UK Forum on
Haemoglobin
Disorders

Caring for haemoglobinopathy patients:

Report of a national workforce survey

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Summary

A survey of the current workforce providing care for patients with haemoglobinopathies (sickle cell disorders, thalassaemia syndromes and other rare inherited anaemias) and future requirements was undertaken in response to the findings of the adult and paediatric peer review programmes which reported inadequate numbers of medical and nursing staff and no evidence for workforce planning to meet the increasing demands of the service.

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Key Findings

The survey confirmed the findings of the peer review programs:

1. Many consultants were single-handed in terms of the haemoglobinopathy service and cover arrangements for leave and other absence was by consultant colleagues with no specialist interest or training.
2. Allocated PAs varied greatly between hospitals, even between those with similar numbers of patients. Some large London centres, in particular, were very poorly staffed.
3. Paediatric haematologists and paediatricians deliver care for children across the UK with adult colleagues providing input in hospitals with no dedicated paediatric haematologists.
4. Significant numbers of consultants intend to retire within the next 5-10years: 8/37 adult consultants (21%) and 8/29 (28%) paediatric consultants within 5 years, and 3/37 and 6/29 within 5-10years respectively. Most intended retirements are outside London where specialist training may be hard to deliver within local training programs.
5. There were very low numbers of dedicated clinical nurse specialists, particularly for paediatric patients. Some of the largest centres surveyed had no acute nurse provision
6. The specialist nursing workforce is also ageing with a number of retirements within the next 10years. Of acute nurse specialists; 30% adult and 16% paediatric nurses were due to retire within 5 years.
7. A significant number of community nurses were due to retire within the next 5 years. Loss of these posts will impact on the acute sector and have implications for effective delivery of national haemoglobinopathy screening programmes.
8. Most of the larger centres delivered haemoglobinopathy training to ST3-7 trainees although the time allocated was generally short and many trainees did not participate in the outpatient aspects of care. Particularly in smaller services /low prevalence areas it is difficult to see how all the core competencies and skills for haemoglobinopathies in the haematology curriculum (2010) can be achieved. This level of experience does not equip consultants to undertake the highly specialised care required for some patients.
9. Paediatric haematology training was restricted to fewer centres and not all paediatric trainees will have exposure to haemoglobinopathies during their general paediatric rotations. Furthermore there are no core competencies in the curriculum.

Key Recommendations

1. **Hospitals should review their medical and nursing staffing to take into account the current and projected numbers of patients. This should recognise the medical and nursing supervision of patients requiring regular blood transfusion and iron chelation and reflect, for adult services, the numbers transferring over from paediatric care and the older patients at risk of developing chronic complications.**

2. **Robust arrangements should be in place to provide expert consultant advice at all times. Hospitals with single-handed consultants should consider new appointments, and all should consider the need to make formal arrangements with other centres to cover out of hours on call and for absence.**

3. **Training programmes must ensure that all haematology consultants are able, at appointment, to deliver essential and emergency care at local level for haemoglobinopathy patients. For trainees in low prevalence areas, with little exposure to haemoglobinopathy patients, this might involve secondment to larger centres or undertaking specific learning modules.**

4. **Additional training should be provided for consultants intending to undertake a specialist role including those responsible for care in smaller centres.**

5. **Curriculum requirements for general paediatrics should be reviewed to include core competencies for the acute care of children with haemoglobinopathies.**

6. **Additional training requirements for specialist paediatric care should be identified and sites identified which can deliver these either to paediatric haematology or paediatric trainees.**

7. **The key contribution of hospital and community based nurses to the acute and chronic disease management of sickle cell and thalassaemia patients should be acknowledged and numbers should be brought into line with those of other long term condition.**

8. **Job planning for specialist nurses must include adequate time to deliver education for other hospital staff and to undertake audit and service development.**

9. **Local arrangements for delivery of the national screening programmes must ensure that specialist haemoglobinopathy counselling is available to all individuals at risk**

Introduction

A survey was performed to gain some understanding as to the current workforce providing care for patients with haemoglobinopathies (sickle cell disorders, thalassaemia syndromes and other rare inherited anaemias) and future requirements. The survey was conducted on behalf of the UK Forum for Haemoglobin disorders in response to the findings of the adult and paediatric peer review programs which reported inadequate numbers of medical and nursing staff and no evidence for workforce planning to meet the increasing demands of the service.

Background

Haemoglobin disorders

1 Sickle cell disease and the thalassaemias are a group of recessively inherited haemoglobin disorders. Care for individuals with these disorders is life-long. SCD affects predominantly people of black African or African-Caribbean origin while Thalassaemia mainly affects those of Mediterranean and Asian origin.

