcranial Doppler (TCD) screening of children with sickle cell disease had improved significantly in many services but some were not yet reaching the expected standards. A number of services were dependent on single members of staff with no cover for absences. Guidelines were not always in place and some services could not demonstrate that staff undertaking TCD screening had undertaken the minimum number of screening procedures.

Although progress had been made on improving arrangements for transition from paediatric to adult services and excellent arrangements were in place in some areas, robust arrangements were not yet in place in all services. This will become increasingly important as the number of young people transitioning to adult services increases.

Despite National Institute for Health and Care Excellence (NICE) guidance, most services were not yet able to demonstrate that they were providing analgesia within 30 minutes where indicated. Patient feedback was better when adult patients were admitted straight under haematologists rather than via general medicine.

Access to community services was highly variable as was the type of service provided.

Evaluations of the peer review programme give evidence of its impact, including changes made before, during and after the review visits. These changes were primarily those which were within the control of staff working in specialist teams. The benefits reviewers gained from participating in the programme are also clear. Organisations were still having difficulty addressing the immediate risks and concerns identified by the review visits and organisations’ ability to do this did not compare favourably with other West Midlands Quality Review Service (WMQRS) review programmes.

In summary, although improvements have been made, services for this vulnerable group of patients remain under-developed in some areas and of variable quality. Growing patient numbers and a shortage of specialist medical and nursing staff threaten the future viability of some services. This report has three main recommendations:

a. More active engagement of specialised and Clinical Commissioning Group (CCG) commissioners in the planning and monitoring of these services
b. On-going work by Trusts in order to achieve the expected Quality Standards (QSs)
c. Further work by Health Education England to address shortfalls in the current and future specialist workforce.
**INTRODUCTION**

Haemoglobin Disorders

26 Sickle cell disease (SCD) and the thalassaemias are a group of recessively inherited haemoglobin disorders. Care for individuals with these disorders is life-long. Sickle cell disease affects predominantly people of black African or African-Caribbean origin while thalassaemia mainly affects those of Mediterranean and Asian origin. Data collected by this review programme suggest that around 1,300 children and adults in England have major thalassaemias and approximately 12,500 have sickle cell disease (Table 1). These figures are in broad agreement with previous estimates and will under-estimate the true prevalence of these conditions due to under-recording in some areas. Scotland, Wales and Ireland have over 500 patients with SCD and about 50 patients with thalassaemia. The number of adults in Wales and Ireland are likely to be underestimates.

Table 1: Number of patients with haemoglobin disorders identified through this review programme

<table>
<thead>
<tr>
<th>Number of Patients</th>
<th>Sickle Cell Disease</th>
<th>Thalassaemia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Children</td>
<td>Adult</td>
</tr>
<tr>
<td>Managed by London networks</td>
<td>4385</td>
<td>5764</td>
</tr>
<tr>
<td>England</td>
<td>5295</td>
<td>6880</td>
</tr>
<tr>
<td>Scotland</td>
<td>54</td>
<td>29</td>
</tr>
<tr>
<td>Wales</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td>Ireland</td>
<td>374</td>
<td>12</td>
</tr>
</tbody>
</table>

28 The prevalence of these disorders varies according to geographical region, being highest in urban ethnic populations, particularly in Greater London, where it has previously been estimated that over 70% of patients with SCD reside. The NHS Sickle Cell and Thalassaemia Screening Programme reports that approximately 310 affected babies are born each year in England. Affected babies are born in all regions of England but approximately 70% are in London. Data gathered by this peer review programme indicate that the London networks managed approximately 83% of English patients with SCD. Areas such as the north-east and south-west of England have much lower prevalence.

29 Geographical distribution of transfusion-dependent thalassaemia is different from that of sickle cell disease, reflecting the different communities in which these disorders are encountered. This review programme found that 71% of English patients with thalassaemia had their care managed by London networks, but this was unevenly distributed between adults, where 77% received care in London, and children where only 57% received care in London. This reflects the high thalassaemia birth rates in the West Midlands and North West England.

30 Adults with sickle cell disease are at risk of both acute and chronic complications, the latter becoming more common with increasing age. Pain is a problem for all ages. Problems encountered during childhood such as acute stroke, recurrent infections and psychosocial issues need continuing care in adulthood. Transition to adult services is a particular issue for young people entering further education or employment. Chronic complications such as renal disease, chronic cardio-respiratory disease and bone and joint problems are common in adults and require specialist management.

31 People with transfusion-dependent thalassaemia major and severe intermedia syndromes require blood transfusions every three to four weeks for life. Iron chelation therapy is essential to prevent

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accumulation of iron in the body. People with thalassaemia who are not being transfused also accumulate iron. Without iron chelation therapy iron overload is harmful, causing cardiac, liver and endocrine disease, and may be fatal by mid-teens. Standard monitoring for iron overload now includes Magnetic Resonance Imaging (MRI) imaging of the liver and heart. Issues of adherence to treatment are important at all ages.

32 The varied prevalence of haemoglobinopathies across England poses a challenge for access to specialist care, particularly in low prevalence areas, leading to different arrangements across the country. This was recognised in England with the introduction of national specialised commissioning for these disorders from 2013. Specialised commissioning is organised through 10 teams which hold contracts with the providers of prescribed specialised services in their area, with four regional teams providing oversight. Clinical Reference Groups provide clinical advice to commissioners, including on services specifications and policies.

33 The need for improvements to services for people with haemoglobinopathies has been identified repeatedly, including by the All-Party Parliamentary Group for Sickle Cell and Thalassaemia and the following published reports:


b. Department of Health sponsored review of haemoglobinopathies (Darbyshire, 2009)

c. National Haemoglobinopathies Project: a guide to effectively commissioning high quality sickle cell and thalassaemia services” (NHS East Midlands Specialised Commissioning Group, July 2011)

d. Services for Children and Young People with Haemoglobin Disorders Peer Review Programme 2010-2011: Overview Report (UK Forum on Haemoglobin Disorders and WMQRS, September 2011)

e. Services for Adults with Haemoglobin Disorders Peer Review Programme 2012-13 Overview Report (UK Forum on Haemoglobin Disorders and WMQRS, September 2013)


34 A full list of guidance documents is included in the Quality Standards for Health Services for People with Haemoglobin Disorders available on the UK Forum or WMQRS websites.

Peer Review Programme

35 This report summarises the findings of a programme of peer review visits to services for people with haemoglobin disorders across the UK and Ireland. A total of 66 services providing care for people with the haemoglobin disorders sickle cell and/or thalassaemia were reviewed between October 2014 and February 2016. Thirty services provided care for adults and 33 for children and young people. Services were reviewed under one of the following categories:

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2 Epsom and St Helier University Hospitals NHS Trust was an Accredited Local Haemoglobinopathy Team for children and for adults but was not reviewed as part of the 2014/16 peer review programme. The Trust was visited in the 2012/13 adult peer review programme and compliance for the Trust is included in the 2012/13 data.

3 The Model Service Specification for Specialised and Accredited Haemoglobinopathy Care (2011) referenced these three types of specialist providers but the term ‘Accredited Local Haemoglobinopathy Team has not been used by NHS England (Specialised Commissioners) or Clinical Commissioning Groups (CCGs) for commissioning services and is not mentioned in the 2013 NHS England Service Specification B08/S/a: Specialised Services for Haemoglobinopathy Care (All Ages).
Specialist Haemoglobinopathy Centre (SHC): A multi-disciplinary team providing specialist care for people with haemoglobinopathies, including annual review and specialist monitoring for patients from across the clinical network. The SHC provides leadership for a geographical area network.

Accredited Local Haemoglobinopathy Team (ALHT): A team that is able to deliver some specialist functions in liaison with the SHC as well as providing Local Haemoglobinopathy Team care. Specialist functions that might be delivered include annual review and hydroxycarbamide initiation and monitoring.

Local Haemoglobinopathy Team (or Linked Providers) (LHT): A team providing local care for people with haemoglobinopathies under the guidance of the Specialist Team, including routine out-patient management, regular blood transfusions, and the management of uncomplicated pain crises and other relatively straightforward complications.

As a result of this review programme, a revised categorisation of services is proposed (section 69), Table 2 summarises the services reviewed and Appendix 1 gives more detail, including the dates of each visit and the type of service provided at each hospital. Data on achievement of Quality Standards are therefore based on 33 services for adults and 33 services for children and young people.

**Table 2: Services Reviewed 2014-2016**

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>No. Reviewed</th>
<th>Adult</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist Haemoglobinopathy Centre</td>
<td>26</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Accredited Local Haemoglobinopathy Team</td>
<td>7</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Local Haemoglobinopathy Team</td>
<td>0</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>33</strong></td>
<td><strong>33</strong></td>
<td></td>
</tr>
</tbody>
</table>

Teams were selected for review either because their Specialised Services Commissioners identified that they were acting as Specialist Centres or because they were known to look after a large number of patients.

The primary purpose of the peer review programme was developmental and supportive, aiming to improve the quality of services for people with haemoglobin disorders. The objectives of the programme were that:

a. Patients and carers would know more about the services they can expect.
b. Commissioners would be supported in assessing and meeting the need of their populations, improving health and reducing health inequalities.
c. Service providers and commissioners would work together to improve service quality
d. Service providers and commissioners would have external assurance of the quality of local services.
e. Reviewers would learn from taking part in review visits.
f. Good practice would be shared.
g. Service providers and commissioners would have better information to give the Care Quality Commission and Monitor.

This 2014-16 round of peer review visits took the same approach as that used for the reviews of services for children and young people with haemoglobin disorders (2010 to 2011) and reviews of care...
of adults with these conditions (2012 to 2013)\(^4\). The 2014-2016 programme covered the care of children and adults. Centres in Wales, Scotland and the Republic of Ireland (children only) were included in the 2014-16 review programme for the first time.

41 The review visits looked at compliance with the Quality Standards for Health Services for People with Haemoglobin Disorders V2.3 (June 2014) and identified related issues. The review visits were led by Clinical Leads appointed by the UK Forum on Haemoglobin Disorders, Dr Jo Howard (Lead) and Dr Josh Wright (Deputy Lead) for adults, and Dr Banu Kaya (Lead) and Dr Subarna Chakravorty (Deputy Lead) for children and young people. Review visits were organised by the West Midlands Quality Review Service (WMQRS) on behalf of the UK Forum on Haemoglobin Disorders and the review programme was run under the governance of WMQRS. Implementation of the review programme was overseen by a Steering Group, membership of which is given in Appendix 2.

42 Each review visit involved a multi-disciplinary team of clinical staff, service users, managers and commissioners. The team met staff and patients, looked at documentary evidence and case notes, visited facilities and then drew conclusions. Visits usually lasted one day with teams looking separately at the care of adults and the care of children and young people. Some aspects of the service, for example, Emergency Departments, were visited by both teams. Transition to adult services was also discussed by both teams. Some visits involved teams looking at more than one service, for example, University College London Hospitals NHS Foundation Trust and The Whittington Hospital NHS Trust were separate SHCs but were visited on a single day as they provide an integrated red cell service with shared protocols and consultants working across both Trusts. The review programme as a whole involved 30 days of visits and 57 ‘team days’ (Appendix 1).

43 Fifteen networks were reviewed, including Wales and Scotland. Network Quality Standards were not reviewed during the review of children’s services in Dublin. A provisional review of network and commissioning Quality Standards took place at each visit. Visits to some networks spanned several days or months and so the network section of the report, including compliance with Quality Standards, was re-issued when the final service in the network had been reviewed. Table 3 shows the number of services reviewed in each network.

Table 3: Services in each Network

<table>
<thead>
<tr>
<th>No. Services Reviewed</th>
<th>SHC</th>
<th>ALHT</th>
<th>LHT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adults</td>
<td>Children</td>
<td>Adults</td>
</tr>
<tr>
<td>East London and Essex</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>South East London</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>South West London</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>North Central London</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>North West London</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>North Middlesex</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>East Midlands</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>West Midlands</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Yorkshire</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>North East England</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

\(^4\)Overview Reports with details of the scope and findings of the first two peer review programmes are available on the UK Forum on Haemoglobin Disorders website: www.haemoglobin.org.uk or the WMQRS website www.wmqrs.nhs.uk
A total of 89 reviewers took part and 284 ‘reviewer days’ were involved in the 2014-16 review programme and Table 4 shows the different types of reviewers who were involved. Undertaking reviewer training and acting as a reviewer is Continuing Professional Development for NHS staff and Appendix 5 gives more detail of the value which reviewers gained from the experience.

### Table 4: Reviewers

<table>
<thead>
<tr>
<th>Discipline</th>
<th>New reviewers trained</th>
<th>Reviewers</th>
<th>Reviewer Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>23</td>
<td>32</td>
<td>78</td>
</tr>
<tr>
<td>Consultants</td>
<td>13</td>
<td>26</td>
<td>112</td>
</tr>
<tr>
<td>Manager</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Psychologist</td>
<td>4</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Commissioner</td>
<td>3</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Service User or Carer</td>
<td>15</td>
<td>19</td>
<td>67</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>61</strong></td>
<td><strong>89</strong></td>
<td><strong>284</strong></td>
</tr>
</tbody>
</table>

Reports of individual visits are available on the WMQRS website: [www.wmqrs.nhs.uk](http://www.wmqrs.nhs.uk). Many of the services were being reviewed for the second time and so it was possible to demonstrate progress from the findings of the first visit. Service re-configuration in some areas meant that meaningful comparisons could not be made.

Issues identified during peer review visits were categorised as follows:

- **Good Practice**
- **Immediate risks to clinical safety and clinical outcomes** (IR)
- **Concerns** (C)
- **Further consideration** (FC)

The number of times particular issues were identified are shown in brackets in the ‘Findings’ section of this report. For example (C:1; FC:1) would indicate one ‘concern’ and one ‘further consideration’.

Appendix 3 gives more detail of the Quality Standards which were used and the 2014-16 review process. Appendix 4 gives a glossary of terms and abbreviations used in this report.

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5 University Hospital Southampton NHS Foundation Trust was reviewed as part of the South Central England network but the visit report suggests that linking with a London network may be more appropriate.

6 Reviewers trained for the 2010-11 or 2012-13 review programmes did not need to be re-trained for this review programme.

7 New reviewers trained: includes one Clinical Lead. Reviewers and Reviewer Days: includes Clinical Leads.
A ‘Good Practice Sharing Event’ is being planned for November 2016 and more detail of the good practice found during this review programme will be made available on the UK Forum on Haemoglobin Disorders website: [www.haemoglobin.org.uk](http://www.haemoglobin.org.uk)

**Acknowledgements**

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; the commitment and dedication of the Programme’s Clinical Leads; Drs Banu Kaya and Subarna Chakravorty for paediatrics, Drs Jo Howard and Josh Wright for adults and the willingness of their NHS Trusts to release them for this work; the cooperation of the teams 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, its Board and Sharon Ensor and Pip Maskell (Key Opps on behalf of WMQRS) for their patient organisation of some the reviews; and the time of the other members of the Peer Review Steering Group. The contribution of all to this programme is gratefully acknowledged.

**FINDINGS**

The findings of the peer review programme firstly summarise issues relating to the geographical distribution of affected children and adults, commissioning and clinical networks. Findings for each of the sections of the Quality Standards are then described. Finally, issues relating to transcranial Doppler screening, transition to adult services, pain management and community-based services are brought together. Individual Trusts are mentioned as examples but, particularly in relation to good practice, there may be other examples which are not included here. A list of Trust abbreviations is given in Appendix 1.

