WM QRS West Midlands Quality Review Service

UK Forum on Haemoglobin Disorders

Services for Adults with Haemoglobin Disorders

Peer Review Programme 2012-13 Overview Report

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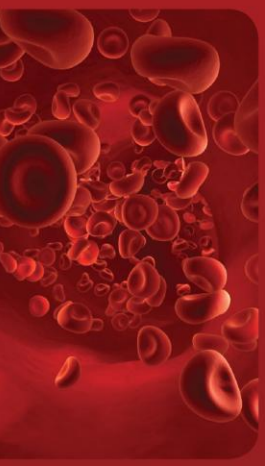

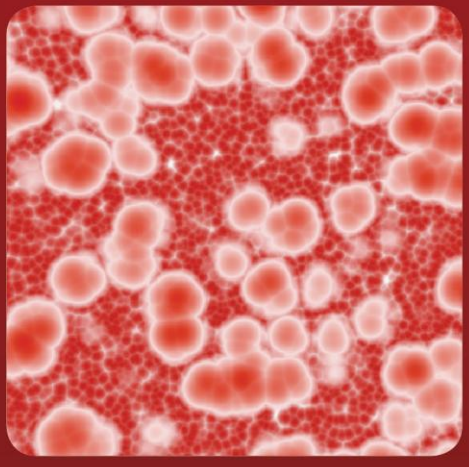

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SUMMARY

1 This report summarises the findings of the peer review visits to services for adults with haemoglobin disorders in England. Visits to 29 hospitals delivering services for adults with sickle cell disease and / or thalassaemia took place during 2012 and 2013. The primary purpose of the programme was developmental, aiming to improve the quality of services for adults with the haemoglobin disorders, sickle cell disease and thalassaemia.

2 Sickle cell disease 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. It is estimated that around 800 children and adults in England have major thalassaemias and approximately 15,000 have sickle cell disease.

3 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 70% of sickle cell disease (SCD) patients live. The NHS Sickle Cell and Thalassaemia Screening Programme reports that approximately 360 affected babies are born each year. Affected babies are born in all regions of England but approximately 70% are in London. Data gathered by this peer review programme indicate that the London-centred networks manage approximately 80% of adults. Areas such as the north-east and south-west of England have much lower prevalence.

4 Geographical distribution of transfusion-dependent thalassaemia is different from that of SCD, reflecting the different communities in which these disorders are encountered. There is high prevalence of thalassaemia in North and East London, West Midlands, North West England and Yorkshire, in contrast to South London which has relatively few patients.

5 Adults with sickle cell disease are at risk of both acute and chronic complications, the latter becoming more common with increasing age. Problems encountered during childhood such as acute stroke, recurrent infections and psychosocial issues need continuing care in adulthood and pose additional issues for adult management in a population that is often in further education and entering work. Chronic complications such as renal disease, chronic cardio-respiratory disease and bone and joint problems are common in adults and require specialist management. Pain continues to be a problem for all ages.

6 Adults with thalassaemia major and severe intermedia syndromes require blood transfusions every three to four weeks for life. This results in an overload of iron in the body that is harmful, and usually fatal by mid-teens, unless appropriately managed. Standard monitoring for iron overload now includes MRI imaging of the liver and heart. Issues of adherence to treatment are important at all ages.

7 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 with the implementation of national specialist commissioning for these disorders from 2013.

8 A need for service improvement had been highlighted by several policy pronouncements and recommendations, including 'The NHS Plan' (2000), the National Confidential Enquiry (2004-2006) into Patients' Outcomes and Deaths (NCEPOD) Report "A Sickle Crisis?" (May 2008), a Department of Health sponsored review of haemoglobinopathies (Darbyshire, 2009) and the All-Party Parliamentary Group for Sickle Cell and Thalassaemia. Discussions at the Department of Health (DH) Clinical Services Development Group and the UK Forum for Haemoglobin Disorders then set the grounds for a peer review of services for haemoglobinopathies across the NHS in England, beginning with paediatric services in 2010. Lessons learnt from the paediatric reviews were taken into account in the planning the adult services review programme. Some of the detail of the paediatric Quality Standards was removed and there was a greater emphasis on outcomes and audit. Recommendations of the DH funded "National Haemoglobinopathies Project: a guide to

effectively commissioning high quality sickle cell and thalassaemia services" (NHS EMSCG, July 2011) were also taken into account.

9 National recommendations are that services should be provided within geographical area networks by Specialist Haemoglobinopathy Teams [SHTs] (also called Specialist Haemoglobinopathy Centres (SHCs),supported by Local Haemoglobinopathy Teams [LHTs] providing much of the planned care. In addition, some LHTs can be accredited to provide some of the specialist functions, for example, annual reviews, hydroxycarbamide initiation and monitoring in liaison with the Specialist Team. These accredited local teams (A-LHTs) are likely to be the very large local teams, mostly in Greater London. This peer review programme found that the organisation of specialist and local teams is based on the number of patients and on historical referral patterns and clinical links, with few formalised clinical networks. Although the 32 teams reviewed during the 29 visits were thought to care for the majority of adults with haemoglobin disorders in England, an unknown number of adults are cared for by haematology teams in hospitals which did not link to a Specialist Team or are not part of an established network of care.

10 In every hospital visited there were key staff members who were remarkably committed to providing high quality care, often in very difficult circumstances. The number of consultant and specialist nurse sessions bore very little relationship to the number of adults cared for by the service. For some teams the workload of the specialist staff was unreasonably high and the provision of consistently good quality care was not feasible. In several hospitals, a single consultant worked with a single specialist nurse, who often had additional responsibilities outside the adult haemoglobinopathy service.

11 Adults admitted with acute complications often had their care managed by non-haematology staff outside normal working hours, although haematology staff were usually on call to give advice. Whilst doctors in training were often involved in the care of adults with haemoglobin disorder, in low prevalence areas they did not gain a lot of experience. Collaboration with paediatric haematology teams to improve the transition to adult care was in place in some but not all services.

12 Cooperation between acute and community nursing teams was sometimes very good but this was not universal. The availability of social work and psychology support was variable despite the important contribution of these disciplines to the care of adults with haemoglobin disorders, with the majority of SHTs having no access to a named social worker or a specific psychologist. Psychology support is key to achieving adherence to treatment for both conditions and in enabling adults to cope with their condition.

13 Several teams had made strenuous efforts to make care responsive to the needs of adults with haemoglobin disorders with some examples of excellent practice including weekend day care and community pain care. Some problems were common, however, including delays in the administration of analgesia for adults presenting with painful sickle crisis in emergency departments and a perception by the patients that their needs were not being taken into account, particularly by non-haematology staff. Some Trusts were not always able to offer planned care outside further education or working hours and so many adults, on monthly transfusions, were missing about one and a half days of education or work every month, or had to take annual leave to attend appointments.

14 Over 80% of patients were being looked after in London where teams were extremely variable and available services were not necessarily related to the number of patients being treated at a given hospital. Length of stay and admission rates varied considerably for sickle cell patients in crisis although this, in part, reflected some very frequent attenders.

15 Some services were provided from excellent facilities. Others were, however, based in premises that were dilapidated or unfit for purpose, with issues ranging from a lack of space through to a lack of basic equipment.

16 The National Haemoglobinopathy Registry provides a means of monitoring the number of affected adults in a clinical centre, for adverse event recording and for demonstrating compliance with key standards of clinical

care. None of the teams reviewed had entered all of their patients onto the Register, although many were well advanced. A lack of data administration support was a common barrier to data collection. Few teams were reporting annual reviews on the National Registry and none were reporting annual reviews on all their patients.

17 Only 12 of the 32 teams reviewed had completed all the expected audits of clinical care for the adult patients managed at their Centre, and no Specialist Team could provide audit data covering the whole of their clinical network.

18 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.

19 Although a Specialised Service National Definition Set was agreed in 2009 for Specialised Haemoglobinopathy Services, most commissioners were not yet actively commissioning these services. Some commissioning work which had been taking place was affected by the move to commissioning by NHS England and major changes in commissioning personnel that occurred during 2012/13.