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

3 The national service specification requires all specialist centres to provide data for consenting patients to the National Haemoglobinopathy Registry (NHR). Data from the NHR shows that of 17% are under the age of 5 (appendix 1). The prevalence of these disorders varies according to geographical region, being highest in urban areas with high minority ethnic populations, particularly in Greater London. 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. Centres in London and their linked hospitals manage approximately 80% patients while other 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 West Midlands, North West England and Yorkshire and North London in contrast to the South London centres, which have relatively few patients.

5 Patients 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 include

recurrent painful episodes, acute stroke, recurrent infections and psychosocial issues. The introduction of screening for stroke risk has led to significant numbers of children on long-term regular transfusion. Improved outcomes are also seen with hydroxycarbamide treatment, which successfully reduces hospital admissions but requires outpatient monitoring. These needs continue through transition into adult care and pose additional issues for adult management in a population that is often in further education and entering work. In addition with increasing age and life expectancy come chronic complications such as renal disease, chronic cardio-respiratory disease and bone and joint problems, which require additional specialist medical and nursing support.

6 Children and adults with thalassaemia major and severe intermedia syndromes require blood transfusions every three to four weeks for the rest of their life. This results in an overload of iron in the body, which is harmful, and usually fatal by mid-teens, unless appropriately managed with iron chelating drugs. Standard monitoring for iron overload now includes MRI imaging of liver and heart. Adherence to treatment is important at all ages and predicts prognosis.

7 The varied prevalence of haemoglobinopathies across England combined with the known difficulties in delivery of care to minority ethnic groups poses a challenge for access to specialist care with the risk for inequity across the country, particularly in low prevalence areas. This was recognised with the introduction of specialist commissioning for these disorders from 2013 (ref).

8 Care for patients with haemoglobin disorders is life-long and the focus of the care over recent years has shifted from predominantly inpatient management of acute complications to chronic disease management delivered in the outpatient, day care and community setting.

9 There are a number of other children and adults with rare anaemias who require long term transfusion and/or iron chelation. Numbers are unclear but these patients have similar requirements to thalassaemia patients and are often managed by the same haematology teams. In recognition of this, these conditions are included in specialist service commissioning.

10 Consultant Haematologists also provide clinical advice in the interpretation of abnormal laboratory results and provide clinical leadership for the local delivery of national antenatal and newborn haemoglobinopathy screening programs.

11 The role of acute and community nursing, though difficult to measure, cannot be understated in empowering patients to self-care at home. Nursing care, delivered by highly trained and experienced nurse specialists, keeps people out of hospital (reducing costs) and living higher quality, healthier, productive lives (improving outcomes in line with the NHS Outcomes Framework).

12 Specialist nurses also have a key role in education for other health professionals thereby maintaining standards in emergency departments and on the wards. The former has been the subject of complaints by patients for many years and was recognised by the publication of a NICE short clinical guideline in 2013. Nurses fulfilling this role have advanced qualifications, knowledge and skills, an essential requirement for this highly specialist field.

13 Community based nurses also provide specialist genetic counselling for antenatal and newborn screening programmes as well as for ad hoc screening. Many specialist centres are managed by practitioners with advanced qualifications (health visiting) and have advanced skills. They are responsible for ensuring babies identified with a clinically significant haemoglobinopathy are referred for clinical care; they monitor antenatal and newborn screening to ensure achievement of national standards

14 Community specialist nurses are instrumental in the training of community health and allied professionals, non-professionals (e.g. teachers, social workers etc). They raise public awareness and promote pre-conceptual and other opportunistic testing. Haemoglobin disorders are now an important issue for public health and for the NHS in England. They are common and sometimes life-threatening. They alter every aspect of the lives of affected people. Good care, especially out-patient monitoring and patient health promotion in self-management and prevention of ill health 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.

National Standards

15 '*Standards for the Care of Adults with Sickle Cell Disease'* were published by the UK Forum on Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Committee jointly with the Sickle Cell Society and published in 2008.

16 '*Standards for the care of children and adults with thalassaemia in the UK'* was written by the UKTS 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.

17 *'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.

18 National Care Standards have been developed for paediatric and adult peer review programmes. The first round of peer reviews was completed for children in 2011 and for adults in 2013. Reports are available on WMQRS website (www.wmqrs.nhs.uk). A second round is currently underway. Standards relating to staffing are given in the appendix.

Findings from peer review of adult services 2011-2013: staffing and training

19 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 or children cared for by the service. In some teams the workload for specialist staff was unreasonably high, the staff were working in excess of contracted hours and the provision of consistently good quality care was not feasible. In several hospitals, a single consultant working with a single specialist nurse mainly provided the service. Staff often had additional responsibilities outside the haemoglobinopathy service.