**GEOGRAPHICAL DISTRIBUTION OF AFFECTED CHILDREN AND ADULTS**

**Summary:**

Patient numbers varied significantly in different parts of the UK and Ireland and some areas had seen rapid changes in patient numbers. Models of service provision are likely to vary depending on local patient numbers. NHS England specialised commissioning teams and Trusts should take account of predicted increases / decreases in patient numbers in future service planning.

A total of 6950 adults and 5760 children with sickle cell disease and 880 adults and 420 children with thalassaemia in England, Scotland, Wales and Ireland were identified during the peer review programme. These numbers are based on those reported to the peer review team at the time of the visit. Data on patient numbers from the linked hospitals was not as accurate. Some SHCs had accurate figures for all patients in their network but others were not aware of all patients seen in their linked hospitals or how many of their regular patients were also seen in other centres. Patient numbers may therefore have been underestimated. More patients were reported than had been registered in the National Haemoglobinopathy Registry. Although the true prevalence of haemoglobinopathies is

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8 Barts Health NHS Trust, Kings College Hospital NHS Foundation Trust, Guy’s and St Thomas’ NHS Foundation Trust and Sheffield Teaching Hospitals NHS Foundation Trust respectively.

9 Figures rounded to the nearest 10.

10 NHR accessed 10.9.2016: 10311 patients with sickle cell disease and 1149 with thalassaemia.
unknown, the quality of data had improved since the previous peer review visits and these numbers represent a reasonable estimate of prevalence.

The prevalence of people with haemoglobin disorders was known to vary across the country. The variation in numbers found by the peer review visits was even more extreme than previously recognised (Figure 1). Fourteen hospitals looked after more than 250 adult patients with sickle cell disease and only two of these were outside London (Manchester and SWBH). The largest centre cared for over 800 adults with sickle cell disease. Ten hospitals looked after more than 250 children with three of these (BCH, Manchester and Dublin) being outside London.

**Figure 1: Size of services for people with haemoglobin disorders**
The distribution of patients with thalassaemia varied according to age. Six centres looked after more than 50 adults and two of these were outside London (Manchester and SWBH). Only three centres looked after more than 50 children with thalassaemia. Two were outside London (Manchester and BCH) and only one within London (Barts Health).

Most centres had larger numbers of adults than children with sickle cell disease although 11 services had more child than adult patients with sickle cell disease. This has significant implications for future planning for adult services. Dublin was an extreme example of this with 374 paediatric but only 12 adult sickle patients identified, although this may be because there was no service for adults in Ireland and so adult numbers may be significantly underestimated. Imperial, Birmingham (BCH and SWBH), Manchester, Bradford, Sheffield (CH and TH) and Glasgow all had larger numbers of child than adult patients with thalassaemia. Conversely, UCLH and the Whittington had very large numbers of adult thalassaemia patients but relatively small numbers of paediatric thalassaemia patients.

Some centres, for example BHR and Croydon, had seen a rapid increase in the number of adults with haemoglobin disorders, reflecting changing population demographics. The relative proportion of sickle

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11 Barts (Royal London), Kings, Dublin, Croydon, Lewisham, Glasgow, Liverpool (Alder Hey, and RLUH), Leeds, Manchester, Newcastle and Southampton.
cell and thalassaemia also varied across the country with some of the large sickle cell teams having fewer than ten thalassaemia patients.

55 The numbers for thalassaemia patients include those with non-transfusion dependent thalassaemia; so the numbers of transfusion dependent thalassaemia patients is lower than given in Figure 1.

**COMMISSIONING OF SERVICES**

**Summary:**

The review programme found that availability of specialist services for people with haemoglobin disorders was not proportional to the local need for this care. Reviewers considered that some areas had more patients than could be cared for to an acceptable quality by the available specialist teams. As a result, pressure on staff was unreasonable and, in some areas, patient care was compromised. In other areas services had difficulty maintaining specialist expertise because of the low total number of patients. These services may benefit from the development of formal links with another centre. Some services had a low number of patients with thalassaemia. These patients may receive better care if they are referred to a centre with a larger number of thalassaemia patients. Access to community services was also highly variable as was the type of community service provided.

56 Specialist Haemoglobinopathy Centres have been commissioned by NHS England Specialised Commissioning since April 2013. In 2013/14 NHS England went through a process of assessment of each specialised service against the national service specification. Some services were derogated to give additional time to achieve the key requirements of the NHS England service specifications for haemoglobinopathy care. During the period of the peer review programme, further restructuring of specialist commissioning resulted in regions being divided into specialised commissioning hubs. For London these teams had responsibility for North West London, South East and South West London, and North Central and North East London. Prescribed specialised services are commissioned on a provider basis, rather than a population basis. There are ten hubs across England which contract with providers in their area. Four Regional Teams provide oversight. A process of commissioner approved designation of haemoglobinopathy services at the time of the review. A national service review has been proposed to complete such a process by the end of 2017.

57 As described in section 35, the peer review programme reviewed services as Specialist Haemoglobinopathy Centres (SHC), Accredited Local Haemoglobinopathy Teams (ALHT) or Local Haemoglobinopathy Teams (LHT) based on the level of service the Trust concerned considered it was providing. Several centres were not aware whether or not they had been commissioned as a specialist centre.

58 In the highest prevalence areas of south and east London, several hospitals reviewed as ALHTs or LHTs were caring for very large numbers of affected adults and children. For example, Queen’s Hospital (Barking, Havering and Redbridge NHS Trust), Lewisham and Greenwich NHS Trust and Croydon University Hospital (Croydon Health Services NHS Trust) each cared between 400 and 1000 patients with sickle cell disease, more than most of the Specialist Centres outside London.

59 Some of the teams with large patient numbers (some reviewed as Specialist Teams and some as accredited local teams) were not providing a full range of specialist services and did not have clear referral pathways for specialist care.

60 Several London teams also provided care for adults from outside their geographical area, for example, for patients from as far away as Southampton, Southend, Norwich, Cambridge, Stevenage and Basingstoke.
Sixty-one centres looked after less than 50 adults or less than 50 children with sickle cell disease. In some cases this represented all the patients within their network. Only one hospital in London looked after less than 50 children with sickle cell disease (UCLH). With regards to thalassaemia, nine adult centres and 16 paediatric centres looked after less than 10 patients. Seven of these small paediatric centres were in London. Twelve of the services reviewed provided care for a total of fewer than 100 adults and 100 children with haemoglobinopathies.

Centres looking after this number of patients may not see enough patients to develop an appropriate level of specialist expertise unless they collaborate with another centre, for example, for guideline development, training, audit and review of difficult cases. The development of relevant expertise by other specialties, for example, in the management of orthopaedic, urology and renal complications, is also more difficult in small centres.

Expertise in the rarer complications of haemoglobin disorders was limited to a few centres. For example, many London sickle cell patients were referred to GSTT for orthopaedic complications or to UCLH or St George’s for urological complications.

Adult thalassaemia patients were referred from all over the country to the specialist clinics at UCLH and Whittington, which were nationally recognised centres of excellence. This was reflected in their large adult thalassaemia caseload. High quality specialist care was also being provided at other centres and both SWBH and Manchester had large numbers of patients with thalassaemia.

A meeting with specialised and local commissioners was scheduled during each of the peer review visits although commissioners were not always able to attend these. Some commissioners who did attend had had little previous involvement with services for people with haemoglobin disorders. Commissioners were either service specialists responsible for a wide portfolio of services or were contract managers leading on that Trust’s specialised services portfolio and so had an overview rather than in depth knowledge of services.

In some areas discussions were taking place with commissioners and, where there was evidence of active specialised commissioner engagement, much had been achieved. The development of an effective South Central Network adult service based out of Oxford was an example of effective commissioning of these services. Specialist commissioners had also been involved in planning services in the North West (Liverpool and Manchester) and East Midlands (Leicester and Nottingham). In London specialist commissioners were hosting regular pan London commissioning – clinician engagement meetings. Reviewers considered that better engagement between commissioners (CCG and specialist) and providers would help in addressing local needs, for example, provision of local transfusion and chelation therapy.

CCG commissioners attended many of the review visits and some were knowledgeable about the services. A few had played an active role in supporting service development including the provision of automated erythrocytophoresis (QEH, Homerton). Support from Brent CCG for a community-based social project and the long-standing close interaction with the Sickle Cell Society was highly appreciated by families. Some commissioners were considering CQUINs (Commissioning for Quality and Innovation) in order to support service development.

All commissioners said they would like more information about services for people with haemoglobin disorders.

The findings of the peer review visits suggests the need for consideration of a different classification of services, in particular, the potential development of a few Lead Specialist Centres. These centres may

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12 Newcastle, South Tees, Bradford, Nottingham, Sheffield, Liverpool, Bristol, Southampton, Cardiff, Glasgow, RWH and UHCW.
be different for sickle cell and thalassaemia and could be a national resource. There are two reasons for this recommendation. Firstly, many of the existing Specialist Centres cared for very few patients with thalassaemia and so had difficulty developing and maintaining appropriate specialist expertise in the care of these patients. Secondly, some of the smaller Specialist Centres, especially those outside London, did not have sufficient patients to be able to provide supra-specialist clinics for the management of complications and leadership of education and research. Also, some of the less well-developed services in London, often with large patient numbers, did not yet have the time or expertise for these supra-specialist functions. The national service review provides the opportunity to address this recommendation.

Table 5 shows the trend in achievement of the commissioning Quality Standards. This shows an improvement since 2010/11 but a reduction since 2012/13 in the extent to which these commissioning standards were met. In 2014/16 the East Midlands was the only area to achieve all three commissioning standards.

**Table 5: Compliance with Commissioning Quality Standards**

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>HZ-601</td>
<td>Commissioning of Services</td>
<td>16</td>
<td>33</td>
<td>25</td>
</tr>
<tr>
<td>HZ-701</td>
<td>Clinical Quality Review Meetings</td>
<td>11</td>
<td>33</td>
<td>11</td>
</tr>
<tr>
<td>HZ-702</td>
<td>Network Review and Learning</td>
<td></td>
<td></td>
<td>19</td>
</tr>
</tbody>
</table>

Recommendations:

i. NHS England Specialised Commissioning Teams are recommended to take the findings for each of the services reviewed into account in their commissioning and contract monitoring for 2017/18 and beyond. In particular, commissioners should review:

- The designation of all specialist centres, especially those with low or very high patient numbers. Where patient numbers are very high, designation of additional specialist centres should be considered.
- The hospitals which are acting as Linked Centres, to be assured that networking roles and responsibilities are documented and supported by appropriate governance arrangements such as Service Level Agreements.
- The pathways for referral for patients with complications

ii. When planning services, commissioners and business planning in Trusts should take account of trends in populations of patients with haemoglobin disorders, including trends in the number of patients transitioning from paediatric to adult services.

iii. The Clinical Reference Group should offer advice to support tariffs’ development appropriate for the different levels of care, including network-wide responsibilities.

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13 Changes were made to the wording of the Quality Standards between Version 1.1 (used in 2012/13) and Version 2.3 of the Standards (used in 2014/16). Comparisons are included only where Quality Standards cover the same topic. They reflect standards expected at the time of the review but this may have changed between the two time periods. NB. This comment applies to all tables showing comparisons of achievement of Quality Standards.
THE STATE OF CLINICAL NETWORKS

Summary:
With some notable exceptions, relatively little progress had been made with the development of clinical networks for the care of people with haemoglobin disorders. No networks had clinical time allocated for network development and very few had dedicated administrative or managerial support. Links with local hospitals were very variable and the expected standards for network-wide guidelines, training, data collection, audit and review and learning were mostly not yet being achieved. As a result, patients had variable access to, and received inconsistent quality of, both specialist and local care. Patients at some Trusts were still not being referred for specialist care which will have had a negative impact on their clinical outcomes.

72 National standards recommending the development of clinical networks have been in place for several years and Quality Standards for clinical networks were reviewed in both 2012/13 and 2014/16. In 2014/16 five of the 15 clinical networks reviewed had made progress and achieved over 50% of the network Quality Standards. Overall compliance with network standards therefore improved slightly (Table 6). Outside of London, the East Midlands Network was the only functional English network. The review programme did not identify any clinicians with time in their job plan for the support of networks and there were very few administrative posts with network responsibility.

Table 6: Compliance with Network Quality Standards

<table>
<thead>
<tr>
<th>Ref</th>
<th>Quality Standard Short Title</th>
<th>% Network QSs met 2012/13 (N=27)</th>
<th>% Network QSs met 2014-16 (N=1515)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>adults</td>
<td>children</td>
</tr>
<tr>
<td>HY-199</td>
<td>Involving Patients and Carers</td>
<td>19</td>
<td>27</td>
</tr>
<tr>
<td>HY-201</td>
<td>Network Leads</td>
<td>11</td>
<td>40</td>
</tr>
<tr>
<td>HY-202</td>
<td>Education and Training</td>
<td>30</td>
<td>47</td>
</tr>
<tr>
<td>HY-501</td>
<td>Transition Guidelines</td>
<td>4</td>
<td>20</td>
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<tr>
<td>HY-502</td>
<td>Clinical Guidelines</td>
<td>4</td>
<td>27</td>
</tr>
<tr>
<td>HY-701 (702)16</td>
<td>Ongoing Monitoring</td>
<td>11</td>
<td>20</td>
</tr>
<tr>
<td>HY-702 (703)</td>
<td>Audit</td>
<td>0</td>
<td>27</td>
</tr>
<tr>
<td>HY-703 (704)</td>
<td>Research</td>
<td>19</td>
<td>20</td>
</tr>
<tr>
<td>HY-798</td>
<td>Network Review and Learning</td>
<td>30</td>
<td>60</td>
</tr>
</tbody>
</table>

14 South East London; North Central London; North West London; East Midlands and Scotland.
15 Includes 13 English networks, Wales and Scotland. Network Quality Standards were not reviewed in Dublin.
16 These Quality Standard was numbered HY-702, 3 and 4 respectively in Version 1.1 (used in 2012/13) and HY-701, 2 and 3 in Version 2.3 of the Standards (used in 2014/16).
A national Managed Clinical Network had been set up in Scotland and effectively provided equitable care. This highly functioning network had a variety of sub-groups developing guidelines, audit programmes and making cases for service development. It had well-defined roles, protocols, patient engagement and an education programme. In addition network-wide multi-disciplinary team meetings occurred on a regular basis. There was no effective network for the adult service in Wales. The paediatric service provided specialist services across Wales but did not fulfil some of the other network functions (for example, education). In Ireland, there was no service for adults with haemoglobin disorders and no formal network for the care of children with these conditions.

English paediatric networks tended to be better developed than networks of adult services. This may be partly because paediatric haematology or critical care services were already centralised and partly because of the need for network-wide arrangements for transcranial Doppler (TCD) screening. Some networks based on geographical areas were envisaged but had not yet been agreed. In some geographical areas there was disagreement between centres about who should provide specialist services and a lack of collaboration between adjacent centres. Review teams saw some examples of smaller centres not referring patients to their nearby specialist centre for annual review or to access specialist clinics or apheresis. This was detrimental to patient care and meant that patients with complex co-morbidities who could have benefited from specialist review were not receiving this. Some review visits suggested that some services should develop links with larger units to access specialist clinics or specialist services, especially Newcastle, South Tees, Bristol and Southampton. Services providing this care should ensure they have clear referral guidelines to ensure appropriate and equitable referral practices.

Within London, networks had been agreed based on geographical area and historical referral patterns and were in variable stages of development. For instance South East Thames Network, centred on GSTT and King’s, had appointed coordinators and had established regular meetings and some common protocols. Although North West London Network had been well established with a co-ordinator, this post had been vacant for a while at the time of the visit so the network was only partially functional. Some other large Specialist Teams provided care for patients attending their own hospitals, but provided little support for other hospitals within the geographical area.