20 Throughout the reviews, there was little evidence of planning for service expansion. In several areas there are large numbers of children on transfusion regimes, which will put pressure on adult services as they transition to adult care. Already stretched teams will be further pressurised as the ageing haemoglobinopathy patient population develop increased complications of their chronic disease and increasingly complex health needs.

21 This report makes several recommendations which, when implemented, will improve the quality of care for adults with haemoglobin disorders. Central to these recommendations is more active commissioning, including defining clinical networks and monitoring of key process and outcome metrics.

22 The care of people with haemoglobin disorders is now an important issue for public health and for the NHS in England. These conditions are common in some parts of the country and sometimes life-threatening. They alter every aspect of the lives of affected people. Good care enables people with haemoglobin disorders to live longer and improves their quality of life. Good care also reduces disease complications, in particular stroke and hospital admissions.

INTRODUCTION

NATIONAL CARE STANDARDS

23 The main national guidance on the care of people with haemoglobin disorders is listed in Appendix 2.

24 'Standards for the Care of Adults with Sickle Cell Disease' were written by the UK Forum on Haemoglobin Disorder and the NHS Sickle Cell and Thalassaemia Screening Programme, jointly with the Sickle Cell Society, and published in 2008. These Standards were produced by groups of professional and service users who wanted to see access to high quality care for all those affected by haemoglobin disorders.

25 'Standards for the care of children and adults with thalassaemia in the UK' was written by the UK Thalassaemia Society in 2005, 2nd edition 2008. These Standards were produced by groups of professional and service users who wanted to see access to high quality care for all those affected by haemoglobin disorders.

26 'Caring for people with sickle cell and thalassaemia syndromes – a framework for nursing staff' was published by the Royal College of Nursing in 2011. This emphasises the role of the specialist nurse in caring for patients and also education for all nurses managing people with these disorders.

27 The UK Forum on Haemoglobin Disorders, the Sickle Cell Society, the UK Thalassaemia Society and the NHS Sickle Cell and Thalassaemia Screening Programme agreed that a peer review programme would be useful - to help teams work towards meeting the National Care Standards and to monitor the extent to which Standards were being implemented. The peer review programme for paediatric services was completed in 2011. The adult programme followed on from this and visits took place between April 2012 and April 2013.

TERMINOLOGY

28 The terminology from the National Definition Set Definition No. 38 *Specialised Haemoglobinopathy Services (all ages)* 3rd Edition refers to Specialist Haemoglobinopathy Teams, Local Teams and Community Care (Appendix 3).

29 The Model Service Specification for Specialised and Accredited Haemoglobinopathy Care (2011) referenced three types of specialist providers:

SHT: Specialist Haemoglobinopathy Team (or designated provider): The multi-disciplinary team providing specialist care for adults with haemoglobinopathies, including annual review and specialist monitoring for patients from across the clinical network. The SHT provides leadership for the geographical area network.

A-LHT Accredited Local Haemoglobinopathy Team: The team that is able to deliver some specialist functions in conjunction with the SHT as well as that care provided by the LHT. An example of a specialist function that might be delivered is annual review.

LHT Local Haemoglobinopathy Team (or Linked Providers): The team providing local care for adults 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.

30 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.

QUALITY STANDARDS

31 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.

32 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 (WMQRS). 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.

33 A section on network standards was included, in line 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

34 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.

35 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

PEER REVIEW PROGRAMME

36 The primary purpose of the peer review programme was developmental, aiming to improve the quality of services for adults with haemoglobin disorders. During 2012 and 2013, 29 review visits involved 32 teams which had indicated that they were acting as Specialist Teams – or 'Centres' of a wider network of linked

hospitals – or as Accredited Local Hospital Teams (A-LHTs). The visits to the A-LHTs were informative and important as these hospitals were managing considerably more adults than most of the out-of-London Specialist Teams that were reviewed. Although the 32 teams reviewed during the 29 visits were thought to care for the majority of adults with haemoglobin disorders in England, an unknown number of adults are cared for by haematology teams in hospitals which did not link to a Specialist Team or are not part of an established network of care, or are cared for in the community without any secondary care input.

37 Visiting teams were made up of service and carer user representatives, consultants (adult and paediatric haematologists), specialist nurses and, when possible, 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 1) with the national clinical leads, Dr Kate Ryan and Dr Jo Howard, attending the majority of visits to ensure consistency of approach and interpretation between visits. Hospitals within the large networks of South East and North East London were reviewed by the same clinical lead.

38 Forty nine reviewers attended one day training and 53 reviewers took part in at least one visit (some reviewers had been trained in previous programmes). Attending training and acting as a reviewer was Continuing Professional Development for health care professionals and 212 days of CPD were provided by this review programme.

39 Chief Executives of all Trusts to be visited agreed that their service could be included in the review programme. Specialist Teams were given at least three months notice of the date of their review visit. Each visit lasted one day and included a review of written documentation, including some sets of medical records, a meeting with 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 4 gives the dates of each review visit.

40 Reviewers and the service being reviewed both commented on the draft report. Final reports were circulated to the Trust concerned and the relevant commissioner. All final reports will be available on the West Midlands Quality Review Service (WMQRS) website www.wmqrs.nhs.uk from September 2013.

41 The peer review programme was run under the governance of WMQRS and WMQRS provided administrative support, supported the development of the Quality Standards, ran reviewer training sessions, supported each visit and provided guidance to the programme's clinical leads. Funding for the review programme was provided by the NHS Sickle Cell and Thalassaemia Screening Programme. Meetings of the Steering Group took place regularly throughout the visits to ensure consistency and to review and sign off reports.

42 A 'Good Practice Sharing Event' is being planned for November 2013 and more detail of the good practice found during this review programme will be made available on the UK Forum website.

ACKNOWLEDGEMENTS

43 This peer review programme could not have taken place without the support of many people and organisations: the UK Forum on Haemoglobin Disorders, the UK Thalassaemia Society, the Sickle Cell Society and the National Sickle Cell and Thalassaemia Screening Programme; the cooperation of the 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 Ops on behalf of WMQRS) for their patient organisation of the reviews; the commitment and dedication of the Programme's Clinical Leads, Dr Kate Ryan and Dr Jo Howard and the willingness of their NHS Trusts, Central Manchester University Hospitals and Guy's and St Thomas' Hospitals to release them for this work; and the time of the other members of the Peer Review Steering Group. The contribution of all to this programme is gratefully acknowledged.

FINDINGS

Abbreviations of Trust names are given in Appendix 4.

GEOGRAPHICAL DISTRIBUTION OF AFFECTED ADULTS

44 The prevalence of people with haemoglobin disorders was known to vary across the country. The variation in numbers found by the peer review visits is, however, even more extreme than previously recognised (Table 1). Over 80% of the sickle cell adults were managed in the London hospitals with six having more than 500 patients and six between 250 and 500. Outside of London the numbers cared for by each service was even more variable. Only Manchester and Birmingham had greater than 250 adult patients while seven teams saw fewer than 100 adult patients.

45 More patients were known than had been registered in the National Haemoglobinopathy Registry. The true prevalence of haemoglobinopathies was unknown; some patients were being managed at hospitals outside those visited and it is likely that some patients were known to more than one Specialist Team.

46 The relative proportion of sickle cell and thalassaemia also varied across the country with some of the large sickle cell teams having fewer than ten thalassaemia patients. Manchester and The Royal London had more than 50 adult thalassaemia patients whilst UCLH and Whittington each regularly managed over 100 thalassaemia patients.

Table 1 Number of Adults Cared for by each Team (SHT and A-LHT)

	Adults with sickle cell disease				
	<50	**50-**	**100-**	**250-**	**500-750**
Number of teams	5	6(1)	7(4)	8(6)	6(6)
	Adults with thalassaemia				
	<10	**10-**	**20-**	**50-**	**> 100**
Number of teams	11(5)	11(7)	6 (2)	2(1)	2(2)

Note: London teams are shown in brackets () after the total.