20 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 called for haemoglobinopathy advice out of hours when not on call or when they were on leave.There was little evidence of planning for service expansion. In several areas there are large numbers of children on transfusion regimes which will put a large pressure on adult services as they move over to adult care. In addition there will be increased stress placed on the already stretched system as the ageing haemoglobinopathy patient population develops chronic disease complications with increasingly complicated health needs. This lack of forward planning is of concern. In addition there was no provision in consultant job plans for service development or for network support and development.

21 Routine care of haemoglobinopathy patients, particularly outpatient care was provided almost entirely by the clinical leads, and medical staff in training and other consultants often did not take part in the routine management of adults with haemoglobin disorders; this impacted on the ability of other consultants to develop expertise in provision of care at other times. Junior haematology doctors were often pulled from haemoglobinopathy posts to attend haematology-oncology patients who were seen as more of a priority. Doctors in training were 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 services is currently difficult. In some services, the lead consultant had been in post for many years and involving a more junior colleague would be useful in succession planning. Where there were

small numbers of patients attending a service, the junior haematology staff may not gain sufficient specialist experience in the management of haemoglobinopathy patients.

22 The following recommendations were made in relation to staffing:

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

- **Specialist commissioners and specialist teams should review consultant workforce and plan appropriate future expansion.**

- **Specialist and Local Teams should ensure that, under the supervision of core team members, doctors in training are actively involved in all aspects of care for adults with sickle cell and thalassaemia, meeting required curriculum standards. This may involve specialist training outside the base region or specific haemoglobinopathy training posts to ensure forward workforce planning.**

- **The UK Forum on Haemoglobin Disorders should produce guidance on appropriate nursing staff levels for Specialist and Local teams, taking into consideration the number of adults or children cared for by the service and facilitate development of clear acute nurse competences.**

Methodology

A questionnaire was sent to all hospitals participating in adult and paediatric peer review programmes as well as to members of UK Forum and also those centres registering patients in NHR. The purpose of the survey was to understand the current medical and nurse staffing in relation to the numbers of patients and provision for specialist medical training in haemoglobinopathies. The survey included an estimation of likely retirements with the next 5 years and 5 to 10 years.

Data was collected on numbers of funded posts; Whole Time Equivalent (WTE) of these posts; Acute Trust posts as well as Community Trusts posts; paediatric and adult coverage, stating where posts are shared between both age groups and those shared between paediatric and adult community posts.

Results

Responses were received from 36 NHS hospitals which provided 27 adult and 30 paediatric services. All Trusts were in England apart from one in Wales.

The total numbers of patients represented by the survey is shown in Table 1:

	Adult	Paediatric	Total
Sickle Cell Disorders	5700	5289	10989
Thalassaemia syndromes	726	536	1262
Other inherited anaemias	293	213	506
Total	6719	6038	12757

MEDICAL STAFFING:

A. Adult services

a. Consultants

A total of 27 hospitals responded to the survey. Care for adult patients was delivered by 39 consultants; the majority of consultants, even in larger centres, were single-handed. Almost all consultants were providing care for other haematology patients amongst their duties.

Consultants were asked to state the number of programmed activities in their job plan allocated for haemoglobinopathy care. A total of 116.7 Pas (1PA= 4 h) were identified for the entire cohort of 6719 patients. Table 2 shows consultant numbers and PAs allocated for the different hospitals. Figure 1 shows comparison between sites for allocated PAs.

2 posts were vacant posts at the time of survey but with locums in position. 4.5 new posts had been identified in London and were undergoing recruitment. Details of the job plans for these posts were not available.

Retirements were planned within 0-5 years by 8 consultants. All these, bar one, were outside London. A further 4 indicated retirement within 5-10 years; of these 3 were in London

Patients/trust	No trusts	Total Consultants	Total Pas	Mean PA/trust	Min PA/ trust	Max PA/trust
<50	9	10	8.25*	1.03	0.25	3
50-100	3	3	3.75	1.25	0.75	2
100-250	3	4	10.2	3.4	3	4.2
250-500	8	11	44.5	4.1	2	10
500-750	3	9	45	15	10	20
>750	1	2	5	5		
Total	**27**	**39**	**116.7**			