In some high prevalence areas, especially in London, adults living in the same areas were accessing different local hospitals and Specialist Teams, and some local teams linked with more than one specialist service. Paediatric and adult patients were sometimes referred to two different specialist providers, which led to complicated transition arrangements. Pathways of care were varied and were often not clear to users or clinicians. Local centres rarely had clear criteria for referral for specialist care, although the North Middlesex Network was a notable exception.

The configuration of clinical networks had not been agreed anywhere in England. Whilst some Specialist Teams had made efforts to contact local teams and engage them in developing patient pathways, other Specialist Teams had not made contact and did not have any formal links with other teams beyond providing ad hoc advice. Some Specialist Teams (for example, Birmingham and the East Midlands) had been in touch with every local acute trust in their geographical area. Commissioner involvement in this process was variable and the process was often clinician-led.

Some specialist centres provided outreach clinics for their local hospitals (for example, Oxford, NNH, King’s, GSTT) which appeared to work well in providing care closer to patients’ homes. These were run at variable frequency from monthly to annually. For paediatrics they often included an outreach TCD service. Some specialist centres had set up multi-disciplinary meetings across their network (for example, St George’s and East Midlands - Leicester and Nottingham). Some teams met regularly in person and others had a ‘virtual’ multi-disciplinary meeting. This was considered to be good practice improving patient care and providing support for smaller services within the network. This idea could be
used in other networks but would need dedicated administrative and clinical time to be effective. The use of a network website (such as that in South East London) was an effective way of sharing guidelines and patient information leaflets across a network and was also useful for sharing information about educational events.

79 The peer review programmes in 2010/11 and 2012/13 identified that an unknown number of children (2010/11) and adults (2012/13) were cared for by haematology teams in hospitals which did not link to a Specialist Team or were not part of an established network of care, or were cared for in the community without any secondary care input. To address this the peer review teams asked each SHC to provide information about patient numbers at every local hospital with which they were linked. Some Specialist Teams were able to provide this information but many were not.

80 In addition, WMQRS contacted every acute hospital in England with an Emergency Department and asked with which SHC they were linked. Some hospitals were unclear about the SHC with which they linked.

81 Several acute Trusts still did not link into any network or with any Specialist Team and review visits identified particular queries over the arrangements for the care of patients at some Trusts. These Trusts, usually with small numbers of patients, should still have protocols for the management of acute complications and patients should have access to specialist review.

82 People with haemoglobin disorders therefore faced variation in the quality of services dependent on where they lived and accessed care. The care available locally depended on the interest of local clinicians and commissioners, and funding arrangements, for example, for community services. This variation in care provided made it difficult for patients to know what to expect, especially if they moved to a new area, and made it difficult for managers and commissioners effectively to monitor service quality.

83 Recommendations:
iv. NHS England Specialised Commissioning Teams working with Clinical Commissioning Groups should clarify the haemoglobin disorders clinical network arrangements for all acute Trusts in their areas.

v. NHS England Specialised Commissioning Teams should ensure Specialist Haemoglobinopathy Centres are fulfilling their network-wide responsibilities

vi. Trusts should ensure that specialist haemoglobinopathy teams have appropriate resources to fulfil their network-wide responsibilities, including clinical time and data collection support.

INFORMATION AND SUPPORT FOR PATIENTS AND CARERS

| Summary: |

Information and support for patients and carers, including patient and carer involvement, had generally improved since the previous peer review visits with several examples of good practice. Ongoing work is needed on ensuring available information is actually given to patients and carers. More structured collection and use of patient feedback is also needed.

Information

The Quality Standards describe the range of information which should be available for patients, including general Trust information, information about the local service, 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 Trusts although it was not clear how systematically it was given to patients (C:3; FC:10). Some information had clearly been produced shortly before the peer review visit. In some Trusts patient information was available on the hospital website and could be directly accessed by patients.

Table 7 shows the extent to which the services reviewed met the expected standards for information and support for patients and carers. Compliance with these standards had improved since the previous peer review visits with paediatric services generally achieving slightly higher compliance than adult services.

### Table 7: Compliance with Standards for Information and Support for Patients and Carers

<table>
<thead>
<tr>
<th>Quality Standard</th>
<th>% Met</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Children</td>
<td>2010/11 (N = 17)</td>
<td>Children</td>
<td>2014/16 (N = 33)</td>
</tr>
<tr>
<td>HN-101 Haemoglobin Disorder Service Information</td>
<td>88</td>
<td>85</td>
<td>75</td>
<td>76</td>
</tr>
<tr>
<td>HN-102 Information about Haemoglobin Disorders</td>
<td>88</td>
<td>82</td>
<td>38</td>
<td>76</td>
</tr>
<tr>
<td>HN-103 Information for Primary Health Care Team</td>
<td>53</td>
<td>94</td>
<td>50</td>
<td>76</td>
</tr>
<tr>
<td>HN-104 Care Plan</td>
<td>53</td>
<td>91</td>
<td>44</td>
<td>76</td>
</tr>
<tr>
<td>HN-105 School Care Plan (Paediatric Services Only)</td>
<td></td>
<td>76</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>HN-106 Transition to Adult Services</td>
<td>53</td>
<td>79</td>
<td>68</td>
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<tr>
<td>HN-107 Information about Transcranial Doppler Ultrasound</td>
<td></td>
<td>73</td>
<td>N/A</td>
<td>N/A</td>
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<tr>
<td>HN-199 Involving Patients and Carers</td>
<td>88</td>
<td>64</td>
<td>56</td>
<td>55</td>
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</table>

Specific information leaflets about haemoglobinopathies and information for primary health care teams were available in most Trusts. Excellent leaflets covered some aspects of care, but there was often duplication and some leaflets were more comprehensive than others. There was generally more information on sickle cell disease than on thalassaemia (FC:5). Some Trusts had developed patient information for particular groups, for example, for students, which could usefully be shared with other centres.

Even within a network there were sometimes marked discrepancies between the amount and quality of patient information provided.

Compliance with the standard on care plans (QS HN-104) had improved, especially for adult services. Although some teams produced individual care plans and gave written copies of annual reviews to all patients, this was not done in all Trusts and patients often did not carry these (C:1; FC:6).

Almost all Trusts sent copies of GP letters to patients so they had a permanent record of changes to care. The team at SWBH wrote letters to the patient, and copied them to the GP. This change of focus meant that the letters were clear and comprehensive and an excellent way of supporting patients and
their GPs. School care plans were available for most paediatric centres, but those with no specific linked community children’s services, such as Oxford and Glasgow, these school care plans were lacking. Quality of school care plans varied widely between regions. Patients felt well supported at BHR where the service effectively combined comprehensive school care plans with education aimed at school nurses.

Compliance with QS HN-106 on information about transition is discussed in section 165.

User and Carer Involvement

Some teams 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 (NMH, LNWH). In some other teams, user involvement had been less successful. Overall compliance with this standard (HN-199) had not improved in paediatric or adult services.

Whilst almost all centres had performed patient surveys, often as part of the preparation for peer review, there was less evidence that actions had been taken following these surveys. Where action had been taken this was not always fed back to patients and those at several centres reported that they felt that there was no action being taken from feedback they had given in surveys or patient meetings (SC:4;C:1;FC:4). A notable exception was SWBH where there was excellent feedback on actions arising from patient surveys.

The South East London Network published a regular patient newsletter for patients highlighting service developments and research. Homerton Hospital had set up weekly sessions entitled ‘Living Well with Sickle Cell and Thalassaemia’ which incorporated physiotherapy, complementary therapies and educational sessions. They also supported monthly patient feedback meetings and quarterly patient newsletters. St George’s was providing educational sessions for patients as part of their chronic pain programme. Alder Hey had set up a ‘sickle kids club’ which provided regular meetings and a patient newsletter.

Recommendations:

vii. The UK Forum on Haemoglobin Disorders should develop a central, on-line patient information resource

viii. Clinical networks and SHCs should ensure patient information is available to Linked Centres and local hospitals and should continue to improve systems for patient feedback.

**STAFFING AND TRAINING**

**Summary:**

- A significant shortfall in medical and nursing staff with specialist expertise in the care of people with haemoglobin disorders was identified in previous peer review programmes and the situation has deteriorated since then. Over 50% of review visits identified a shortage of medical staffing, high workload or a lack of cover. Many consultants were working far above their contracted hours and most job plans had insufficient time allocated for care of patients with haemoglobin disorders, no provision for service development and no acknowledgement of network-wide roles and responsibilities. This issue poses a significant and urgent challenge to the provision of high quality care for people with haemoglobin disorders in the UK. The combination of the existing staffing pressures, growing number of patients and the expected retirement of 20 to 30% of consultants and specialist nurses over the next five years means that many services will be unsustainable. The number of doctors in training is likely to be insufficient to fill expected vacancies and training programmes often do not provide sufficient experience of caring for people with haemoglobin disorders.
Levels of specialist nurse staffing had also deteriorated since the previous peer review visits. In some services nurses were taking advanced roles, improving service quality and reducing pressure on medical staff, as well as providing training for ward and Emergency Department staff. In others, workload pressures, vacancies and recruitment difficulties were evident and appropriate specialist nursing support was not available.

Many services did not have a psychologist with time allocated for work with people with haemoglobin disorders and specialist expertise in their care. Where psychological support was available, the amount of time allocated was usually insufficient for the number of patients and the extent of their needs. Psychological support is particularly important for people with haemoglobin disorders because of the lifelong nature of the disease, the ongoing, frequent interactions with hospital services, the impact on all stages of development, including cognitive development, and the psychological consequences of a lifetime living with pain. These needs are additional to the underlying socio-economic challenges already faced by many people with haemoglobin disorders.

Only 40% services had sufficient administrative and data collection support. As a result, already overworked medical and nursing staff were often spending time on administrative and data collection duties which could have been undertaken by others.

At the sites visited, the review programme identified highly committed teams of medical, nursing and allied health professionals involved in the care of patients with haemoglobinopathies. There were some excellent models of multidisciplinary working within services.

Table 8 shows the compliance with standards for staffing and competences. The percentage of standards met had reduced for most standards both paediatric and adult services. Improvements were seen in staff training, access to specialist advice and training for Emergency Department staff.

**Table 8: Compliance with Standards for Staffing**

<table>
<thead>
<tr>
<th>Quality Standard</th>
<th>% met</th>
<th>2010/11 (N = 17)</th>
<th>2014/16 (N = 33)</th>
<th>2012/13 (N = 34)</th>
<th>2014/16 (N = 33)</th>
</tr>
</thead>
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<td>91</td>
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<td>HN-202 Cover for Lead Consultant</td>
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<td>HN-203 Lead Nurse</td>
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<td>68</td>
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<td>HN-204 Staffing Levels and Competences</td>
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<td>HN-205 Competences and Training</td>
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<td>HN-206 Specialist Advice</td>
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<td>HN-207 Training for Emergency Department Staff</td>
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<td>HN-208 Safeguarding Training</td>
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<tr>
<td>HN-209 Doctors in Training</td>
<td></td>
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<td></td>
<td>88</td>
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<tr>
<td>HN-210 Transcranial Doppler Ultrasound Competences (Paediatric Services Only)</td>
<td></td>
<td>70</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>
Medical and nurse staffing

97 In 35% of the services reviewed consultants did not have sufficient time allocated for the workload caring for patients with haemoglobin disorders and job plans did not reflect the significant demands of these services (SC:3; C:19; FC2). The lead consultants almost invariably had several roles and responsibilities outside the management of patients with haemoglobinopathies. Many were working far above their contracted hours in order to provide the service and consultant job plans had no provision for service development or acknowledgement of network development and support or the additional responsibilities of being a centre lead. Consultant staff sessions did not meet the minimum standards suggested by the UK Forum for Haemoglobin Disorders. A lack of cover for the lead consultant was also identified as a concern in 18% of services (C:9; FC:3).

98 This issue is of particular concern because of the rapidly growing numbers of patients in some services. Taken in conjunction with anticipated loss of established consultants to retirement over the next few years and the shortage of newly trained individuals to replace them there are significant concerns about the sustainability of many services over the next five to ten years.

99 The availability of a lead nurse had also reduced since the previous peer review visits. Some large services had no lead nurse at all (Lewisham). Even where these posts were in place they often had a very high workload which included inappropriate tasks (for example, completion of benefits forms). Often lead nurses were overwhelmed with clinical duties and had little time for their leadership and service development role. Concerns around availability or workload of specialist nurses were raised in 32% visits and some aspect identified for ‘further consideration’ in a further seven per cent (C:22; FC:5).

100 It was clear from the review visits that nursing staff with specialist training in haemoglobin disorders were difficult to recruit. Worryingly several services had lost their lead nurses and been unable to replace them, others had funding for new posts but had been unable to appoint.

101 The staffing shortages impacted on service delivery in many ways including the provision of a network model of care. This ranged from consultants and nurses being unable to provide regular out-reach clinics at linked hospitals to the general administration and management of the network due to limited administrative support. A workforce survey undertaken by the UK Forum on Haemoglobin Disorders has identified that around 20 to 30% of consultants and specialist nursing staff are planning to retire within the next five years, so the staffing shortages are likely to worsen.

102 In some services, however, expansion in service personnel was evident and the positive impact on morale was clear.

103 Of the paediatric services visited there appeared to be similar numbers of paediatricians, haematologists and paediatric haematologists in clinical lead positions. In one service this was a neonatologist (Croydon). Most services employed a model of shared attending duties to manage in-patients with lead clinician support when not attending. Out of hours cover was similarly organised.

104 A number of paediatric services relied upon out of hours specialist support from adult haematology consultants. Although some services had robust out of hours cover from consultants with specialist expertise, many relied upon unsustainable 24 hour availability of the lead or deputy. There were many
examples of good working relationships between paediatricians and haematologists within the same service but also a few occasions when paediatricians were working in isolation.

105 The standard covering doctors in training (QS HN-209) was met in 88% of both adult and paediatric services. Doctors in training on paediatric rotational training schemes included paediatricians and haematologists although some specialist centres were not formally represented on training grids. The demands of general paediatric rotas often meant trainees were pulled away from routine care including out-patient or day case work and within some haematology training schemes there was inadequate exposure to paediatric haemoglobinopathy. Similar issues were apparent within adult training. The majority of trainees were pulled in to haemato-oncology service delivery, many received inadequate exposure and training in haemoglobin disorders. Even in centres with large patient numbers trainees did not always get the opportunity to attend haemoglobinopathy clinics. This does not adequately equip trainees for running haemoglobinopathy services in the future. Because of the pressures on training programmes very few trainees from low prevalence areas had the opportunity to attend larger centres. Exceptions to this include the North East London network where trainees from Cambridge were able to attend North Middlesex. Trainees from Newcastle, Dublin and Oxford also attended GSTT for short attachments.

Training and competences

106 Within adult services there had been a 37% improvement in the number of services with evidence of staff training programmes since the last review. Whilst some units had robust training plans, in many these were inconsistent and could not be delivered due to time constraints on the medical and nursing staff. Particular issues were raised about training of specialist and ward staff (C:12; FC:3) and documentation of competences achieved (C:2; FC:2). At Imperial, however, nurse educator initiatives had helped to train ward based paediatric nursing teams in the use of patient/nurse controlled analgesia (PCA/NCA) helping to support timely pain management.