47 Some Accredited LHTs, for example Barking, Havering and Redbridge, and Croydon, had seen a rapid increase in the number of adults with haemoglobin disorders, which reflected changing population demographics.

SERVICE ORGANISATION AND LIAISON – THE STATE OF CLINICAL NETWORKS

48 In most areas of the country clinical networks had not been established or were in the early stages of development. Outside of London, only the East Midlands Network had been commissioned. Other networks based on geographical areas were envisaged but were not yet agreed. 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 Guys and St Thomas' and Kings, 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 - even when they were within the same city.

49 London teams cared for adults from outside their geographical area, providing care for patients from as far away as Southampton, Southend, Norwich, Cambridge, Stevenage, Reading and Milton Keynes. At the time of the visits there was no clear lead specialist centre for the South Central region.

50 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. Pathways of care were varied and sometimes complex, and were often not clear to users or clinicians.

51 Some of the unusual pathways of care were appropriate. Some adults were referred for specific sub-specialty expertise, although these referral patterns had not been formally agreed. For example, many London sickle cell patients were referred to Guy's and St Thomas' for orthopaedic complications or to UCLH or St George's for urological complications.

52 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 thalassaemia caseload.

53 In the highest prevalence areas of south and east London, some of the A-LHTs in hospitals were caring for very large numbers of affected adults. For example, Queen's Hospital (Barking, Havering and Redbridge NHS Trust), Queen Elizabeth Hospital Woolwich (South London Healthcare NHS Trust), Newham University Hospital (Barts Health NHS Trust) and Croydon University Hospital (Croydon Health Services NHS Trust), each cared for over 250 adults with sickle cell disease - more than most of the Specialist Teams outside London. Size alone does not imply that a centre is able to provide a specialist service and the quality of specialist care should be considered even in the largest teams. 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.

54 Many of the smaller services which were reviewed as Specialist Teams, for example, Newcastle, Middlesbrough, Bradford, Oxford, Nottingham, Coventry, and Sheffield provided care for fewer than 100 adults with haemoglobinopathies. Small Specialist Teams may not be able to provide adequate specialist services unless they collaborate with another centre, for example, for guideline development, training, audit, review of difficult cases and development of specialist expertise in the management of orthopaedic, urology and renal complications.

55 Several acute Trusts did not link formally or informally into any network or with any Specialist Team. 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. Whilst some Specialist Teams had made efforts to contact local teams and engage them in developing patient pathways, other Specialist Teams had not made any contact with local teams and did not have any formal links with other teams beyond providing ad hoc advice.

56 In general, data collection on adults with haemoglobin disorders was poor. No Specialist Team could accurately enumerate all the adults for which they had responsibility and some were not sure about the exact number cared for within the proposed geographical area network. Teams were aware of patients who were not accessing care which could, in part, be due to patients moving away but was also due to enforcement of Trusts' policies for non-attendance. The National Haemoglobinopathy Register, a vehicle for recording the number of adults within a clinical network and movement between teams, was not yet fully utilised. It is not clear how Specialist Teams will be able to take on responsibility for data collection for all patients in the network without investment in additional administrative staff.

Information and Support for Patients

Information

57 The Quality Standards detailed a range of information expected to be available for patients, including general Trust information and local information giving a description of the services available, how to access care out of hours, names of core team members and details of how to contact them. This information was available in most Trusts although it was not clear how systematically it was given to patients. Some information had clearly been produced for the peer review visit. In some Trusts patient information was available on the hospital website and could be directly accessed by patients.

58 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 a lot of duplication and some leaflets were more comprehensive than others. There was generally more information on sickle cell disease than on thalassaemia.

59 Although some teams produced individual care plans for all patients and gave written copies of annual reviews to patients, this was not done in all Trusts and patients often did not carry these. The majority of Trusts held individualised care plans in the Emergency Department, either on paper or electronically, to ensure personal pain management. Almost all Trusts sent copies of GP letters to patients so they had a permanent record of changes to care.

User Involvement

60 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 (North Middlesex, North West London). Leicester had a three monthly 'Sickle Cell and Thalassaemia Advisory Board' - a multidisciplinary group made up of service users and other stakeholders. In some other teams, user involvement had been less successful.

Staffing

61 The overwhelming impression of the peer review visits was that every service relied on highly committed individuals working far beyond their job plans with limited support.

62 In some Trusts senior management was well informed about the service for adults with haemoglobin disorders and the issues it faced. In a few, senior management appeared to have little or no involvement and awareness of the service for people with haemoglobin disorders.

Medical Staffing

63 The number of consultant sessions bore very little relationship to the number of adults cared for by the service. It proved impossible to quantify the consultant PAs dedicated to caring for adults with haemoglobin disorders and in some instances there were no dedicated PAs in the lead consultant's job plan. The lead consultants almost invariably had several roles and responsibilities outside the management of patients with haemoglobinopathies and so had numerous calls on their time. In many cases the workload of consultant staff was unreasonably high and they were working far above their contracted hours in order to provide the service.

64 In the majority of teams, routine care of haemoglobinopathy patients, particularly out-patient care, was provided almost entirely by the clinical leads and medical staff in training. Other consultants often did not take part in the routine management of adults with haemoglobin disorders. There was little provision for cover of out of hours care or for routine care when the clinical lead took expected or unexpected leave.

Consultants reported that they were sometimes called for haemoglobinopathy advice out of hours when not on call or when on leave.

65 Junior haematology doctors were often pulled from haemoglobinopathy work to attend haematology-oncology patients. Doctors in training were generally not being encouraged to develop an interest in managing the growing numbers of adults with haemoglobin disorders. This is particularly important because consultant recruitment in these teams was often difficult. In some teams, the lead consultant had been in post for many years and involving a more junior colleague could be useful succession planning. Where small numbers of patients attended a service, the junior haematology staff may not gain sufficient specialist experience in the management of haemoglobinopathy patients.

66 There was little evidence of planning for service expansion. In several areas there are large numbers of children on transfusion regimes, which will put pressure on adult services as they transition to adult care. Already stretched teams will be further pressurised as the ageing haemoglobinopathy patient population develop increased complications of their chronic disease and increasingly complex health needs. This lack of forward planning is of concern.

67 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.

Nursing Roles

68 Specialist nurses and nursing teams in several Trusts were making an outstanding contribution to the care of adults with haemoglobin disorders. Some teams worked flexibly across different clinical areas of the hospital and community and so got to know the adults very well. This was highly appreciated by patients. In some cases the community nurses covered antenatal, paediatric and adult services and had no time identified in their job plan for the adult services. Some provided acute care for adults without formal agreement for this.

69 Some acute and community teams co-operated very well, for example, Lewisham, Kings, Manchester, North West London. In others, the interface between acute and community services was less well developed.

70 In many teams there were inadequate numbers of nursing staff for the number of patients, or in some cases no acute nurse specialist at all. Even where these posts were in place they often had a very high workload which included inappropriate tasks (such as routine manual or automated exchanges, filling in benefit forms) with very poor cover arrangements. One service had a single Clinical Nurse Specialist who covered acute and community teams and was on call 24/7, being called by patients during the night and when on holiday. Some acute nursing posts were on short-term contracts or had recently been abolished.

71 There were some good examples of advanced nurse practitioners and clinical nurse specialists providing innovative care, for example, annual reviews and monitoring tests for thalassaemia (Whittington) and sickle cell patients (Guy's and St Thomas'), nurse-led hydroxycarbamide clinics (Queen Elizabeth Hospital Woolwich, Manchester, Guy's and St Thomas'), nurse prescribing of iron chelation (Sheffield), nurse-led evening clinics in Croydon and nurse-led clinics in Newham. The specialist nursing staff also had a vital role in co-ordinating nurse training and implementation of RCN competences. The range of duties undertaken by hospital nurse specialists was wide. Some were very clinically skilled but others offered more general support and health promotion advice.

72 As with core hospital team staff, the number of community nurses bore little relationship to the size of their service. Some small, hard-pressed teams provided a highly organised, good quality service and delivered training to other hospital staff.