107 Some centres had developed innovative training packages using Powerpoint presentations with self-test questions which were available on the intranet (RWH, Sheffield). These would be easily transferrable and the idea could be used by other Trusts. In others teaching on haemoglobinopathies was part of nursing induction (Croydon). Royal College of Nursing competences\(^\text{18}\) were not being used as a basis for training and assessment in the majority of units.

108 See also section 169 in relation to training of Emergency Department staff.

Nursing Roles

109 Specialist nurses and nursing teams in several Trusts were making an outstanding contribution to the care of adults with haemoglobin disorders. Nursing roles were diverse with high variability in responsibilities. Examples included lead nurses covering acute and community work as well as general health promotion and genetic counselling duties. This helped with continuity of cover and was highly appreciated by families. In low prevalence areas nurses often worked part-time in the haemoglobinopathy services also covering other aspects of haematology (eg haemophilia, transfusion or day care). For some services, particularly those with low staff to patient ratios, this was proving considerably challenging often with community care suffering at the expense of acute care. Teams with better staffing levels sometimes employed a rotational scheme with the nursing team interchangeably covering acute and community services. This helped maintain skill sets and allowed appropriate cross cover for absence or sickness. Some nurses participated in a 24/7 on call telephone advice service

\(\text{18 Caring for People with Sickle Cell Disease and Thalassaemia Syndromes – A Framework for Nursing Staff, Royal College of Nursing 2011.} \)
(Imperial, Homerton). In other centres a 24/7 service was provided only by the nurses answering calls when they were not on duty (BHR).

Many day-case facilities were nurse led and much progress had been made with training and accreditation to facilitate this. This included increasing numbers of nurses who had completed advanced nurse practitioner training with competences in cannulation, prescribing, acute assessment and treatment. There were also many examples of efficiently run nurse-led clinics including for medication monitoring (hydroxycarbamide and chelation), general health maintenance and advice and annual review / post discharge monitoring.

In addition to nurse-led clinics, some centres had adopted novel approaches to shortages in medical cover with consideration being given to training nurses to commence manual exchanges out of hours (Croydon) and patient group directives to allow first dose analgesia delivery (BCH).

Administrative support

Whilst most teams had administrative and clerical staff, few Trusts had adequate data management support, this limited consistency of data collection. Issues about administrative support were identified in 32% review visits (C:9; FC:13). In many centres clinical staff were responsible for performing data collection and entry and compliance with expected standards of data collection and audit was highly variable. Network data collection, facilitation of learning and review meetings and input of annual review data onto the National Haemoglobinopathy Register (NHR) was often compromised as a result. In contrast, occasional services had developed a quality management team (Imperial) and data collection and entry was robust and well organised.

Psychology

Despite notable exceptions (GSTT, St George’s, UCLH, Oxford, King’s, LNWH), once again this round of reviews has identified poor access to psychology services. Issues around access to psychology were identified in 65% of services reviewed (SC:4; C:31; FC:9). Most services did not meet the 1:300 psychologists to patient ratio recommended by the British Psychological Society Special Interest Group.

Limited progress had been made since the last peer review visits with provision of health and neuropsychology. Many services had access to local, usually community-based, services for general psychology support but there were often long waiting times and specialist expertise in haemoglobin disorders was limited. Psychology staff did not usually have time allocated for work with the specialist haemoglobinopathy team and so had little opportunity to develop specialist expertise. A few services did, however, have dedicated psychologists and good health psychology support, which helped with provision of in- and out-patient care including detailed neuro-psychometric assessments.

Recommendations:

ix. As a matter of urgency Health Education England should review its plans for future staffing of services for people with haemoglobin disorders, including:

   a. Number of consultants needed

   b. Number of specialist nurses needed and the availability of post-registration specialist training, including outside London

x. Health Education England should review the training of junior haematologists to ensure they are gaining appropriate experience in the care of people with haemoglobin disorders.

19 British Psychology Society Special Interest Group in Haemoglobinopathies, October 2016
xi. Trusts should review the job plans of senior medical and nursing staff working in services for people with haemoglobin disorders to ensure these adequately reflect the responsibilities of the post, including network-wide responsibilities.

xii. Trusts should review the staffing of their specialist haemoglobinopathy teams to ensure:
   a. A sustainable workforce plan is in place
   b. The service has sufficient time allocated from a psychologist with experience in the care of people with haemoglobin disorders
   c. The service has appropriate administrative and data collection support, including for network-wide responsibilities

xiii. The Royal College of Nursing should review the competences expected for nurses providing care for people with haemoglobin disorders.

**Support Services**

**Summary:**

- Neuro-psychology, play specialists, social workers and benefits advisers all provided highly valued support for the care of people with haemoglobin disorders when they were available but access was inconsistent and was improved when these services had time allocated for work with the specialist haemoglobinopathy team.

- Access to automated erythrocytopheresis was variable with some large services having no access. Several out of London services had worked closely with NHS Blood and Transplant to ensure good access. Several other services lacked robust arrangements for emergency manual exchange transfusion.

The requirements of the Quality Standards for support services have changed significantly since 2010 and comparisons between years may not be valid (table 9). Only 33% of services reviewed in 2014/16 met the standard for the expected support services, partly because the standard had become more stringent. Particular problems were psychology provision, access to social workers and play specialists (in children’s services). (NB. QS HN-301 is a less stringent requirement for psychology support than the desirable level described in QS HN-204 but was still not met in several services.) This was significantly less than compliance with the equivalent standard in 2010/11 (94%) and 2012/13 (88%).

**Table 9: Compliance with Quality Standards for Support Services**

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<th>Quality Standard</th>
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<td></td>
<td></td>
<td>Children</td>
<td>Children</td>
<td>Adults</td>
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<td></td>
<td>2010/11</td>
<td>2014/16</td>
<td>2012/13</td>
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<td></td>
<td></td>
<td>(N = 17)</td>
<td>(N = 33)</td>
<td>(N = 34)</td>
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<tr>
<td>HN-301 Support Services</td>
<td></td>
<td>94</td>
<td>33</td>
<td>88</td>
</tr>
<tr>
<td>HN-302 Specialist On-site Support</td>
<td></td>
<td>93</td>
<td>82</td>
<td>90</td>
</tr>
<tr>
<td>HN-303 Specialist Services - Network</td>
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<td>100</td>
<td>70</td>
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<tr>
<td>HN-304 Laboratory Services</td>
<td></td>
<td>94</td>
<td>94</td>
<td>94</td>
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</tbody>
</table>
Many Trusts had seen a reduction in play specialist provision. These teams provided much needed support for children, families and health professionals particularly when children were adversely affected by repeated interventions and procedures, including cannulation. Play specialists were highly valued but often covered many areas within the hospital setting and were not immediately available when needed.

Services generally had little access to social work support. A few teams had specific social work support (Imperial, Manchester Children’s) or benefits advice (SE London, Homerton, BHR, Croydon, Nottingham). When available, social work support received very positive feedback from service users. Where this was not in place, clinical staff often spent a lot of time completing benefits forms and writing supporting letters.

Several hospitals ran joint clinics with haemoglobinopathy and other specialties. These included endocrine, neurology, orthopaedic, cardiology, renal, respiratory, urology, hepatology (King’s, GSTT, Royal London, UCLH, SWBH, Manchester).

Specialist teams trained in the provision of holistic, counselling and alternative therapies including acupuncture and massage therapy, were available to service users and their families in some Trusts (UCLH, South Tees, St George’s). Some patients had access to these therapies through their community service (Homerton). When available, this support was highly appreciated by patients.

Where QS HN-303 was not met this was usually because of difficulties accessing red cell apheresis and neuropsychology provision. Access to automated erythrocytopheresis was patchy, with some teams (for example, St George’s, UCLH, Liverpool, Sheffield, Leeds, Imperial, Glasgow) having 24/7 access, others having good access during the working week but some large teams having no service at all (Royal London, SWBH). Even where automated apheresis was available, some units had limited capacity. Some large centres in London did not have automated apheresis on site but had to refer to nearby units (NMH, Croydon, Lewisham). Several teams worked with the NHS Blood and Transplant to provide good access (for example, Sheffield, Leeds, Bristol, Liverpool, Oxford) but across England there was significant variation in access to erythrocytopheresis.

All teams could provide emergency manual exchanges but in some teams these were done so infrequently that reviewers were concerned staff may not be maintaining their competences. Clear protocols for manual exchanges were not always available and, occasionally, these manual exchange procedures required out of hours attendance by the single handed lead clinician.

Access to specialist imaging had improved but was still inconsistent. Access to specialist MRI to assess iron overload had improved generally but sometimes patients had to travel long distances to receive specialist MRI scans or they were not easily available.

School teachers were available Monday to Friday within most Trusts to support learning in hospital whilst children were in patients and when attending for their transfusions. Some teachers were also able to attend multi-disciplinary psycho-social meetings and provided an important link between medical services and the school. Some trusts had recently removed hospital-school provision and this is likely to impact most on children with chronic disease complications such as the haemoglobinopathies. BCH had excellent links between the hospital school and local education services, including young people being marked as ‘present’ at their school if they were present at the hospital school.

Recommendations:

xiv. Trusts should review the support available from neuropsychology, play specialists, social workers and benefits advisers to ensure these are sufficient for the needs of people with haemoglobin disorders.
xv. Each clinical network should have arrangements for the provision of automated apheresis and emergency manual exchange, ensuring all patients have access to these services.

**FACILITIES AND EQUIPMENT**

**Summary:**

- The quality of facilities and equipment available to patients with haemoglobin disorders was highly variable and the proportion of services with facilities which were appropriate for the number of patients had reduced.

- Availability of ‘out of hours’ transfusion, phlebotomy and clinic services had improved for paediatric but not adult services. As a result, some patients were missing approximately one and a half days each month from school or work. This lack of improvement was disappointing as this was one of the most important issues (after pain management) highlighted by patients.

**Table 10: Compliance with Quality Standards for Facilities and Equipment**

<table>
<thead>
<tr>
<th>Quality Standard</th>
<th>% Met</th>
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<tbody>
<tr>
<td></td>
<td>Children</td>
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<tr>
<td>----------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>HN-401 Facilities Available</td>
<td>100</td>
</tr>
<tr>
<td>HN-402 Facilities for Out of Hours Care</td>
<td>12</td>
</tr>
</tbody>
</table>

Review teams visited 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 Trusts had outstanding facilities while, at others, facilities fell short of appropriate standards being too small for purpose and in need of refurbishment (C3; FC:3). Ninety one per cent of paediatric services but only 79% of adult services were considered to have adequate facilities which compared adversely with previous review visits (100% and 85% respectively). In some Trusts segregation of children’s facilities for example, phlebotomy, from adult services had not been possible. A number of Trusts had invested in new purpose built facilities that met the needs of different age groups, including young children and adolescents, very well (Sheffield CH, Leicester, UHCW, Alder Hey).

The Teenage Cancer Trust, the Roald Dahl Foundation and other charities had supported refurbishment of some of facilities and the upkeep of play equipment and toys was often dependent on donations.

Some Trusts were able to provide day case pain management services in dedicated facilities (SWBH, GSTT, Imperial). When available these facilities were universally praised by patients and provided excellent care. The effective working of such units was often limited by restricted opening hours and limited capacity. SWBH had a stand-alone comprehensive Sickle Cell and Thalassaemia Unit providing both acute pain services and transfusions.

The expected standard for out of hours care is that all service should provide facilities for ‘out of hours’ transfusion, phlebotomy and out-patient clinics. Some services were providing evening and late clinics (for example, Barts Health, Leicester, UCLH, Whittington, NMH). NMH also provided a family clinic so
affected adults and children from the same family could be seen together. Facilities for out of hours phlebotomy and transfusion were limited for both children and adults and compliance with the expected standard had improved from 12% to 55% for paediatric (but not adult) services. This lack of improvement was disappointing as this was one of the most important issues in the patient feedback. Weekend transfusions were rarely available but were highly appreciated by families and patients (LNWH, Whittington, Leicester, UHCW, Nottingham, Sheffield) and some units were providing Saturday clinics (Leicester). The day unit at the Whittington was open seven days a week and had a pleasant purpose-built environment, where the patients had input into the design process. Out-reach blood testing where a nurse visited the patient at home to take pre-transfusion or hydroxycarbamide monitoring samples, for example, as provided by the Whittington, was highly valued by families but was uncommon. As a result, many children having monthly transfusions missed up to one and a half school days each month. Some children were unable to have transfusions locally and travelled long distances to the specialist centre for treatment. Many adult patients were in a similar situation often needing to make multiple hospital visits during working hours for cross-matching, transfusion, scans and clinic attendance.

130 Recommendations:

xvi. NHS England should address the issue of access to ‘out of hours’ transfusion and phlebotomy in the updated service specification for specialist haemoglobinopathy services.

**CLINICAL GUIDELINES**

Summary:

In general, the availability of clinical guidelines had improved but the detail and document control of these guidelines was highly variable. Robust arrangements for annual reviews of all patients with haemoglobin disorders were still not in place in some services with potentially serious implications for patient outcomes.

131 As part of the review visit reviewers looked in detail at clinical and referral guidelines in use in each service. The Quality Standards are clear about which guidelines should be available 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. 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. In general, compliance with the standards for clinical guidelines had improved since the previous peer reviews in adult services but the position for paediatric services was more variable (Table 11). Clinical guidelines were appropriately available in 79% services but issues relating to out of date guidelines, multiple guidelines or guidelines with insufficient information were raised in many of the services reviewed (IR:2; C: 13; FC:19).
Table 11  Compliance with Quality Standards for Clinical Guidelines

<table>
<thead>
<tr>
<th>Quality Standard</th>
<th>% Met</th>
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<tbody>
<tr>
<td></td>
<td>Children 2010/11 (N = 17)</td>
<td>Children 2014/16 (N = 33)</td>
<td>Adults 2012/13 (N = 34)</td>
<td>Adults 2014/16 (N = 33)</td>
</tr>
<tr>
<td>HN-501 Transition Guidelines</td>
<td>73</td>
<td>70</td>
<td>68</td>
<td>70</td>
</tr>
<tr>
<td>HN-502 Monitoring Checklists</td>
<td>87</td>
<td>91</td>
<td>48</td>
<td>76</td>
</tr>
<tr>
<td>HN-503 Clinical Guidelines: LHT Management and Referral</td>
<td>59</td>
<td>67</td>
<td>65</td>
<td>90</td>
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<tr>
<td>HN-504 Transfusion Guidelines</td>
<td>76</td>
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<td>85</td>
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<td>HN-505 Chelation Therapy</td>
<td>76</td>
<td>94</td>
<td>62</td>
<td>82</td>
</tr>
<tr>
<td>HN-506 Clinical Guidelines: Acute Complications</td>
<td>76</td>
<td>70</td>
<td>53</td>
<td>67</td>
</tr>
<tr>
<td>HN-507 Specialist Management Guidelines</td>
<td>94</td>
<td>70</td>
<td>79</td>
<td>76</td>
</tr>
<tr>
<td>HN-508 Clinical Guidelines: Chronic complications</td>
<td>93</td>
<td>61</td>
<td>56</td>
<td>63</td>
</tr>
<tr>
<td>HN-509 Referral for Consideration of Bone Marrow Transplantation</td>
<td>71</td>
<td>88</td>
<td></td>
<td></td>
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<tr>
<td>HN-510 Thalassaemia Intermedia</td>
<td>71</td>
<td>67</td>
<td>61</td>
<td>69</td>
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<tr>
<td>HN-511 Clinical Guideline Availability</td>
<td>94</td>
<td>79</td>
<td>71</td>
<td>79</td>
</tr>
<tr>
<td>HN-512 Transcranial Doppler Ultrasound Guidelines (Paediatric Services Only)</td>
<td>67</td>
<td>N/A</td>
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<td>N/A</td>
</tr>
</tbody>
</table>

The proportion of services with guidelines covering referral criteria from local to specialist teams had improved in adult (but not paediatric) services (QS HN-503). The quality of these was, however, variable and there was little guidance as to when patients in linked hospitals who develop acute complications should be referred to Specialist Teams. North Middlesex did have clear referral guidelines for their linked hospitals.