73 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. Training about haemoglobin disorders in the Emergency Department was often problematic, confounded by high staff turnover in these areas. North West London

had mandatory sickle cell and thalassaemia training for staff, which was a robust method of ensuring that all staff were up to date.

74 Nurse staffing levels on the wards and day unit were often not adequate and robust training plans for nursing staff were rarely comprehensive. This was reflected in feedback from service users, who often said that ward nursing staff were poorly informed about haemoglobinopathies. Ward nursing care was generally better when specific haematology-oncology or medical wards were used for haemoglobinopathy patients. In some hospitals with large haematology-oncology workloads, sickle cell patients were not prioritised for ward admission and were often looked after as 'outliers'.

Other Team Members

75 Whilst most teams had administrative and clerical staff, few Trusts had adequate data management support. UCLH had a data manager available in clinics to complete National Haemoglobinopathy Registry entry and input annual review data. Clinical staff usually performed data collection and entry. Compliance with expected standards of data collection and audit will be difficult without further investment in data collection.

76 Access to an appropriately experienced psychologist is essential in managing haemoglobin disorders in adults. For those with thalassaemia, a psychologist is key to addressing difficulties with acceptance and adherence to treatment. In both conditions there may be family difficulties or behavioural issues relating to long-term illness or frequent pain. In adults with sickle cell disease cerebrovascular problems can give rise to, sometimes subtle, learning disabilities. Identification of these by careful neuro-cognitive assessment may be the first indication of brain ischaemia needing further investigation and treatment. Understanding an adult's limitations is also important in further education and in the workplace, where extra support may be needed. In practice, teams rarely included a psychologist on a regular basis and in some services there was no access to an appropriately experienced psychologist anywhere in the network. Most teams were not able to access a neuro-cognitive assessment other than for adults with obvious impairments. The model of an integrated psychology service with the psychologists attending ward rounds and clinics as an integral part of the team (as at Guy's & St Thomas' and North West London), seemed to work effectively and increased patient acceptance of treatment.

77 Most teams had access to other specialist services, for example, obstetric, nephrology or orthopaedic services. These were often at different locations across the network, meaning that a patient with several co-morbidities would be attending several hospitals. Pathways into specialist clinics were not always clear or equitable across networks. For example, in both South East and North East London, patients in the Specialist Teams had access to on-site specialist renal clinics but these were not readily accessible to patients attending the linked hospitals. Some large teams did not have access to a full range of specialist clinics. Furthermore, although teams may have a named specialist, in areas of low prevalence it was not clear how much haemoglobinopathy experience this specialist would have. For example if an orthopaedic surgeon was only seeing a patient with sickle cell disease every three to four years they would be unlikely to have adequate experience in managing the complications of this disease.

78 There were some examples of excellent Specialist Teams and clinics, for example the haemoglobinopathy cardiac clinic and endocrine clinics at UCLH, pulmonary hypertension clinics at King's and Imperial, sickle/respiratory clinic at North West London, thalassaemia/cardiology clinic at Manchester, quarterly endocrine clinic at Birmingham, endocrine clinic at Whittington and Coventry, and chronic pain clinic at Sheffield. Guy's & St Thomas' (renal, orthopaedic, neurology, obstetric) and The Royal London (hepatology, renal, endocrinology, obstetric) both had a good range of supra-specialist clinics. Several hospitals ran joint haemoglobinopathy/obstetric clinics.

79 Some teams had specific social work support (for example, Imperial) or benefits advice (The Royal London, Homerton, Barking and Havering, Nottingham – provided by OSCAR). This received very positive feedback

from service users. Where this was not in place clinical staff spent a lot of time completing benefits forms and writing supporting letters.

SERVICE ORGANISATION

80 Operational policies were generally in place and were usually very thorough. Although these had often been produced for the peer review visit, they will provide a useful resource in the future and can be further developed over time. In addition, several units (for example, UCLH, The Royal London) had produced thorough annual reports, which will prove useful for service development and monitoring.

81 Service level agreements covering the work of community teams were rarely evident and acute Trusts were not always clear what they could expect from community teams. In some areas there appeared to be variable access to community teams depending on area of residence. Services seemed to work best where community nursing teams were part of the same organisation as the acute team.

82 Multi-disciplinary meetings were happening in most Trusts but were often not clearly documented. Some services had well established multi-disciplinary teams which provided good patient care and clear channels for communication between the hospital and community teams (for example, Croydon, North West London).

83 The majority of in-patients were looked after by the attending haematologist or by specialist haemoglobinopathy teams. In some Trusts in-patients were looked after by general medical teams with advice from the haematology team.

84 The 'did not attend' (DNA) rate for out-patient clinics was remarkably consistent between teams at around 30% for sickle cell patients. This is a poor use of resources and impairs the ability of teams to deliver annual reviews. In addition adherence to standard 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, Guy's & St Thomas', Leeds, Kings), for instance by texting or telephoning patients. Reminders were usually done by the specialist or community staff, or by the consultant's secretary in Liverpool, 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.

FACILITIES AND EQUIPMENT

85 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. One London hospital lacked basic equipment in the clinic causing prolonged waiting times while staff borrowed equipment. The Whittington and North Middlesex Hospital Trusts had established a separate day care facility for transfusion-dependent patients, which was highly appreciated.

86 In most hospitals patients with sickle cell disease were managed on haematology wards. Procedures for admission varied with some of the smaller outside-London Trusts having direct access to the wards (for example, South Tees, Newcastle, Sheffield) or to acute haematology/oncology assessment units (for example, Oxford), though hours of access and cover arrangements varied. In Bristol patients with acute painful crisis attended the day unit during working hours and were admitted directly to the ward out of hours. In Nottingham patients called the haematology bleep-holder if they required admission and were directed to either the day unit, Specialist Receiving Room or haematology ward, depending on bed availability. In Croydon all patients presenting to the Emergency Department with sickle crisis were treated in the resuscitation bays, leading to very rapid 'door to analgesia' times. In Coventry patients were asked to contact

the clinical nurse specialist during working hours or the haematology ward out of hours and were directed to the haematology ward if a bed was available (or the Emergency Department if not). In most Trusts, particularly the larger ones, patients were admitted via Emergency Department teams with immediate admission to an assessment facility whilst waiting for a haematology bed. In some Trusts, particularly those with a large haematology-oncology practice, patients with sickle cell disease often could not be accommodated on haematology wards and were placed in outlying wards where expertise and facilities were very varied and patient controlled analgesia (PCA) could not be offered. At many visits service users said that they felt this to be unfair and perceived they were viewed as being "second class" haematology patients.

87 Patient controlled analgesia was not available in all teams and availability was sometimes restricted to particular wards or times of day. The amount of support from the local Acute Pain Teams was very variable. Some teams had excellent daily input from Pain Teams (for example, Sheffield), whereas others had very little support from their Acute Pain Teams.

88 Several Trusts had developed drop-in day care facilities, sometimes as stand-alone red cell facilities and sometimes combined with haematology-oncology services (for example, Sheffield, Guy's & St Thomas', Homerton, Nottingham, Birmingham, North West London, The Royal London, Kings). Whilst these were highly regarded by patients and usually allowed rapid access to expert care, they were limited by their opening hours, and patients reported that they would wait in pain for several hours until the day unit was opened, rather than attend the Emergency Department. The peer review teams also considered that practices in some of these day care facilities needed review as a small numbers of patients attended on an almost daily basis for parenteral opiates. This was not only inappropriate management of patients with chronic pain issues, but also limited access to the facility for other patients with acute pain.

89 Most Trusts were able to offer some out of hours transfusion for regularly transfused thalassaemia patients with extended opening hours and/or weekend transfusions. Homerton and Royal London both provided an extended hours day unit. Coventry had developed a monthly Saturday morning session for thalassaemia patients, which was popular with the patients. Nottingham and Imperial provided Saturday morning transfusions and the Whittington had evening and weekend transfusions. Some teams also provided evening clinics (UCLH, Whittington, North Middlesex, The Royal London). North Middlesex ran a three-monthly 'family clinic'. Some of the large teams were not able to offer weekend transfusions, however, despite having relatively large numbers of adults in work or full-time education who expressed a wish for this to be available. A rapid transfusion protocol for suitable patients had been adopted in Manchester which enabled transfusions to be completed much more quickly and was appreciated by the users.

90 Access to erythrocytopheresis was patchy, with some teams (for example, St George's, UCLH) having 24/7 access, others having good access during the working week, and other large teams having no service at all. Several teams worked with the NHS Blood and Transplant to provide good access (for example, Leeds, Bristol, Liverpool, Oxford) but across England there was significant inequity in access to erythrocytopheresis.

91 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. Furthermore, clear protocols for manual exchanges were not always available.

92 Access to specialist imaging was inconsistent. Patients often had to travel long distances (for example, from Birmingham to London) to receive specialist MRI scans, or they were not easily available.

93 There was little evidence of community review clinics and no examples of good practice, although this may be an option for patient-centred care of this long-term condition. An example of GP-led community clinics was seen during the peer review visits but did not have robust governance arrangements, clear protocols for care and pathways for referral to specialist care.

CLINICAL GUIDELINES

94 The document review part of the peer review visit looked in detail at clinical and referral guidelines in use in each service. The Quality Standards are clear about which guidelines should be available. These were considered necessary in order to reduce variation within clinical teams and give guidance to more junior members of the multi-disciplinary team and to staff providing out of hours cover. Many excellent, comprehensive, user-friendly clinical guidelines were seen. Some guidelines appeared to have been drawn up, or revised, just in time for the visit but reviewers were satisfied that the guidelines would help to improve the standard of care as long as relevant staff were familiar with their contents. Some teams, especially those with few staff, did not have the expected clinical guidelines. This was of particular concern as specialist staff could not always be expected to be available. In a small number of cases the clinical guidelines were misleading, out of date or inaccurate.

95 In general, the 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.

96 It is expected that guidelines in use across a clinical network of Specialist and Local Teams will be the same or, at least, consistent. The review visits found that sharing of clinical guidelines was an aspiration for most networks although already in place in some, for example, East Midlands. Many networks had begun sharing guidelines but this work was not yet complete, so a mixture of shared and local guidelines was in use.

97 Annual review guidelines were available at most sites and were noted to be very thorough at some: Leeds, Nottingham, Manchester, Coventry. Annual reviews were not always being performed in a systematic way and it was not possible to ascertain how many patients were having annual reviews in most Trusts. Some teams, for example, Coventry, had been performing annual reviews in a consistent way for some years. Some teams were using nursing staff to perform annual reviews. Entry of annual review data onto the National Haemoglobinopathy Registry was inconsistent involving a variety of staff from consultants, nurses and data managers.

98 Although the management of acute complications is a key part of the haemoglobinopathy service, 28% departments did not have clear Emergency Department Guidelines (HN-507 9/32 non-compliant). Even where available, they were sometimes unclear and Emergency Department staff were not always aware of their existence or where to find them. The guidelines did not always include reference to NICE guidance on management of painful crises in sickle cell disease. Emergency Department guidelines are particularly important when a small numbers of patients attend infrequently or when the majority of patients are admitted directly to the ward, as Emergency Department are less used to managing the condition. Some Trusts had very clear pathways of care and/or readily available individual pain protocols in the Emergency Department and some had an effective system of alerting the haemoglobinopathy doctors when a patient came through Emergency Department (Whittington).

99 The clinical guidelines for acute and chronic complications of haemoglobinopathies were clear and thorough in some, but not all services. Common gaps in protocols included the acute management of complications in thalassaemia patients and the management of chronic pain and chronic respiratory disease in sickle cell disease. Guidelines were not always user-friendly and should be aimed more at the non-specialist (for example, specialist registrar, clinical nurse specialist). Pathways of care were often not clear, 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 addition, there was very little guidance as to when patients in linked hospitals who develop acute complications should be referred to Specialist Teams, although North Middlesex did have clear referral guidelines for their linked hospitals.

Clinical Thresholds

100 The peer review visits did not set out to compare activity levels in different Trusts. The impression was, however, that the variation in the number of Emergency Department attendances, hospital admission rates, average length of stay, frequency of out-patient review and number of adults with sickle cell disease on a regular transfusion programme was greater than could be explained by case mix variations. It appeared that different teams may be giving different messages about when to attend the Emergency Department and when home care, supported by a telephone consultation or visit by a community nurse, is appropriate. There is no 'right answer' on when an adult needs emergency assessment or admission, as much depends on the capability, knowledge and experience of the patient but the extent of variation was surprising. Similarly, the proportion of adults with sickle cell disease on regular transfusion varied from 1:10 to 1:30 and there was great inconsistency of numbers of patients on hydroxycarbamide. This degree of variation suggests that adults in different teams may be started on hydroxycarbamide or on regular transfusion according to different criteria or that uptake rates vary. This needs further investigation as this may imply differing quality of service provision or unacceptable variation in clinical thresholds.

Transition from Paediatric Services

101 Most Trusts had not given consideration to the needs of teenagers and young adults. On some sites, for example, UCLH and Sheffield , Teenage Cancer Trust ward areas were able to accommodate teenagers with red cell disorders.

102 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 clinical nurse specialist at Guy's & St Thomas', paediatric nurse at Liverpool and community nurse at Coventry. North Middlesex 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, Liverpool, Oxford, Newham, Bradford, Coventry, Imperial and Oxford. Some teams put on transition days or transition events for small groups of teenagers (for example, GSTT, Sheffield). In several teams, however, the transition process was not adequately developed or supported.

103 In some teams the consultant lead worked across paediatric and adult teams (for example, The Royal London, North Middlesex, North West London) but this, in itself, did not ensure good transition arrangements unless also backed up by support from adult and paediatric nursing staff. Transition was less well organised if children and adults were cared for on different sites. This situation was managed well by some teams but some stand-alone adult teams had no transition facilities.

Governance

104 The National Haemoglobinopathy Registry (NHR) 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. At the time of the visits full functionality of the NHR was still being developed. Full entry of data into the NHR was not in place in any of the Trusts visited though almost all teams had made significant progress in registering patients, particularly in the months leading up to the visit. Two hospitals, with large patient caseloads had entered very few of their patients. 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. Entry was over 90% in those teams with data managers with time allocated for this work.

105 Some teams were not sure how many patients were under their care and figures quoted could refer to:

a. patients seen in the last 12 or 24 months
b. patients in active follow up
c. patients who had been seen 'ever' in the centre, even transiently.

106 Although many teams were performing annual reviews, the majority did not use the National Haemoglobinopathy Registry to record these. Most cited a lack of data management support and others considered that the annual review screens, still under development, were not complete enough. Some teams, for example, Kings and The Royal London had developed their own database for recording clinical data as well as audit and clinical research.

107 Most teams were recording adverse events though the National Haemoglobinopathy Registry but it was not possible to ascertain the completeness of recording.

108 The Quality Standards (HN-702) required evidence of ongoing monitoring of the service. Such information could be used to benchmark care across and between geographical areas and provide information for local commissioners. Most teams had information of numbers of acute admissions, day unit and Emergency Department attendances, which were obtained from hospital administration systems. Lengths of in-patient stay and readmission rates were also usually available. It was notable that there was marked discrepancy between hospitals, particularly in London, in the numbers of hospital and day care admissions for the stated number of sickle cell patients and this reflected some hospitals which 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. Other monitoring requirements, such as waiting times for transfusion and proportion of patients having annual review, were less consistently collected, usually due to lack of data management support.

109 Quality Standard HN-703 expected regular audits of compliance with key clinical standards. Only 38% centres met this standard in full:

a. For adults with sickle cell disease: proportion taking regular penicillin or have supply for use; proportion fully immunised; and proportion of those with acute pain who have adequate pain control in accordance with NICE guidelines

Information on immunisation and penicillin use was not always available from primary care. Some teams had arrangements, agreed with primary care, to administer immunisations in the clinic (North Middlesex).