Quality Standards for monitoring at first out-patient appointment, routine monitoring and annual reviews have changed significantly since 2010 and so compliance may not be comparable. Monitoring checklists were available in 91% of paediatric and 76% of adult services. Annual reviews were being undertaken more systematically compared to the previous rounds of peer review and some teams, for example, UHCW, had been performing annual reviews in a consistent way for some years. Some services were still not routinely undertaking annual reviews (C:3; FC:2). Even when annual reviews were being performed, they were not always being recorded in a systematic way or entered onto the NHR (see section 148). Some teams had developed their own database for recording clinical data as well as audit and clinical research. These centres should be encouraged to work with the NHR to help develop satisfactory annual review screens and to use the NHR to ensure accuracy of national data.

Guidelines on the management of chronic pain and chronic respiratory disease in sickle cell disease were often poor or lacking. Pathways of care were unclear, for example, a guideline would say that patients should be screened for renal disease or have echocardiography for pulmonary hypertension screening, but it was not clear at what point patients should be referred on for a specialist opinion. In general, sickle cell guidelines were more comprehensive and more complete than the thalassaemia...
guidelines, reflecting the differential workload. Teams with large numbers of thalassaemia patients had more complete thalassaemia guidelines, which had already been shared with other teams. Some services elected to use available international guidelines for the management of thalassaemia but most of these documents had not been adapted to reflect local needs and practice. Guidelines on the acute management of thalassaemia complications were often unavailable. Availability of thalassaemia intermedia guidelines had improved in adult (but not paediatric) services.

135 Recommendations:

xvii. Trusts should ensure that appropriate clinical guidelines are in place and updated regularly.

xviii. The UK Forum on Haemoglobin Disorders should develop a central, on-line repository or clinical guidelines.

CLINICAL THRESHOLDS

Summary:

Significant variation in the proportion of patients with sickle cell disease on regular transfusion, the proportion of patients being treated with hydroxycarbamide and criteria for referral for stem cell transplantation for children were observed. This variation in clinical thresholds is likely to have significant impact on clinical outcomes.

136 Information was collected on the number of patients with sickle cell disease receiving transfusion therapy and showed marked variation. Rates of transfusion in adults with SCD varied from 0% to 42% and in children varied from 1% to 20%.

137 Information about numbers of patients treated with hydroxycarbamide was not collected for all services but data provided during the visits showed inconsistencies in initiation of treatment with hydroxycarbamide. Differences in thresholds for escalation of treatment for adults and children were also evident. Differences in clinical outcomes would be expected as a result. Investigation of variation in clinical outcomes was beyond the scope of the review but further work in this area may be helpful.

138 Eighty eight per cent of paediatric centres had guidelines for referral for stem cell transplantation but reviewers noted variation between services in the stage at which patients would be referred to a transplant centre.

139 Inconsistencies in clinical thresholds were identified during both the previous paediatric and adult review programmes and recommendations for further research into the impact on clinical outcomes have not yet been implemented.

140 Recommendations:

xix. The UK Forum on Haemoglobin Disorders should explore the reasons for the surprising level of variation in clinical thresholds.

xx. Specialist and local centres should audit their adherence to national guidance on transfusion and other disease modifying therapies.
**SERVICE ORGANISATION AND LIAISON WITH OTHER SERVICES**

**Summary:**
Clinic ‘Did Not Attend’ rates were approximately 30% although this had been reduced in some Trusts through use of text reminders or through improved cooperation with community services. Some patients were lost to follow up because of Trusts’ ‘DNA policies with potential serious implications for patient outcomes.

### Table 12: Compliance with Quality Standards for Service Organisation and Liaison with Other Services

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<thead>
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<td></td>
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<tr>
<td></td>
<td>Children</td>
</tr>
<tr>
<td>HN-601 Service Organisation</td>
<td>82</td>
</tr>
<tr>
<td>HN-602 Multi-Disciplinary Meetings</td>
<td>60</td>
</tr>
<tr>
<td>HN-603 Service Level Agreement with Community Services</td>
<td>24</td>
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<tr>
<td>HN-604 Network Review and Learning Meetings</td>
<td>100</td>
</tr>
<tr>
<td>HN-605 Neonatal screening programme review meetings</td>
<td>87</td>
</tr>
</tbody>
</table>

### 141 Operational policies (QS HN-601) were in place in 55% of paediatric services and 52% of the adult services and were usually very thorough. Although some had been produced for the peer review visit, they will provide a useful resource in the future and can be developed over time. In addition, several units (for example, UCLH, Royal London and the East Midlands Haemoglobinopathy Network) had produced thorough annual reports, which will prove useful for service development and monitoring.

### 142 Multi-disciplinary meetings were happening in most Trusts (67% paediatrics, 73% adults) but these were often not clearly documented. Some services ran regional multi-disciplinary meetings (East Midlands) which may be useful for low prevalence areas. Some centres expanded their multidisciplinary meetings to cover a broader aspect of haemoglobinopathy care appropriate for their local needs, for example, the paediatric service at Cardiff had a joint laboratory/clinical/medical genetics multi-disciplinary team meeting and at Homerton, Emergency Department staff attended the multi-disciplinary team meeting.

### 143 The majority of adult in-patients were looked after by the attending haematologist or by specialist haemoglobinopathy teams. In some Trusts adult in-patients were looked after by general medical teams with advice from the haematology team for their whole admission or for a day or two until a haematology bed was available. Patient feedback in these services was often poor. Patients often stated that they felt like second class citizens in bed allocation. Haemoglobinopathy patients could be housed on over ten different wards around the hospital. Patient satisfaction was improved when they were nursed together on certain wards where staff had appropriate education and training. Procedures for admission also varied with most adults being admitted via the Emergency Department. Patients in some units had direct access to an acute assessment ward or haematology-oncology unit (Leeds,
Children were either admitted under the paediatric haematology-oncology specialist teams, often in their designated wards, or under the general paediatric team with specialist input as needed. Procedures for admission varied with some Trusts having direct access to a paediatric assessment unit (for example, South Tees, Whittington, Southampton) or acute haemophilia assessment unit (for example, Newcastle) although hours of access and cover arrangements varied. Many services operated a telephone advice service for screen and triage.

The ‘Did Not Attend’ (DNA) rate for out-patient clinics was remarkably consistent between services at around 30% for sickle cell patients. This was a poor use of resources and impaired the ability of teams to deliver annual reviews. Adherence to Trusts’ DNA policies meant that many patients were lost to follow up. DNA rates improved where hospitals had developed ways to remind patients (for example, Sheffield, GSTT, Leeds, King’s, St George’s), for instance by texting or telephoning patients. Reminders were usually done by the specialist or community staff, or by the consultant’s secretary in RLUH, though it was recognised that this was labour-intensive and a poor use of skilled nursing time. In Nottingham all patients had a phone reminder from the community nurse a couple of days prior to their appointment. If they did not attend they were phoned by the acute nurse specialist. If they did not attend twice they were referred to the community team. Most community teams would follow up serial non-attending patients with a home visit and the community team at Leicester developed a specific questionnaire to explore causes for recurrent DNA. The team at SWBH organised patient reviews at the GP surgery if the patient had failed to attend on multiple occasions.

Operational policies and multi-disciplinary meetings were in place in the majority of services and helped to ensure good care. Other issues relating to service organisation are discussed in the sections of this report relating to commissioning, state of clinical networks, transcranial Doppler screening, pain management, transition from paediatric to adult care and community-based services.

Recommendations:

xxi. Trusts should monitor ‘did not attend’ rates and introduce mechanisms to tackle high rates. As part of this work, Trusts should consider measures to reduce fragmented and multiple service provision in order to improve increase attendance rates.

xxii. The UK Forum and Clinical Reference Group should discuss with patient groups measures which could be used to increase adherence to treatment and reduce the number of patients who do not have contact with a Specialist Centre.

xxiii. Trusts should introduce multi-disciplinary meetings to discuss the care of patients with haemoglobin disorders, where these are not already in place.

Governance

Summary:

- Data entry on to the National Haemoglobinopathy Registry (NHR) had improved but only 52% of paediatric and 55% of adult services were using the NHR to register patients and to record annual reviews and adverse incidents. Data collection had improved but was still incomplete, especially in networks where the specialist centre did not have strong links with local services.

- Only 24% of adult and 35% of paediatric services had undertaken the audits of compliance with key clinical standards. Most services were unaware if they were achieving important clinical indicators.
### Table 13: Compliance with Quality Standards for Governance

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<th>Quality Standard</th>
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<td></td>
<td>Children</td>
<td>Children</td>
<td>Adults</td>
<td>Adults</td>
</tr>
<tr>
<td></td>
<td>2010/11 (N = 17)</td>
<td>2014/16 (N = 33)</td>
<td>2012/13 (N = 34)</td>
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<td>HN-702 Annual Data Collection - Activity</td>
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<td>HN-703 Annual Data Collection - Network Patient Data</td>
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<td>31</td>
<td></td>
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<tr>
<td>HN-704 Audit</td>
<td>35</td>
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<td>HN-705 Guidelines Audit</td>
<td>36</td>
<td>15</td>
<td>30</td>
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<tr>
<td>HN-706 Research</td>
<td>68</td>
<td>59</td>
<td>72</td>
<td></td>
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<tr>
<td>HN-707 Transcranial Doppler Quality Assurance (Paediatric Services Only)</td>
<td>59</td>
<td>N/A</td>
<td>N/A</td>
<td></td>
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<tr>
<td>HN-798 Review and Learning</td>
<td>88</td>
<td>71</td>
<td>97</td>
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<tr>
<td>HN-799 Document Control</td>
<td>73</td>
<td>59</td>
<td>73</td>
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</table>

The National Haemoglobinopathy Registry provides a means of monitoring the number of adults being treated by a team or within a geographical area. The NHR also provides a means for demonstrating compliance with key standards of clinical care, and gives a denominator for clinical audits and service planning. It is also a tool for review and learning from adverse events. Adult services demonstrated improved data entry into the NHR with compliance with the relevant standard (HN-701) increased from 44% to 52%. Most services which were non-compliant with this standard were using the NHR to register patients but were not entering all their adverse events or annual reviews (C:7; FC:2). Nearly all teams had made significant progress in registering patients, particularly in the months leading up to the visit and some hospitals which had not been using the NHR on previous visits were now engaged with it. All teams saw the value of the NHR and were intending to use it. The main reason cited for non-entry was a lack of time by clinical staff and few resources for data administration (see Summary: Staffing & Training), although others considered that the NHR annual review screens, still under development, were not yet complete enough. Data entry was best in those teams with data managers with time allocated for this work.

The Quality Standards (HN-702) required evidence of ongoing monitoring of the service’s activity. Such information could be used to benchmark care across and between geographical areas and provide information for local commissioners. In 2012/13 most teams had poor compliance with this standard (11% compliance). In 2014/16, data collection was divided into two standards, HN-702 which requested data on activity and HN-703 which collected additional data from the network. In 2014/16, activity data were available in 64% services but some centres were still not monitoring basic activity data (hospital admissions, DNA rate). Collection of data about the number of patients in the network was still poor (28%).
There was marked discrepancy between hospitals, particularly those in London, in the numbers of hospital and day care admissions for the stated number of sickle cell patients. This may be because some hospitals had small numbers of very frequent attenders for pain management. This is an example of how benchmarking of data could be used to examine pathways of care and identify areas needing service redesign and/or additional resources.

Services were asked to provide data on numbers of transfused patients as part of their annual reviews. Data on waiting times for transfusion, the proportion of patients having annual reviews, number of patients on hydroxycarbamide or numbers of patients who are iron overloaded may be useful background information for any future peer review programmes or benchmarking processes.

Quality Standard HN-704 expected regular audits of compliance with key clinical standards. Only 24% of adult and 35% of paediatric centres met this standard in full which compared adversely with previous compliance (both 35%). Additional audits were specified in Version 2.3 of the standards which may explain this reduction.

Compliance with the expected standard for a rolling programme of audit of implementation of guidelines had increased from 15% to 30% for adult services. Participation in research had also increased although in some centres this was limited to one or two studies. Some centres had a comprehensive trial protocol and were recruiting effectively into local, national and international trials (GSTT, Royal London, King’s, UCLH, Manchester, Oxford). Some centres had identified funding for Research Nurses (Imperial) but most were reliant upon the commitment and enthusiasm of existing staff. Improved Network arrangements in SE Thames had allowed the patients in linked centres access to trials (Lewisham, Croydon).

Most services had multi-disciplinary review of any serious adverse events, deaths and critical care admissions although some issues were raised about these meetings (C:3; FC: 13). Future peer reviews programmes could review data from mortality and morbidity meetings and look at correlation with data entered onto the NHR.

Document control had improved to 73% for both paediatric and adult services. Some guidelines were in use after their review date and, more commonly, guidelines had no clear authorship, formal ratification or review date (C:9; FC:2). Sometimes more than one guideline was found for a particular clinical problem, sometimes contradictory, with the obvious potential for confusion and error. The peer review steering group recognise that writing and updating guidelines is time-consuming, particularly for small centres. The use of shared network or national guidelines or an national repository of guidelines may decrease the workload involved for smaller centres.

Managerial engagement continued to be highly variable with some examples of outstanding support in contrast to other services where awareness of the needs of the service was limited. There were many examples of progress with service development where managerial engagement and interest was high (GSTT, St George’s, BHR, Oxford, UHCW). Some large complex services had had little management input and were lacking a clear strategy for development and integration of services (Barts Health)

Recommendations:

xxiv. Trusts should ensure all patients with haemoglobin disorders have an annual review which is recorded on the NHR. All patients should be registered on the NHR and adverse events should be reported to it. (NB. This recommendation links with the recommendation about adequate resourcing of specialist teams, including data collection support).

xxv. NHS England specialised commissioning teams should continue to assess providers against the service specification and should review compliance with the Quality Standards as part of their on-going quality monitoring arrangements.
**Transcranial Doppler Ultrasound Scanning**

**Summary:**
Arrangements for Transcranial Doppler (TCD) screening of children with sickle cell disease had improved significantly in many services but some were not yet reaching the expected standards. A number of services were dependent on single members of staff with no cover for absences. Guidelines were not always in place and some services could not demonstrate that staff undertaking TCD screening had undertaken the minimum number of screening procedures.

<table>
<thead>
<tr>
<th>Quality Standard</th>
<th>% Met Children 2014/16 (N = 33)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HN-107 Information about Transcranial Doppler Ultrasound</td>
<td>73</td>
</tr>
<tr>
<td>HN-210 Transcranial Doppler Ultrasound Competences (Paediatric Services Only)</td>
<td>70</td>
</tr>
<tr>
<td>HN-512 Transcranial Doppler Ultrasound Guidelines (Paediatric Services Only)</td>
<td>67</td>
</tr>
<tr>
<td>HN-707 Transcranial Doppler Quality Assurance (Paediatric Services Only)</td>
<td>59</td>
</tr>
</tbody>
</table>

158 Transcranial Doppler ultrasound scanning is recommended for children with sickle cell disease in order to identify those at increased risk of stroke. Scanning was provided by a combination of imaging experts (radiologists, ultrasonographers) and the core haemoglobinopathy team (clinicians or nurses). Many services were dependent on single individuals with no cover for absences and reviewers were concerned about the sustainability of some services. In some cases, TCD scanning may not have been the best use of consultants’ and nurses’ time given their other high workload.