Pain management had been audited in most teams and results were inconsistent ranging from 100% (Croydon University Hospital) to 13% of adults receiving analgesia within 30 minutes of presentation with acute pain. This was reflected in the feedback from the users who reported unacceptable delays in receiving analgesia in some Emergency Departments and a perception of a lack of empathy amongst medical and nursing staff in these areas. Where hospitals were able to offer day care analgesia or direct access to haematology assessment, care was perceived as being much better although some patients would wait in pain for the day unit to become available rather than attend the Emergency Department service.

b. For adults with thalassaemia: evidence of effective monitoring of iron overload including imaging and proportion who have developed new iron-related complications.

Audit of thalassaemia care was done less well with only Whittington and UCLH being able to produce systematic data on effective monitoring of iron overload. Some units had less than five patients, so had not performed systematic audits but had the data available.

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

COMMISSIONING OF TEAMS

111 A Specialised Services National Definition Set for Specialised Haemoglobinopathy Services was published in 2010 although, at the time of the peer review visits, most Specialised Commissioning Groups / Teams were not yet actively engaged in commissioning these services. NHS England took over responsibility for specialist commissioning from April 2013 and changes in personnel meant that many commissioners were new in post so had little information about haemoglobin disorder services. Some acknowledged that they were only aware that the service existed. Local commissioners attended many of the review visits and some were knowledgeable about the services. Commissioners of the service at St George's were planning to include a CQUIN on the quality of in-patient care in the service contract. All commissioners said they would like more information. Specialist commissioners had been actively involved in planning services in the North West (Liverpool and Manchester), East Midlands (Leicester and Nottingham) and in London.

COMPLIANCE WITH QUALITY STANDARDS

112 Comparisons of percentage compliance with Quality Standards have not been produced for this round of peer review visits, especially because the relative importance of different Quality Standards is not taken into account in crude percentage comparisons. Percentage compliance also takes no account of 'working towards' a particular Quality Standards. 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.

113 Further work is taking place in summarising the findings of each peer review visit for use by individual teams. It is hoped that this will produce a more a useful overall assessment than percentage compliance which can also be used to look at progress over time.

114 Appendix 5 details compliance with each standard and can be used by teams to compare their performance with others.

EVALUATION

115 This was the first peer review programme of services for adults with haemoglobin disorders and built on lessons from the paediatric peer review carried out in 2010/11. 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. The programme additionally offered useful 'continuous professional development' for reviewers.

116 This adult peer review process asked for data on activity and outcomes and specific audit data but several teams were not able to supply accurate data or had not completed all the audits. In future it would be helpful if this information was available to the visiting teams before the visit.

117 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 material submitted after the visit will not be taken into account.

118 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.

119 This peer review process has identified some hospitals that have not engaged with the process, some of which are known to care for patients with haemoglobinopathies. These should be incorporated into the next round of peer review visits. In the meantime, relevant commissioners and clinical staff should be working to establish links between these services and appropriate Specialist Teams.

120 The 2012/13 peer review programme was externally evaluated by Harry Ward (Economic and Commissioning Consultancy). The Evaluation Report is available on the WMQRS website: www.wmqrs.nhs.uk

121 Key points from the evaluation were:

a. The training sessions were highly rated by participants.
b. Trust leads were positive about the both the preparation phase and the conduct and organisation of the visit.
c. Reviewers rated the organisation of the visit highly but the rating for information sent before the visit was lower, owing to late or incomplete submissions by Trusts.
d. The response rate for Trust leads and reviewers for the overall evaluation was disappointing (22 and 24% respectively)..
e. Reviewers found both being a reviewer and the review of their own service was useful in improving services.
f. Users found membership of the review team a good and useful experience.
g. Trust leads reported service improvements were made both before and after the peer review visit.
h. In the majority of Trusts concerns remain to be addressed.
i. Trust leads reported shortage of clinical staff and resources as the main barrier to service improvement.

122 Table 2 compares the evaluation results for this review programme with previous WMQRS reviews.

Table 2 Overall Evaluation and Comparison with Other WMQRS Review Programmes

Question	Response	%								
		WM Peer Review Team			WMQRS					
		CIC 2003	Cancer 2005	CIC 2006	Renal 2009	SC&T 2010/ 11	2010 *	2011 **	2012 ***	This programme
Did the preparation for the visit to your own organisation lead to changes in the services provided?	Improvement or Significant Improvement	34	41	71	14	50	33	32	0	**56**
Was the peer review visit to your own organisation a helpful or unhelpful experience?	Helpful or Very Helpful	72	47	78	80	100	73	74	79	**100**
Did the report of the visit give a fair reflection of the services at your own organisation at the time of the visit?	Fair or Very Fair	83	58	65	66	100	73	68	84	**88**
Was the experience of being a reviewer useful in developing your own services?	Useful or Very Useful	81	74	89	91	92	88	80	88	**89**
Has your organisation been able to address the 'immediate risks' (if any) and 'concerns' identified in the visit report?	Addressed in full or nearly addressed		43		48	23	56	60	58	**35**
Has the peer review process overall been useful to your organisation in improving services?	Useful or Very Useful	67	45	61	52	73	73	71	60	**75**

Key

CIC Care of critically ill and injured children

SC&T Services for children and young people with sickle cell disease or thalassaemia (2010/11 reviews)

* WMQRS 2010/11 review programme covered urgent care, critical care, stroke (acute phase) & TIA, and vascular services.

** WMQRS 2011/12 review programme covered mental health services, health services for people with learning disabilities, dementia services and care of vulnerable adults in acute hospitals.

*** WMQRS 2012/13 review programme covered care of adults with long-term conditions and the care of children and young people with diabetes.

RECOMMENDATIONS

Rec. No.	Recommendation
1	NHS England (Specialised Commissioning Teams) should ensure that all adults with haemoglobin disorders have access to a Specialist Haemoglobinopathy Centre. Each Specialist Haemoglobinopathy Centre should have a geographic region where it has responsibility for the care of adults with haemoglobin disorders. The commissioning of Specialist Haemoglobinopathy Centres should take into account: a. The number of adults with haemoglobin disorders, the rapid increase in numbers in some areas, and the expected number transferring from paediatric care. b. Existing clinical relationships and referral patterns. c. The views of adults with haemoglobin disorders. Particular consideration should be given to the arrangements for low-prevalence areas where there are fewer than 100 adults with haemoglobin disorders. Specialist Haemoglobinopathy Centres serving less than 100 adults are unlikely to be able to maintain appropriate specialist competences without collaborative arrangements with another Specialist Centre. Although there is no nationally recommended maximum size for a Specialist Centre, where the number of patients is over 250 it may be appropriate for an Accredited Local Haemoglobinopathy Team to undertake annual reviews of patients with less complex needs and to manage some more complex acute presentations, in conjunction with the Specialist Haemoglobinopathy Centre. This should be agreed only where access to care would be improved and when staffing and expertise of the Local Team is appropriate for this level of care. This system of 'geographically responsible' Specialist Haemoglobinopathy Centres should be supported by agreed arrangements for notifying relevant Centres of patients who choose to access care elsewhere, and of patients who move or who are lost to follow up.
2	NHS England (Specialised Commissioning Teams) should work with Clinical Commissioning Groups in their area to ensure that all adults with haemoglobin disorders have access to: a. Local hospital care b. Community care, including responsibility for follow up of people who do not attend c. Social work support and benefits advice. This support may be commissioned from the Specialist Haemoglobinopathy Centre or from other local providers. Where other providers provide this care, they should be required to work in collaboration with the Specialist Haemoglobinopathy Centre with responsibility for their geographical region, including notification of patients moving into and out of the area.

Rec. No.	Recommendation
3	NHS England should ensure that commissioning of Specialist Haemoglobinopathy Centres includes: a. Providing all relevant data to the National Haemoglobinopathy Registry for all patients from their geographical region, or ensuring this information is provided by Accredited Local Haemoglobinopathy Teams and other local services. b. Access to automated erythrocytopheresis for, at least, routine care and, ideally, also emergency care. c. Access to Cardiac T2* magnetic resonance imaging(MRI) and Liver R2 MRI d. Access to experienced psychological support e. Providing training and support to local hospitals and community teams within the geographical region for which they are responsible.
4	NHS England (Specialised Commission Teams) should make publicly available key process and outcome indicators from all Specialist Haemoglobinopathy Centres so that these can be used by providers to improve their care.
5	NHS England should commission an ongoing programme of joint peer review of services for children and adults with haemoglobin disorders. (In due course, the need for separate funding may be replaced by incentives for peer review / accreditation built into the Care Quality Commission's 'The Next Steps' proposals (June 2013)).
6	NHS England should specifically include the Quality Standards used for the peer review visits within the service specification for services for children and adults with haemoglobin disorders.
7	Specialist Haemoglobinopathy Centres should pay particular attention to the areas highlighted in this report: a. Medical and nurse staffing levels should be sufficient to: i. Provide specialist care for all patients with haemoglobin disorders from the geographical region served by the Centre ii. Provide training and support for staff within the Specialist Centre and those from local hospitals and community teams within the Centre's geographical region. b. In Centres where only one consultant specialises in the care of people with haemoglobin disorders, robust arrangements for cover should be implemented, including local cover for routine care and access to urgent specialist advice from another Centre. c. Doctors in training should be actively involved in all aspects of the care of people with haemoglobin disorders, under the supervision of the Specialist Haemoglobinopathy Team. In low prevalence areas this may involve specialist training outside their base region or specific training post. d. Transfusions should be offered outside normal working hours to reduce the impact of regular hospital visits on work, education and family commitments. e. Access to neuro-psychological assessment should be available. f. Provision of all relevant data to the National Haemoglobinopathy Registry for all patients from their geographical region, or ensuring this information is provided by Accredited Local Haemoglobinopathy Teams and other local services.

Rec. No.	Recommendation
8	Specialist Haemoglobinopathy Centres should work with Local Haemoglobinopathy Teams and community teams within their geographical region to: a. Continue to work towards compliance with all applicable Quality Standards b. In the absence of national guidance, agree arrangements for notifying the Specialist Haemoglobinopathy Centre/s of patients who choose to access care elsewhere, and of patients who move or who are lost to follow up. c. Audit admission procedures to ensure patients with haemoglobin disorders are admitted to clinical settings where staff have specialist competences in their care. d. Review 'Did Not Attend' (DNA) policies with the aim of reducing high DNA rates and the number of people lost to follow up. e. Regularly audit achievement of recommended times to administration of analgesia. f. Agree and regularly update operational policies, clinical and referral guidelines for: i. The process and documentation of annual reviews ii. Management of acute complications in Emergency Departments and Acute Medical Admissions Units. Guidelines on pain management should be consistent with NICE guidelines. iii. Pathways of care, especially referral of acutely unwell patients to the Specialist Centre and referral of patients with chronic complications for specialist review (for example, with cardiology, orthopaedic, renal or urology services). g. Ensure a full range of relevant information is available for patients and that all patients have access to psychological support. h. Ensure staff competent to perform emergency manual exchange transfusion should be available at all times i. Implement robust arrangements for transition from paediatric to adult care.
9	NHS Health Education England should: a. Review the workforce plan for staff specialising in the care of people with haemoglobin disorders to ensure an adequate supply of consultants (haematologists and paediatricians) and nurses with specialist competences, taking account of the rapidly increasing prevalence in some areas. b. Ensure all doctors in haematology training posts have experience in all aspects of the care of people with haemoglobin disorders. In low prevalence areas this may involve specialist training outside their base region or specific training post.

Rec. No.	Recommendation
10	The UK Forum on Haemoglobin Disorders should: a Produce guidance on appropriate staffing levels for Specialist Centres and local teams, taking into account the number of adults cared for by the service and the need for support for other services within the geographical region. b Work with the Clinical Reference Group and Healthcare Quality Improvement Partnership to agree and implement national audits of key activity and clinical indicators, in particular relating to access to chronic transfusion programmes and hydroxycarbamide treatment in sickle cell disease, in order to understand variation in current clinical practice and the relationship with clinical outcomes. c Work with the West Midlands Quality Review Service to revise the Quality Standards for the Care of Children, Young People and Adults with Haemoglobin Disorder to: i. combine Children's and Adults' Standards into a single version, with appropriate age-specific references where necessary. ii. reflect the recommended geographical region responsibilities of Specialist Haemoglobinopathy Centres iii. include arrangements for collaborative working across the geographical region through, for example, participation in regular tele-conferenced multi-disciplinary team meetings. iv. Include production of an annual report by each Specialist Haemoglobinopathy Centre and Accredited Local Haemoglobinopathy Team. v. include a requirement for 'Did Not Attend' policies to take specific account of the needs of people with haemoglobin disorders.

APPENDIX 1 STEERING GROUP MEMBERSHIP

Name	Job Title	Organisation
Dr Jo Howard	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Guy's and St Thomas' NHS Foundation Trust
Dr Kate Ryan	Consultant Haematologist – Joint Clinical Lead for Peer Review Programme	Central Manchester University Hospitals NHS Foundation Trust.
Dr Bernard Davis	Consultant Haematologist	The Whittington Hospital NHS Trust
Elaine Miller	Voluntary Sector Representative	Thalassaemia Society
Dr Asa'ah Nkohkwo	Adviser	Sickle Cell Society
Sekayi Tangayi	Service Manager/Nurse Lead & Specialist Nurse	East London NHS Foundation Trust
Dr Josh Wright	Consultant Haematologist	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Anne Yardumian	Consultant Haematologist	North Middlesex University Hospital NHS Trust
Jane Eminson	Acting Director	West Midlands Quality Review Service
Sharon Ensor	Director	KeyOpps Ltd on behalf of West Midlands Quality Review Service
Pip Maskell	Director	KeyOpps Ltd on behalf of West Midlands Quality Review Service

APPENDIX 2 NATIONAL GUIDANCE ON THE CARE OF PEOPLE WITH HAEMOGLOBIN DISORDERS

2000	The Department of Health	*The NHS Plan*
2005	United Kingdom Thalassaemia Society	*Standards for the care of children and adults with thalassaemia in the UK, first edition 2005*
2008	United Kingdom Thalassaemia Society	*Standards for the care of children and adults with thalassaemia in the UK, 2nd edition 2008 ; ISBN 978-1-900254-19-9.*
2008	Sickel Cell Society	Standards for the clinical care of adults with sickle cell disease in the UK, first edition 2008 www.sicklecellsociety.org
May 2008	National Confidential Enquiry into Patient Outcome and Death (NCEPOD)	*National Confidential Enquiry (2004-2006) into Patients' Outcomes and Deaths (NCEPOD) Report "A Sickle Crisis?"*
2009	Darbyshire. P	*A Department of Health sponsored review of haemoglobinopathies*
2009	NHS Specialised Services	*National Definition Set Definition No. 38 Specialised Haemoglobinopathy Services (all ages) 3rd Edition*
2009	West Midlands Quality Review Service	*Quality Requirements for Health Services Caring for Children and Young People with Haemoglobinopathies Version 1.1*
2011	Binal Nathwani, East Midlands Specialised Commissioning Group	*The National Haemoglobinopathies Project: a guide to effectively commissioning high quality sickle cell and thalassaemia services ISBN 978-0-9565846-5-6*
2011	Royal College of Nursing	*Caring for people with sickle cell and thalassaemia syndromes – a framework for nursing staff*
2011	Anionwu, E., Tankayi, S., Westerdale, N.	*RCN Competences: Caring for people with sickle cell disease and thalassaemia syndromes - A framework for nursing staff*
2012	National Institute for Health and Care Excellence (NICE)	*NICE Clinical Guideline 143: Management of an acute painful sickle cell episode in hospital*
2013	NHS England	*2013/14 NHS Standard Contract for Specialised Services for Haemoglobinopathy Care (All Ages). Section B Part 1 – Service Specifications.*

APPENDIX 3 LEVELS OF CARE FOR SICKLE CELL DISEASE AND THALASSAEMIA

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

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

Specialist team care includes:

- Institution and supervision of blood transfusion management (SCD and thalassaemia)
- Institution and supervision of iron chelation management, prescribing of iron chelating drugs, monitoring adverse event management and optimization of compliance (SCD and thalassaemia)
- Management of severe and life-threatening acute complications (SCD and thalassaemia)
- Management of chronic complications (SCD and thalassaemia)
- Surgical management (SCD and thalassaemia)
- Management of pregnancy (SCD and thalassaemia))
- Annual out-patient review (SCD and thalassaemia)
- Out-reach clinics in local hospitals (SCD and thalassaemia)

Local team care includes:

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

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

Community care includes:

- Education of and support to patients and carers in self-management of these long-term conditions
- Support to patients and carers in home management of milder sickle cell crises and supervision after discharge from hospital
- Education of and support to patients and carers in adherence with home medication (oral penicillin prophylaxis for SCD, regular iron chelating therapy for patients with thalassaemia major and for patients with SCD on regular transfusion)
- Liaison with and facilitation of access to community health teams, social teams, educational teams, welfare benefits etc
- Support for local users' groups.