159 The mode of delivery and choice of TCD scanning equipment was dependent on configuration of services within Trusts. For example, imaging departments tended to use TCDi (imaging) as the scanning technique whereas haematology and paediatric medical and nursing staff were trained in the non-imaging technique. Likewise scanning was provided either in the imaging department or out-patient clinic (hospital or community-based).

160 Many services tried to combine TCD scanning and clinic visits as a ‘one stop’ clinic. This helped to increase attendance though in some clinics DNA rates remained high despite this approach (BHR). Some Trusts had established outreach TCD clinics to linked hospitals (NMH, King’s, LNW, Newcastle). This impacted on clinician time but was highly valued by local clinicians and families.

161 Transcranial Doppler guidelines did not always fulfil all the requirements in the Quality Standards. This was mainly when transcranial Doppler ultrasounds were undertaken by vascular scientists or sonographers and guidelines were drawn up in their respective departments. There was also discrepancy in clinical practice between different services and sometimes between different sites in a single Trust. Most services had systems in place for servicing of equipment, storing of images and reporting.

162 Robust arrangements for quality assurance of TCD scanning were in place in 59% Trusts. Methods to demonstrate sonographer competence with TCD scanning were variable. Records of scanning activity,
with demonstration of at least 40 scans per annum were not available in some cases, mainly due to systems not being in place to tract, monitor and audit this information. External review and assessment had taken place for some services and others were able to demonstrate robust internal quality assurance methods to determine quality and accuracy of scanning, record keeping and reporting. Long running and well established services provided specialist training and were committed to development of a national quality assurance scheme (GSTT, King’s).

163 Some Trusts were actively considering the sustainability of their TCD scanning service and whether provision by imaging departments would provide a more sustainable service.

164 Recommendations:

xxvi. Trusts should review the sustainability of their transcranial Doppler screening services.

xxvii. The UK Forum on Haemoglobin Disorders should complete its work on standards and quality assurance for TCD scanning, including expected competences and training implications. The UK Forum should work with Public Health England on the recognition of TCD scanning as a national screening programme.

xxviii. Public Health England should consider whether the TCD scanning programme should be included in the national screening programmes and whether Public Health England should therefore take on responsibility for on-going quality assurance.

TRANSITION FROM PAEDIATRIC SERVICES

Summary:

Although progress had been made on improving arrangements for transition from paediatric to adult services and excellent arrangements were in place in some areas, robust arrangements were not yet in place in all services. This will become increasingly important as the number of young people transitioning to adult services increases.

Table 15: Compliance with transition-related Quality Standards

<table>
<thead>
<tr>
<th>Quality Standard</th>
<th>% Met</th>
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<tbody>
<tr>
<td></td>
<td>2010/11</td>
</tr>
<tr>
<td></td>
<td>Children (N = 17)</td>
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<tr>
<td>HN-106 Transition to Adult Services</td>
<td>53</td>
</tr>
<tr>
<td>HN-501 Transition Guidelines</td>
<td>73</td>
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</tbody>
</table>

165 Most services recognised the importance of supporting and preparing young people in the transition to adult care. Some teams had well-developed transition services, joint transition clinics, clear transition protocols and excellent patient information. Transition seemed to work well where there was a named co-ordinator who led the transition process and had responsibility across the paediatric and adult service, for example, the transition advanced nurse practitioner at GSTT, paediatric nurse at Alder Hey and community nurse at UHCW. NMH ran a clinic for the 15 to 25 year age group which had good patient feedback, and several other teams had transition clinics, for example, Manchester, Alder Hey, Oxford, Newham, Bradford, UHCW, Imperial and Oxford. Some teams put on transition days or transition events for small groups of teenagers (for example, GSTT, Sheffield CH). In several teams,
however, the transition process was not adequately developed or supported. Some issue about the transition pathway or information available was identified in several services (C:1; FC:12).

Compliance with QS HN-106 on information about transition had improved in both paediatric and adult services and guidelines pertaining to transition of patients from paediatric to adult services were available in 70% of the services. Many of these were adapted from the Department of Health ‘Ready Steady Go’ guidelines for transition of care.

Recommendation:
xxix. Trusts should review and further improve their arrangements for transition from paediatric to adult care.

PAIN MANAGEMENT

Summary:
Despite National Institute for Health and Care Excellence (NICE) guidance, most services were not yet able to demonstrate that they were providing analgesia within 30 minutes where indicated. Patient feedback was better when adult patients were admitted straight under haematologists rather than via general medicine.

Rapid access to pain relief is a key issue for patients and NICE guidelines and standards are in place. This review programme identified issues about pain management in both Emergency Departments (C:8; FC:5) and following admission (C:7; FC:2). Service users who met the visiting teams often reported unacceptable delays in receiving analgesia in Emergency Departments and a perception of a lack of empathy amongst medical and nursing staff in these areas. Care was considered to be better where hospitals were able to offer day care analgesia or direct access to haematology assessment and some patients would wait in pain for the day unit to become available rather than attend the Emergency Department. Some units were using Patient Group Directives in the Emergency Department to allow rapid nurse-led provision of analgesia (BCH).

Training about haemoglobin disorders for Emergency Department staff had increased from 35% to 55% but was still identified as a problem in some services (C:2; FC:6). This problem was highlighted repeatedly in the feedback the review teams received from the service users and their families. Reviewers recognised that high staff turnover in some Emergency Departments meant that ongoing training had to be provided. Some departments had assigned link nurses to improve communication with Emergency Departments and provision of care (Lewisham, King’s).

Most Emergency Department held individualised care plans in for adult patients, either on paper or electronically, to ensure personal pain management. Many adult centres also admitted emergency cases to their day care unit, where guidelines were generally available. Individualised care plans for children were not as common but almost all Trusts had paediatric sickle cell pain management protocols available and these were often supported by the acute pain team. Some Trusts had an effective system of alerting the haemoglobinopathy teams when a patient arrived at Emergency Department (Whittington and UHCW). Most Emergency Departments were able to access relevant clinical guidelines through the Trust intranet.

Patient controlled analgesia was not available in all teams and availability was sometimes restricted to particular wards or times of day. Nursing experience around use of PCAs was also highly variable. Some teams operated good training schemes (Imperial) and ensured training needs were regularly reviewed.

NB. Adult and paediatric services counted separately.
and met. In other Trusts robust arrangements were not in place and often depended on the availability of the nurse specialists.

172 Liaison with pain services in adult units was variable. Some trusts had excellent relationships with the acute pain teams who gave good support to in-patients (Royal London, Sheffield TH, Southampton) and sometimes supported patients after discharge. Support from chronic pain teams was more variable but some centres had comprehensive specialist chronic pain services (St George’s, Sheffield TH, Bristol).

173 The majority of services reviewed had performed audits against NICE pain guidelines. Several audits had shown that the service was not meeting the requirements for administration of analgesia. The audits were of variable quality and very few included action plans or could show repeated audits with improvement in standards. Some centres had repeated the pain audit but had failed to show an improvement in outcomes.

174 **Recommendation:**

xxx. Trusts should audit their services against the NICE Standards for pain relief in sickle crisis and take action to improve compliance with these standards.

### COMMUNITY-BASED SERVICES

<table>
<thead>
<tr>
<th>Summary:</th>
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<tr>
<td>Access to community services was highly variable as was the type of service provided.</td>
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175 The number of community nurses bore little relationship to the size of their service although some small teams provided a highly organised, good quality service and delivered training to other staff. There was inequity in provision of community services even within a network and in some areas community services were available only for patients with particular postcodes. For example, BCH had excellent community support for children resident within Birmingham, but this did not extend to a large number of children who resided outside the Birmingham area but still used the hospital as their local and specialist centre. The provision of community based nursing in some smaller specialist centres was particularly problematic, for example, Oxford and Alder Hey had no community service provision to their local patients.

176 The link between community based nursing teams and acute services was generally good although issues around community services were identified in 24% services reviewed (C:8; FC:8). Most community services were operationally independent of the acute hospital team whereas some were integrated (Croydon, GSTT, Homerton, Whittington). Service Level Agreements covering the work of community teams were present in 50% of paediatric and 53% of adult services (QS HN-603) which was an improvement on previous reviews. Acute hospital teams were not always clear what they could expect from community teams although communication was improved when regular multi-disciplinary meetings were in place (SWBH, GSTT). There were some good examples of innovative models of care run through community services including a newborn clinic (Manchester), transcranial Doppler and evening clinic (Newham), holistic adolescent clinic supported by clinicians, nurse specialists and GP with a special interest in haemoglobin disorders (Whipps Cross), nurse-led social project and clinic (LNWH and Brent CCG). Most community services supported service user’s meetings and some were very well-engaged with local general practitioners (Homerton, Barts: Whipps Cross).

177 Community support may effectively be provided by a combined acute and community team, especially in low prevalence areas. The national Service Review will be looking at the role of community-based services.
Recommendations:

xxxi. Clinical Commissioning Groups should ensure that access to community-based support for people with haemoglobin disorders is available.

xxxii. Community services are considered to be an important part of the care pathway and the national service review should take the opportunity to define more clearly the role of such services.

COMPLIANCE WITH QUALITY STANDARDS

Comparisons of percentage compliance with Quality Standards should be interpreted with caution. The wording of the standards has changed over time. Reviewing teams are trained to be consistent but the clinical environment within which teams are working changes over time which impacts on their judgement of whether or not arrangements are satisfactory. Visit reports include comments on ‘working towards’ particular Quality Standards but these are not reflected in the percentages of standards met. 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.

This second round of review visits with a very similar set of Quality Standards has provided the opportunity to compare performance against these standards. Figures 2 and 3 demonstrate the significant improvement in compliance with Quality Standards in the recent reviews, more marked within paediatric services. Although the standards had changed, these graphs show compliance against the standards expected at the time of the visit. Review visits which occur later in a review programme are likely to have a higher percentage of standards met.
Figure 2  Compliance with Quality Standards: Services for Children and Young People

![Compliance with Quality Standards: Services for Children and Young People](image)

**Key:**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>EL</td>
<td>East London &amp; Essex</td>
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<tr>
<td>EM</td>
<td>East Midlands</td>
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<tr>
<td>IRE</td>
<td>Ireland</td>
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<tr>
<td>NCL</td>
<td>North Central London</td>
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<tr>
<td>NE</td>
<td>North East England</td>
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<tr>
<td>NM</td>
<td>North Middlesex</td>
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<td>NWE</td>
<td>North West England</td>
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<tr>
<td>NWL</td>
<td>North West London</td>
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<tr>
<td>SCE</td>
<td>South Central England</td>
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<td>SCOT</td>
<td>Scotland</td>
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<td>SEL</td>
<td>South East London</td>
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<td>SWE</td>
<td>South West England</td>
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<tr>
<td>SWL</td>
<td>South West London</td>
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<td>Y</td>
<td>Yorkshire</td>
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**Percentage Compliance with Quality Standards:** Percentage of Applicable Standards Met

- % met 2012
- % met 2015/16
Figure 3  Compliance with Quality Standards: Services for Adults

![Compliance with Quality Standards: Services for Adults](image)

Percentage of Applicable Standards Met

- % met 2012
- % met 2015/16
This review programme included, for the first time, services in Scotland, Wales and the Republic of Ireland. The health care systems in these countries differ from those in England for which the Quality Standards were developed. The principles underpinning the care of people with haemoglobin disorders were common between countries but the funding systems, commissioning arrangements, organisation of health services and expectations of haemoglobin disorders networks were different. The reviews of services in Dublin, Glasgow and Cardiff are included in the main text of this report and individual visit reports are available on the WMQRS website: [www.wmqrs.nhs.uk](http://www.wmqrs.nhs.uk). The main findings of these reviews are as follows:

1. In Ireland, the number of children and young people with haemoglobin disorders had significantly increased in recent years. Despite this large population of children, the service was not able to implement transition arrangements as a functioning adult specialist haemoglobinopathy service was not yet in place in the Republic of Ireland.

2. The majority of haemoglobinopathy patients within Wales lived within the catchment area of the Cardiff and Vale Health Board and receive specialist care at University Hospital of Wales (Cardiff). The number of haemoglobinopathy patients attending other services was not known but was thought to be small and these patients may not have access to specialist haemoglobinopathy care.

3. The number of patients with haemoglobin disorders in Scotland was small and distributed over a large geographical area. Services compared favourably with those south of the border. A strong network of clinicians had been developed. This network had administrator support and provided teleconferenced MDTs, guidelines and national audits.

**Recommendations:**

- xxxiii. A specialist centre for the care of adults with haemoglobin disorders in Ireland should be developed.
- xxxiv. A clinical network for the care of adults with haemoglobin disorders in Wales should be developed with the aim of ensuring all adults with these conditions have access to appropriate specialist and local care.

**Evaluation**

**Summary:**

Evaluations of the peer review programme give evidence of its impact, including changes made before, during and after the review visits. These changes were primarily those which were within the control of staff working in specialist teams. The benefits reviewers gained from participating in the programme are also clear. Organisations were still having difficulty addressing the immediate risks and concerns identified by the review visits and organisations’ ability to do this did not compare favourably with other West Midlands Quality Review Service (WMQRS) review programmes.

**Appendix 5 summarises the evaluations undertaken during the course of this peer review programme:**

- a. Training: Evaluation forms completed on the day of training
- b. Reviewers’ views: Evaluation forms completed on the day of the review visit or shortly afterwards.
c. Evaluation from those being reviewed: Information collected by telephone interview with the Trust lead contact shortly after the review visit
d. Overall evaluation: Evaluation forms completed approximately two months after the final report of the review visit was issued.

187 This was the first peer review programme of combined services for adults and children with haemoglobin disorders and built on lessons from the paediatric peer review carried out in 2010/11 and the adult peer review 2012-2013.

188 Almost all the teams 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. Some Trusts and reviewers reported the combined review of paediatric and adult services or multiple sites on a single day was challenging and felt future programmes should take this into account. Many Trusts valued the verbal feedback and the opportunity to discuss or clarify the findings.

189 Many reviewers were very satisfied with the preparation, organisation and conduct of the visits. Some reviewers found the day was time pressured however and struggled with time keeping. They felt the standard of the evidence presented for review was good on the whole with some Trusts demonstrating a very good awareness of the requirements and preparing appropriately. Some Trusts had prepared very thoroughly and presented their data effectively with the data pertaining to each standard clearly labelled. This made the document reviews on the day run very smoothly. Other Trusts did not clearly present their documentation and did not relate it to the standards so the reviewers found it difficult to find the appropriate information in limited time available. This often led to additional queries after the visit which could have been avoided if the information had been more clearly presented or made available at the visit. The quality of evidence was generally better if staff at the reviewed centre had participated in review visits as reviewers. The programme additionally offered useful ‘continuous professional development’ for reviewers.

190 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, Trusts should be made aware that Trusts have the opportunity to comment on the factual accuracy of review teams’ findings but that material submitted after the visit will not be taken into account.

191 There has now been a complete programme of peer review visits of paediatric and adult services. It is essential that this continues as a rolling programme to ensure continued quality improvements. There are several models by which this could be done, but a rolling programme over three years may work well. Teams could be asked to fill in a self-assessment every year, but have an actual visit every three years, unless major concerns indicate the need for an earlier visit. It may be practical to perform the review of the paediatric and adult service at the same time.

192 There are some interesting comparisons between the evaluations of the three haemoglobin disorders review programmes. Most importantly, there has been a progressive increase in the number of teams stating that they have been able to address immediate risks and concerns following the review visits. This demonstrates the importance of the programme in driving up standards. Counter-intuitively, however, feedback suggests a sequential decline in the proportion of Trusts reporting that the process

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21 NHSE has introduced a revised process for the assessment of compliance with service specifications which include provider self-declaration and an annual assessment undertaken by the Quality Surveillance Team. Services prioritised as part of this process will form part of the national peer review programme for the following year.
is helpful or that it assists in improving services. The reasons for this disparity are not clear. This may be related to the way the 2014/16 review programme was organised, with four clinical leads, two of which were usually present on each visit but without a WMQRS support person. This led to some problems of inconsistencies between reports and delays in publication which were not less evident in previous haemoglobin disorders review programmes. Running adult and paediatric programmes at the same time was also difficult for some Trusts, especially those with larger and more complex services.

Overall, the haemoglobin disorders peer review programmes compare favourably with other review programmes run by WMQRS (Table 16).

**Recommendations:**

xxxv. An on-going rolling programme of peer review of services for people with haemoglobin disorders should be established. This could take place over three to five years with services completing a self-assessment every year and having an actual visit every three to five years, unless major concerns indicate the need for an earlier visit.

xxxvi. The Quality Standards for Health Services for People with Haemoglobin Disorders should be updated to reflect latest national guidance and as a result of experience of using them in the 2014/16 peer review programme.

**SUMMARY OF RECOMMENDATIONS**

The table below summarises the recommendations made in this report.

<table>
<thead>
<tr>
<th>No.</th>
<th>Recommendation</th>
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| 1   | NHS England Specialised Commissioning Teams are recommended to take the findings for each of the services reviewed into account in their commissioning and contract monitoring for 2017/18 and beyond. In particular, commissioners should review:  
  - The designation of all specialist centres, especially those with low or very high patient numbers. Where patient numbers are very high, designation of additional specialist centres should be considered.  
  - The hospitals which are acting as Linked Centres, to be assured that networking roles and responsibilities are documented and supported by appropriate governance arrangements such as Service Level Agreements.  
  - The pathways for referral for patients with complications |
<p>| 2   | When planning services, commissioners and business planning in Trusts should take account of trends in populations of patients with haemoglobin disorders, including trends in the number of patients transitioning from paediatric to adult services. |
| 3   | The Clinical Reference Group should offer advice to support tariffs’ development appropriate for the different levels of care, including network-wide responsibilities. |
| 4   | NHS England Specialised Commissioning Teams working with Clinical Commissioning Groups should clarify the haemoglobin disorders clinical network arrangements for all acute Trusts in their areas. |
| 5   | NHS England Specialised Commissioning Teams should ensure Specialist Haemoglobinopathy Centres are fulfilling their network-wide responsibilities. |</p>
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<tr>
<th>No.</th>
<th>Recommendation</th>
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<tr>
<td>6</td>
<td>Trusts should ensure that specialist haemoglobinopathy teams have appropriate resources to fulfil their network-wide responsibilities, including clinical time and data collection support.</td>
</tr>
<tr>
<td>7</td>
<td>The UK Forum on Haemoglobin Disorders should develop a central, on-line patient information resource.</td>
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<tr>
<td>8</td>
<td>Clinical networks and SHCs should ensure patient information is available to Linked Centres and local hospitals and should continue to improve systems for patient feedback.</td>
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</tbody>
</table>
| 9   | As a matter of urgency Health Education England should review its plans for future staffing of services for people with haemoglobin disorders, including:  
  a. Number of consultants needed  
  b. Number of specialist nurses needed and the availability of post-registration specialist training, including outside London |
| 10  | Health Education England should review the training of junior haematologists to ensure they are gaining appropriate experience in the care of people with haemoglobin disorders. |
| 11  | Trusts should review the job plans of senior medical and nursing staff working in services for people with haemoglobin disorders to ensure these adequately reflect the responsibilities of the post, including network-wide responsibilities. |
| 12  | Trusts should review the staffing of their specialist haemoglobinopathy teams to ensure:  
  a. A sustainable workforce plan is in place  
  b. The service has sufficient time allocated from a psychologist with experience in the care of people with haemoglobin disorders  
  c. The service has appropriate administrative and data collection support, including for network-wide responsibilities |
<p>| 13  | The Royal College of Nursing should review the competences expected for nurses providing care for people with haemoglobin disorders. |
| 14  | Trusts should review the support available from neuropsychology, play specialists, social workers and benefits advisers to ensure these are sufficient for the needs of people with haemoglobin disorders. |
| 15  | Each clinical network should have arrangements for the provision of automated apheresis and emergency manual exchange, ensuring all patients have access to these services. |
| 16  | NHS England should address the issue of access to ‘out of hours’ transfusion and phlebotomy in the updated service specification for specialist haemoglobinopathy services. |
| 17  | Trusts should ensure that appropriate clinical guidelines are in place and updated regularly. |
| 18  | The UK Forum on Haemoglobin Disorders should develop a central, on-line repository or clinical guidelines. |
| 19  | The UK Forum on Haemoglobin Disorders should explore the reasons for the surprising level of variation in clinical thresholds. |</p>
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<tr>
<th>No.</th>
<th>Recommendation</th>
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<tr>
<td>20</td>
<td>Specialist and local centres should audit their adherence to national guidance on transfusion and other disease modifying therapies.</td>
</tr>
<tr>
<td>21</td>
<td>Trusts should monitor ‘did not attend’ rates and introduce mechanisms to tackle high rates. As part of this work, Trusts should consider measures to reduce fragmented and multiple service provision in order to improve attendance rates.</td>
</tr>
<tr>
<td>22</td>
<td>The UK Forum and Clinical Reference Group should discuss with patient groups measures which could be used to increase adherence to treatment and reduce the number of patients who do not have contact with a Specialist Centre.</td>
</tr>
<tr>
<td>23</td>
<td>Trusts should introduce multi-disciplinary meetings to discuss the care of patients with haemoglobin disorders, where these are not already in place.</td>
</tr>
<tr>
<td>24</td>
<td>Trusts should ensure all patients with haemoglobin disorders have an annual review which is recorded on the NHR. All patients should be registered on the NHR and adverse events should be reported to it. (NB. This recommendation links with the recommendation about adequate resourcing of specialist teams, including data collection support).</td>
</tr>
<tr>
<td>25</td>
<td>NHS England specialised commissioning teams should continue to assess providers against the service specification and should review compliance with the Quality Standards as part of their on-going quality monitoring arrangements.</td>
</tr>
<tr>
<td>26</td>
<td>Trusts should review the sustainability of their transcranial Doppler screening services.</td>
</tr>
<tr>
<td>27</td>
<td>The UK Forum on Haemoglobin Disorders should complete its work on standards and quality assurance for TCD scanning, including expected competences and training implications. The UK Forum should work with Public Health England on the recognition of TCD scanning as a national screening programme.</td>
</tr>
<tr>
<td>28</td>
<td>Public Health England should consider whether the TCD scanning programme should be included in the national screening programmes and whether Public Health England should therefore take on responsibility for on-going quality assurance.</td>
</tr>
<tr>
<td>29</td>
<td>Trusts should review and further improve their arrangements for transition from paediatric to adult care.</td>
</tr>
<tr>
<td>30</td>
<td>Trusts should audit their services against the NICE Standards for pain relief in sickle crisis and take action to improve compliance with these standards.</td>
</tr>
<tr>
<td>31</td>
<td>Clinical Commissioning Groups should ensure that access to community-based support for people with haemoglobin disorders is available.</td>
</tr>
<tr>
<td>32</td>
<td>Community services are considered to be an important part of the care pathway and the national service review should take the opportunity to define more clearly the role of such services.</td>
</tr>
<tr>
<td>33</td>
<td>A specialist centre for the care of adults with haemoglobin disorders in Ireland should be developed.</td>
</tr>
<tr>
<td>No.</td>
<td>Recommendation</td>
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<tr>
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</tr>
<tr>
<td>34</td>
<td>A clinical network for the care of adults with haemoglobin disorders in Wales should be developed with the aim of ensuring all adults with these conditions have access to appropriate specialist and local care.</td>
</tr>
<tr>
<td>35</td>
<td>An on-going rolling programme of peer review of services for people with haemoglobin disorders should be established. This could take place over three to five years with services completing a self-assessment every year and having an actual visit every three to five years, unless major concerns indicate the need for an earlier visit.</td>
</tr>
<tr>
<td>36</td>
<td>The Quality Standards for Health Services for People with Haemoglobin Disorders should be updated to reflect latest national guidance and as a result of experience of using them in the 2014/16 peer review programme.</td>
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<tr>
<td>------------------------------------------------------------------------</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td>Did the preparation for the visit to your own organisation lead to changes in the services provided?</td>
<td>Improvement or Significant Improvement</td>
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<tr>
<td>Was the peer review visit to your own organisation a helpful or unhelpful experience?</td>
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<tr>
<td>Did the report of the visit give a fair reflection of the services at your own organisation at the time of the visit?</td>
<td>Fair or Very Fair</td>
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<tr>
<td>Was the experience of being a reviewer useful in developing your own services?</td>
<td>Useful or Very Useful</td>
</tr>
<tr>
<td>Has your organisation been able to address the ‘immediate risks’ (if any) and ‘concerns’ identified in the visit report?</td>
<td>Addressed in full or nearly addressed</td>
</tr>
<tr>
<td>Has the peer review process overall been useful to your organisation in improving services?</td>
<td>Useful or Very Useful</td>
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**Key**
- CIC  Care of critically ill and injured children
- Haem  Services for children and young people with sickle cell disease or thalassaemia (2010/11); Services for adults with haemoglobin disorders (2012/13); Services for people with haemoglobin disorders (all ages) (2014 to 2016).
## APPENDIX 1  SERVICES REVIEWED

**KEY:**

- **Days:** The number of days over which the review took place
- **Review Team Days:** The number of review teams involved in each visit. For example, a one day visit with an adult and paediatric team would count as two ‘review team days’

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<th>Review date</th>
<th>Days</th>
<th>Review Team Days</th>
<th>Adult Service</th>
<th>C&amp;YP Service</th>
<th>Abbreviation in text</th>
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## Appendix 2  Steering Group Membership

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<thead>
<tr>
<th>Name</th>
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</thead>
<tbody>
<tr>
<td>Dr Jo Howard</td>
<td>Consultant Haematologist – Joint Clinical Lead for Peer Review Programme</td>
<td>Guy’s and St Thomas’ NHS Foundation Trust</td>
</tr>
<tr>
<td>Dr Josh Wright</td>
<td>Consultant Haematologist – Joint Clinical Lead for Peer Review Programme</td>
<td>Sheffield Teaching Hospitals NHS Foundation Trust</td>
</tr>
<tr>
<td>Dr Banu Kaya</td>
<td>Consultant Paediatric Haematologist – Joint Clinical Lead for Peer Review Programme</td>
<td>Barts Health NHS Trust</td>
</tr>
<tr>
<td>Dr Subarna Chakravorty</td>
<td>Consultant Paediatric Haematologist – Joint Clinical Lead for Peer Review Programme</td>
<td>King’s College Hospital NHS Foundation Trust</td>
</tr>
<tr>
<td>Dr Kate Ryan</td>
<td>Consultant Haematologist</td>
<td>Central Manchester University Hospitals NHS Foundation Trust</td>
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<tr>
<td>Dr Anne Yardumian</td>
<td>Consultant Haematologist</td>
<td>North Middlesex University Hospital NHS Trust</td>
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<tr>
<td>Joanne Bloomfield</td>
<td>Specialist Nurse &amp; Manager</td>
<td>Nottingham Sickle Cell and Thalassaemia Service</td>
</tr>
<tr>
<td>Neill Westerdale</td>
<td>Advanced Nurse Practitioner</td>
<td>Guy’s and St Thomas’ NHS Foundation Trust</td>
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<tr>
<td>Natasha Lewis</td>
<td>Lead Nurse - Sickle Cell &amp; Thalassemia</td>
<td>Homerton University Hospital NHS Foundation Trust</td>
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<tr>
<td>Louise Smith</td>
<td>Sickle Cell Clinical Nurse Specialist</td>
<td>Alder Hey Children’s NHS Foundation Trust</td>
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<tr>
<td>Heather Rawle</td>
<td>Clinical Psychologist</td>
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<tr>
<td>John James</td>
<td>Chief Executive</td>
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<tr>
<td>Penelope Cream</td>
<td>Clinical Psychologist</td>
<td>St George’s University Hospitals NHS Foundation Trust</td>
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<tr>
<td>Claire Foreman</td>
<td>Senior Programme of Care Manager – Blood &amp; Infection Specialised Commissioning</td>
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<tr>
<td>Elaine Miller</td>
<td>Co-ordinator - Voluntary Sector Representative</td>
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<td>Jane Eminson</td>
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<tr>
<td>Sharon Ensor</td>
<td>Director</td>
<td>KeyOpps Ltd on behalf of West Midlands Quality Review Service</td>
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<tr>
<td>Pip Maskell</td>
<td>Director</td>
<td>KeyOpps Ltd on behalf of West Midlands Quality Review Service</td>
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APPENDIX 3  QUALITY STANDARDS AND REVIEW PROCESS

196 Quality Standards, suitable for use in quality reviews, are fundamental to the clinical review processes used by WMQRS. They are also useful for services to monitor their own progress toward implementation of best practice guidance. Quality Standards are usually measures of structure and process quality (rather than outcomes) but include a) processes of collecting and using data on outcomes and b) processes for collecting information on patient and carer experience and for involving patients and carers in improving the service and care pathway. Quality Standards aim to ensure implementation of national guidance and follow the patient. They reflect the latest national guidance and help to answer the question “If I walk into a service, how will I know that best-practice guidance has been implemented?”. National guidance on which the standards are based is given in an appendix. Where evidence-based guidance is not available, Quality Standards are based on a consensus of professional and service users’ and carers’ views.

197 The Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies were developed between 2006 and 2008 and were used for a pilot visit to the Royal London Hospital in 2007 and for visits to 19 hospitals across England in 2010-11.

198 Development of Quality Standards for Adult Services took place during 2010 and 2011 through a sub-group of both the UK Forum on Haemoglobin Disorders and the West Midlands Quality Review Service. Lessons learnt from the paediatric peer review process were taken into account. Some of the detail of the paediatric Quality Requirements was removed and there was a greater emphasis on outcomes and audit. Version 1 of the Quality Standards for Health Services Caring for Adults with Haemoglobin Disorders (July 2012) were used for the 2012-13 peer review programme.

199 Between 2013 and 2014 the steering group developed a single set of standards for a joint paediatric and adult peer review programme. The resulting Quality Standards (V2, 2014) were largely modelled on the adult programme (2012-2013). The majority of the standards were applicable to services for all patients with the addition of some paediatric specific standards on transcranial Doppler screening programmes and school care plans.

200 The new standards recognised the increasing importance of networks and the commissioning process and sought to clarify the referral pathways for the large number of hospitals with small patient populations.