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

APPENDIX 4 VISIT DATES

Service	Abbreviation	Visit date
Sheffield Teaching Hospitals NHS Foundation Trust	Sheffield	March 20th 2012
South Tees Hospitals NHS Foundation Trust The Newcastle Upon Tyne Hospitals NHS Foundation Trust *	South Tees Newcastle	March 29th 2012
Central Manchester University Hospitals NHS Foundation Trust Royal Liverpool and Broadgreen University Hospitals NHS Trust **	Manchester Liverpool	May 3rd 2012
Leeds Teaching Hospitals NHS Trust	Leeds	May 10th 2012
University Hospitals of Leicester NHS Trust Nottingham University Hospitals NHS Trust ***	Leicester Nottingham	June 12th 2012
University Hospital Southampton NHS Foundation Trust	Southampton	July 10th 2012
Bradford Teaching Hospitals NHS Foundation Trust	Bradford	Sept 13th 2012
Guy's and St Thomas' NHS Foundation Trust	Guy's and St Thomas'	Sept 19th 2012
Lewisham Healthcare NHS Trust, University Hospital Lewisham	Lewisham	Sept 27th 2012
Croydon Health Services NHS Trust	Croydon	Oct 2nd 2012
St George's Healthcare NHS Trust Epsom and St Helier University Hospitals NHS Trust **	St George's	Oct 10th 2012
South London Healthcare NHS Trust	Queen Elizabeth, Woolwich	Oct 18th 2012
Sandwell and West Birmingham Hospitals NHS Trust	Birmingham	Oct 24th 2012
The North West London Hospitals NHS Trust	North West London	Nov 1st 2012
University College London Hospitals NHS Foundation Trust The Whittington Hospital NHS Trust ***	UCLH Whittington	Nov 13th 2012
University Hospitals Bristol NHS Foundation Trust	Bristol	Nov 14th 2012
North Middlesex University Hospital NHS Trust	North Middlesex	Nov 21st 2012
Barts Health NHS Trust (The Royal London Hospital)	The Royal London	Jan 9th 2013
Homerton University Hospital NHS Foundation Trust	Homerton	Jan 15th 2013
University Hospitals Coventry and Warwickshire NHS Trust	Coventry	Jan 17th 2013
Barts Health NHS Trust (Newham University Hospital)	Newham	Jan 24th 2013
Imperial College Healthcare NHS Trust	Imperial	Jan 29th 2013
Barts Health NHS Trust (Whipps Cross University Hospital)	-	Jan 30th 2013
Barking, Havering and Redbridge University Hospitals NHS Trust	Barking, Havering and Redbridge	Feb 5th 2013
King's College Hospital NHS Foundation Trust	Kings	Feb 7th 2013

Service	Abbreviation	Visit date
Oxford University Hospitals NHS Trust	Oxford	Feb 14th 2013
The Royal Wolverhampton Hospitals NHS Trust	-	April 29th 2013

Notes:

1 Full Trust titles are given here. Elsewhere in the report shortened versions are mostly used.

2 * indicates two Trusts reviewed as SHT and A-LHT but only the A-LHT was visited

3 ** indicates two Trusts reviewed as SHT and A-LHT and the SHT only was visited

4 *** indicates two Trusts both reviewed as SHT and both were visited on same day. These Trusts worked very closely together in same Network so a joint report was produced.

APPENDIX 5 COMPLIANCE WITH QUALITY STANDARDS

NB. The report for one centre was still in draft at the time of publication, but significant changes to these percentages are not anticipated.

Ref	Short Title	Met	Not met	N/A	Total	% Applicable standards met
HN-101	General Support for Service Users and Carers	28	6	0	34	82
HN-102	Haemoglobin Disorder Service Information	23	11	0	34	68
HN-103	Information about Haemoglobin Disorders	13	21	0	34	38
HN-104	Information for Primary Health Care Team	17	17	0	34	50
HN-105	Care Plan	15	19	0	34	44
HN-106	Transition Information	23	11	0	34	68
HN-199	Involving Patients and Carers	19	15	0	34	56
HN-201	Lead Consultant	31	3	0	34	91
HN-202	Cover for Lead Consultant	24	10	0	34	71
HN-203	Lead Nurse	23	11	0	34	68
HN-204	Cover for Lead Nurse	10	24	0	34	29
HN-205	Staffing Levels and Competences	7	27	0	34	21
HN-206	Training Plan	10	24	0	34	29
HN-207	Training Plan – Other Staff	12	22	0	34	35
HN-298	Administrative and Clerical Support	11	23	0	34	32
HN-301	Support Services	30	4	0	34	88
HN-302	Specialist Services	17	17	0	34	50
HN-303	Laboratory Services	32	2	0	34	94
HN-401	Facilities available	28	5	1	34	85
HN-402	Facilities for Out of Hours Care	17	16	1	34	52
HN-501	Transition Guidelines	23	11	0	34	68
HN-502	Clinical Guidelines: Annual Review	16	17	1	34	48
HN-503	Clinical Guidelines: Routine Monitoring	22	12	0	34	65
HN-504	Transfusion Guidelines	25	9	0	34	74
HN-505	Chelation Therapy	21	13	0	34	62
HN-506	Clinical Guidelines: Acute Complications	18	16	0	34	53
HN-507	Emergency Department Guidelines	24	10	0	34	71
HN-508	Clinical Guidelines: Chronic complications	19	15	0	34	56

Ref	Short Title	Met	Not met	N/A	Total	% Applicable standards met
HN-509	Transfer for Critical Care	9	4	21	34	69
HN-510	Specialist Management Guidelines	27	7	0	34	79
HN-511	Thalassaemia Intermedia	20	13	1	34	61
HN-601	Operational Policy	15	19	0	34	44
HN-602	Multi-Disciplinary Meetings	16	18	0	34	47
HN-603	Service Level Agreement with Community Services	9	21	4	34	30
HN-701	Data Collection	8	25	1	34	24
HN-702	Ongoing Monitoring	11	23	0	34	32
HN-703	Audit	12	22	0	34	35
HN-704	Guidelines Audit	5	29	0	34	15
HN-705	Research	17	12	5	34	59
HN-798	Review and Learning	24	10	0	34	71
HN-799	Document Control	20	14	0	34	59
HY-199	Involving Patients and Carers	5	22	0	27	19
HY-201	Network Leads	3	24	0	27	11
HY-202	Education and Training	8	19	0	27	30
HY-501	Transition Guidelines	1	26	0	27	4
HY-502	Clinical Guidelines	1	26	0	27	4
HY-701	Annual Meeting	8	19	0	27	30
HY-702	Ongoing Monitoring	3	24	0	27	11
HY-703	Audit	0	27	0	27	0
HY-704	Research	5	22	0	27	19
HY-798	Review and Learning	8	19	0	27	30
HZ-601	Commissioning of Services	9	18	0	27	33
HZ-701	Clinical Quality Review Meetings	9	18	0	27	33