201 The section on network standards was added to the Quality Standards in 2012 and was retained in the latest version with the aim of formalising adult haemoglobinopathy networks across the UK. The Quality Standards aimed to ensure that all commissioners and providers of care, including voluntary sector organisations and local authorities within the network, work effectively together to deliver high quality care for patients with sickle cell and thalassaemia. Quality Standards for haemoglobinopathy networks covered:

- Establishment of an effective network management group which will develop and implement the strategy for the network in line with national policy.
- Clear leadership of the network with adequate time and support being given to the network lead clinician, network lead nurse and network manager.
- Agreement and implementation of network-wide policies and pathways of care

202 These network standards can be achieved in a variety of ways. Low prevalence areas are likely to have one Specialist Team which will also act as the focus for the work of the network. Some high prevalence areas, particularly in Greater London, have sufficient patient numbers for several Specialist Teams to
work together, and with hospitals providing local care closer to home, to achieve the network standards.

203 The Quality Standards apply to Specialist and Local Teams caring for adults with haemoglobin disorders and their commissioners. The Quality Standards for Specialist and Local Teams covered:
a. Information and Support for Patients and their Carers  
b. Staffing  
c. Support Services  
d. Facilities and Equipment  
e. Guidelines and Protocols  
f. Service Organisation and Liaison with other Services  
g. Governance

204 Visiting teams were made up of service and carer user representatives, consultants (adult and paediatric haematologists and paediatricians), specialist nurses and, when possible, a psychologist, a non-clinical manager or a commissioner. Each team consisted of between six and eight reviewers. Each visit was led by a consultant member of the Peer Review Steering Group (Appendix 2) with one of the adult (Dr Jo Howard or Dr Josh Wright) and paediatric (Dr Banu Kaya or Dr Subarna Chakravorty) clinical leads attending the majority of visits to ensure consistency of approach and interpretation between visits. Hospitals within the same network were reviewed by the same clinical leads where possible.

205 Chief Executives of all Trusts to be visited agreed that their service could be included in the review programme. All visited teams were given at least three months’ notice of the date of their review visit. Each visit lasted one or two days (if more than one centre was reviewed at a single visit) and included a review of written documentation, including some sets of medical records, a meeting with users and their families, 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. Appendix 1 gives the dates of each review visit.

206 Reviewers and the service 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.wmqrs.nhs.uk
APPENDIX 4 GLOSSARY OF TERMS AND ABBREVIATIONS

The terminology from the NHS England National Programme of Care Blood and Infection subgroup F05 haemoglobinopathies, Welsh Health Specialist Services Committee (WHSCC) (Appendix 4) and the Scottish Haemoglobinopathies Managed Clinical Network for Paediatric and Adult services (http://nsd.scott.nhs.uk) is applicable to this document.

Other terms used in this report are:

**Community Care or Community Teams:** Community-based education and support to service users and carers in self-management of long term conditions. These teams also facilitate access to community health services, and social care, and provide support for local user groups.

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

**Specialist Haemoglobinopathy Centre (SHC):** A multi-disciplinary team providing specialist care for people with haemoglobinopathies, including annual review and specialist monitoring for patients from across the clinical network. The SHC provides leadership for a geographical area network.

**Accredited Local Haemoglobinopathy Team (ALHT):** A team that is able to deliver some specialist functions in liaison with the SHC as well as providing Local Haemoglobinopathy Team care. Specialist functions that might be delivered include annual review and hydroxycarbamide initiation and monitoring.

**Local Haemoglobinopathy Team (or Linked Providers) (LHT):** A team providing local care for people with haemoglobinopathies under the guidance of the Specialist Team, including routine out-patient management, regular blood transfusions, and the management of uncomplicated pain crises and other relatively straightforward complications.

**Abbreviations:**

Abbreviations of Trust names can be found in Appendix 1.

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALHT</td>
<td>Accredited Local Haemoglobinopathy Centre</td>
</tr>
<tr>
<td>C</td>
<td>Concerns</td>
</tr>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
</tr>
<tr>
<td>CQUIN</td>
<td>Commissioning for Quality and Innovation</td>
</tr>
<tr>
<td>DNA</td>
<td>Did Not Attend</td>
</tr>
<tr>
<td>FC</td>
<td>Further Consideration</td>
</tr>
<tr>
<td>IR</td>
<td>Immediate risks to clinical safety and clinical outcomes</td>
</tr>
<tr>
<td>LHT</td>
<td>Local Haemoglobinopathy Team (or Linked Providers)</td>
</tr>
<tr>
<td>MDT</td>
<td>Multi-disciplinary Team</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
</tr>
<tr>
<td>NCA</td>
<td>Nurse Controlled Analgesia</td>
</tr>
<tr>
<td>NCEPOD</td>
<td>National Confidential Enquiry into Patient Outcome and Death</td>
</tr>
<tr>
<td>NHR</td>
<td>National Haemoglobinopathy Registry</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>PCA</td>
<td>Patient Controlled Analgesia</td>
</tr>
<tr>
<td>QS</td>
<td>Quality Standard</td>
</tr>
<tr>
<td>SCD</td>
<td>Sickle Cell Disease</td>
</tr>
<tr>
<td>SHC</td>
<td>Specialist Haemoglobinopathy Centre</td>
</tr>
<tr>
<td>TCD</td>
<td>Transcranial Doppler</td>
</tr>
<tr>
<td>WMQRS</td>
<td>West Midlands Quality Review Service</td>
</tr>
</tbody>
</table>
APPENDIX 5  EVALUATION

REVIEWERS’ VIEWS

Evaluations were issued to 264 reviewers and 87 responses were received, giving a response rate of 33%.

Reviewers’ Comments 2014/16:

INFORMATION RECEIVED BEFORE THE VISIT

Positive:
- Gave working insight (1)
- Info received in good time (4)
- Clear information (3)
- Logistical info (4)
- Good documentation (4)
- Comprehensive (2)

Negative:
- Info not sent to normal email address (1)
- Late information (1)
- Not enough clinical info from hospital (1)
- Difficulty finding location (Wolverhampton) (1)

Suggested improvements:
- Seeing previous peer review report (2)
ORGANISATION OF THE VISIT

Positive:
- Well organised (2)
- Trust organisation (1)
- WMQRS organisation (1)
- Staff (4)
- Welcome (5)
- Dinner (2)

Negative:
- Timekeeping (4)
- Trust organisation (1)
- Taxis (3)
- Telephone conference organisation (1)

RECORDING FORM

Positive:
- Easy to understand (2)
- Helpful (1)

Suggested improvements:
- Larger font size (1)

VISIT OVERALL

Went well:
- Whole day (8)
- Organisation (11)
- Timekeeping (5)
- Admin (1)
- Lead (6)
- Staff enthusiastic/friendly/welcoming (6)
- Attendance (4)
- Teamwork (6)
- Feedback (3)
- Evidence (3)
- Amount of service users (1)
- Trust hospitality (5)
- Overview (1)
- Venue/signposting (2)
- Meeting patients/parents (2)
- Meetings (1)

Went less well/badly:
- Nothing (6)
- Time restraints (6)
- Telephone conference (2)
- No patients attended/came late (3)
- Venue/signposting (4)
- Very long day (3)
- Schedule complex (3)
- Evidence difficult to find (2)
- Refreshments (1)
- Lack of some positions (Senior Trust Representative and Commissioner) (1)
- Paeds lead unsure (1)
- Patient notes (1)
- Not much achieved since last review (1)

**Suggested improvements:**
- More reviewers (as 2 sites) (1)
- More drinks throughout day (1)
- More notice of visit (1)
- Have adult and paed services on different pages (1)
- Too much in too little time (2)
- Guidance to the level of evidence expected (2)
- More time for patients (1)
- Less time on other services in hospital (respiratory, orthopaedics) (1)
- Visit on one site unless real advantage to seeing more than one site (1)
- Trust fund own review (travel) (1)
- Do not need to review mandatory training (1)
- Keep to timetable (1)
- Transition pathway clearer (1)

**TRUST VIEWS**

Trust evaluations were issued to 30 Trusts. Fifteen responses (relating to 13 Trusts) were received, giving a response rate of 43% (based on 13 Trusts).

---

**INFORMATION RECEIVED BEFORE THE VISIT**

**Negative:**
- Confusing (different messages from different sources) (1)
- Self-assessment – difficult to fill in (1)
- Adult and paeds on one spreadsheet, difficult to navigate (1)
ORGANISATION OF THE VISIT

Negative:
- Time restraints (1)
- No Wifi – and no printouts (1)
- Skewed team (no nurse or adult haematologist) (1)

VISITING TEAM

Positive:
- Pleasant (2)

Negative:
- Lots of paeds feedback, not much adult (1)
- Two reviewers missing so rushed (1)
- Unsure if one person was a patient or carer (2)

VISIT OVERALL

Went well:
- Whole day (4)
- Timekeeping (4)
- Good feedback (balanced) (4)
- Everyone helpful, friendly, professional (3)
- Flexible (1)
- Detailed information (1)
- Good organisation between Trust and WMQRS (1)

Went less well or badly:
- Staff felt that some questioning had been persistent and aggressive (1)
- Staff felt uncomfortable (1)
- Felt reviewers did not believe the answers given and so asked other staff (1)
- Some inappropriate questions (nationality of staff) (1)
- Time constraints (2)
- Did not feel collaborative (1)
- Transport between sites (taxi’s fault) (1)
- Set up of the notes was frustrating for reviewers (1)
- Reviewers showed little interest in tours (1)
- Nursing staff felt they weren’t given the chance to explain what they did (1)
- A lot of new reviewers (1)
- Timetable changes (3)
- Unsure who to contact with questions (1)
- Miscommunication about how much information required (1)

Suggested improvements:
- Do adult and paediatric review on different days (1)
- More of a mix of new and experienced reviewers (1)
- Minimise timetable changes (1)
- Have a single point of contact between Trust and WMQRS (2)
- Spend time with the team going through evidence supplied (1)
OVERALL EVALUATION

Overall evaluations were issued to 30 Trusts. Twenty-two responses (relating to 18 Trusts) were received, giving a response rate of 60% (based on 18 Trusts). A table showing 2014/16 results and comparisons with other review programmes is included in the main report.

PRE-VISIT SUPPORT FROM WMQRS

- Documentation useful (1)
- Smooth process due to designated contact (1)
- Queries answered timely (1)
- No revisit support given (1)
- Staff changes did not make process easy (1)

DID THE PREPARATION FOR THE VISIT LEAD TO CHANGES IN THE SERVICES PROVIDED BY THE TRUST?

- Improved documentation/procedures/guidelines (3)
- Examination of what do and why (1)
- Identified things would like to change (1)
- Plan to implement change (1)
- Closer team working (1)
- Audits completed quicker (1)
- Help from research nurse with on-going audits (1)
- Better NHS England engagement (1)
- Already developing and improving service independently of peer review (1)

WAS THE ACTUAL VISIT A HELPFUL OR UNHELPFUL EXPERIENCE FOR STAFF WITHIN THE TRUST?

- Very useful (1)
- Helpful feedback (1)
- Lot of work pre-visit (distracted from clinical duties) (2)
- Profile raising (2)
- Confirmed strengths and weaknesses (1)
- Sensible way forward outlined (1)
- Encouraged other departments too (1)
- Good to reflect on changes since last visit (1)
- Should be done every 4-5 years (1)

DOES THE REPORT OF THE VISIT GIVE A FAIR REFLECTION OF YOUR SERVICES AT THE TIME?

- Initial draft:
  - did not reflect service (2)
  - contained multiple inaccuracies (1)
  - critical and morale damaging (1)
- Final report:
  - Fine (1)
  - Reflected Trust comments (1)
  - Acceptable but not entirely fair reflection – better to have had separate visits and reports and subsequent regional synopsis (1)
  - Yes, once corrected (after challenging three times) (1)
  - Liked having adults and paediatrics together (1)
  - Focussed too much on small things not met than big things met (1)
  - Not able to reflect changes to be made from forthcoming move to new hospital (1)
Overall very fair. Occasionally measures marked differently for adult and paediatrics though doing the same thing (1)

HAVE YOU BEEN ABLE TO ADDRESS THE ‘IMMEDIATE RISKS’ (IF ANY) AND ‘CONCERNS’ IDENTIFIED IN THE REPORT OF THE VISIT TO YOUR SERVICES?

Examples of changes made as a result of the visit:
- Transition process started/improved (2)
- Upskilling nurses to perform phlebotomy and cannulation (1)
- Initiated rolling programme of nursing & medical training in ED (1)
- More allocated social worker time (1)
- Re-alignment of paediatrics (1)
- Further development of nursing infrastructure (1)
- Funding for automated apheresis (1)
- Funding for psychologist (1)
- Funding for data manager (1)
- Dedicated part-time psychologist (1)
- Becoming official regional centre (1)
- Using network guidelines (1)
- Network now formalised (1)
- Revisited guidelines / rewritten guidelines (2)
- Draft transition guidelines (1)
- Better planned transitions clinics (1)
- Performing automated exchanges (purchased 2 optia machines) (1)
- Discussions in progress (1)
- Identified guidelines not available in Scotland which now addressing (1)
- Improvements in nursing provision being actively pursued with management (1)
- Change to 2 annual reviews per clinic with MDT input (1)
- Attending meetings with screening group at least yearly (1)
- Started regular mother and toddler and transitions sessions (1)
- More education of staff (1)
- Changes to practices in paediatric day unit (1)
- Adult and paediatric networks set up with better defined roles (1)

Areas that have proved very difficult to address:
- Increased staffing (2)
- Job plans (1)
- Nurse led clinics (1)
- Neonatal screening (1)
- Data management (2)
- Training ‘peripheral’ staff (1)
- Changes taking a lot of time (1)
- Psychology support (2)
- Appointment of lead consultant in haemoglobinopathy (1)
- Community nursing (1)
- AED training (1)
- TCD services require review (1)
- Writing of guidelines (2)
- Access to comprehensive & timely care within ED/Obs departments (1)
HAS THE INVOLVEMENT OF REVIEWERS FROM YOUR ORGANISATION IN VISITS TO OTHER PLACES BEEN HELPFUL IN IMPROVING YOUR OWN SERVICES?

- Yes (2)
- Benchmarking helpful (1)
- Good practice sharing helpful (2)
- Seeing barriers to development (1)
- Seeing how others solve problems (1)
- Reassurance (2)
- Now know need to engage commissioners more (1)
- Gained ideas about improving transition (1)
- Highlighted areas for improvement and actions plan written (1)

IF YOU ALSO ACTED AS A REVIEWER: WAS THE EXPERIENCE OF BEING A REVIEWER USEFUL TO DEVELOPING YOUR OWN SERVICES?

- Invaluable preparation for own review (1)
- See what others are doing (3)
- Hear patient views about service (1)
- Reassuring (1)
- Strengthened relationships with colleagues (1)

HAS THE PEER REVIEW PROCESS OVERALL BEEN USEFUL IN IMPROVING SERVICES IN YOUR LOCALITY?

- Trust listening more (2)
- Reassurance (1)
- Lots of ideas (1)
- Lack of resources/time so not much change (1)
- Benchmarking particularly beneficial (as only comprehensive centre in Ireland) (1)
- Helped focus on improvements needed (1)
- Guidance on functioning of network useful (1)
- Reports used as basis of how to improve services in region (1)

ANY OTHER COMMENTS ABOUT THE QUALITY STANDARDS OR PEER REVIEW PROCESS?

- Whole team visited all areas – inefficient time management (1)
- Needs another cycle in 3-4 years (1)
- Useful in all aspects (1)
- Bringing whole group everywhere raised profile of audit (1)
- Limited time (not in depth) (1)
- Good standard of visit (1)
- WMQRS accommodating (telephone feedback next day) (1)
- More appreciative of standards achieved locally (1)
- Management teams more aware of service and it’s needs (1)
- Standards comprehensive and appropriate (1)
- Clearer guidance needed on evidence required (1)
- More systematic review of evidence (1)
- Possibly review adults and paediatrics separately next time (1)