Table 2: Adult services * PAs for 1 hospital not supplied: mean calculated for 8

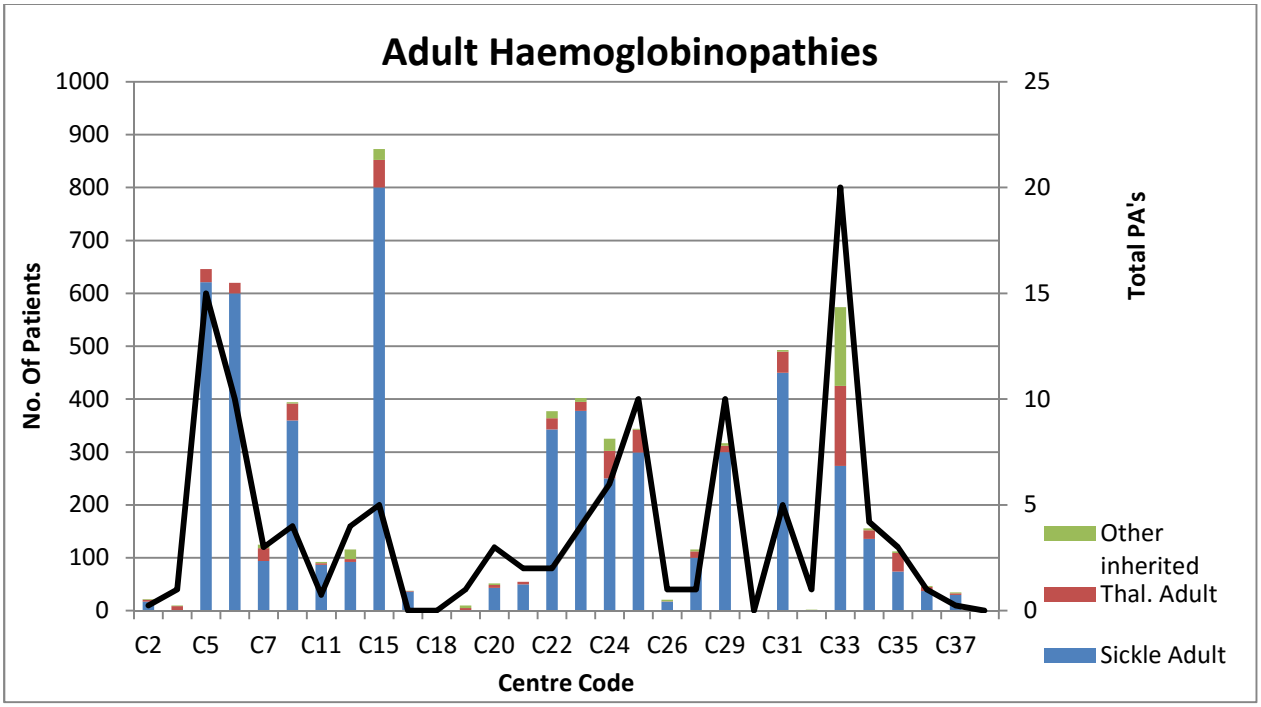


Fig 2: Adults service: allocated Consultant PAs by numbers of patients.

b. Non-training grades

I London Trust had a research fellow in post. No other dedicated non-training grade doctors were reported though several trusts had Specialty Drs who looked after haemoglobinopathy inpatient and day patients as part of their general duties.

c. Trainees

23 Hospitals delivered training to ST3-5 trainees as part of a local haematology rotation. Training in larger centres usually involved 3 months adults and 3 months children though mixed in with other duties. Not all posts involved regular outpatient clinics or day care sessions.

B. Children's services

a. Consultants

Replies were received from 30 hospitals where a total of 51 consultants delivered care for 6038 children. The majority of consultants were single-handed. A total of 87.45 PAs were declared from 28 hospitals as 2 services did not supply details of allocated PAs. The results are shown in Table 3. Figure 2 shows comparison between sites for allocated PAs.

Patient numbers	No	Consultants	Total Pas	Mean PA/trust	Min PA/ trust	Max PA/trust
<50	6	10	8.9*	1.8	0.4	4
50-100	11	14	15.85**	1.58	0.5	3
100-250	4	6	16.2	4.25	1.2	8
250-500	6	14	21.5	3.5	1	5.5
500-750	2	4	13	6.5	4	9
>750	1	3	10	10		10
Total	**30**	**51**	**87.45**			

Table 3: Childrens' services

*PAs for 1 hospital not supplied were not stated: mean calculated for 5

** PAs for 1 hospital not supplied were not stated: mean calculated for 10

The service was delivered by 22 paediatricians (10 alone without Haematologist), 24 paediatric haematologists and 5 adult haematologists (who also looked after adult patients).

Paediatricians were the main providers of care in the smaller centres.

Retirements were planned within 0-5 years by 8 consultants. All these, bar 2 were outside London. A further 6 indicated retirement within 5-10 years; of these 1 was in London. I new post was under recruitment and a further paediatric post with 2 allocated PA was unfilled.

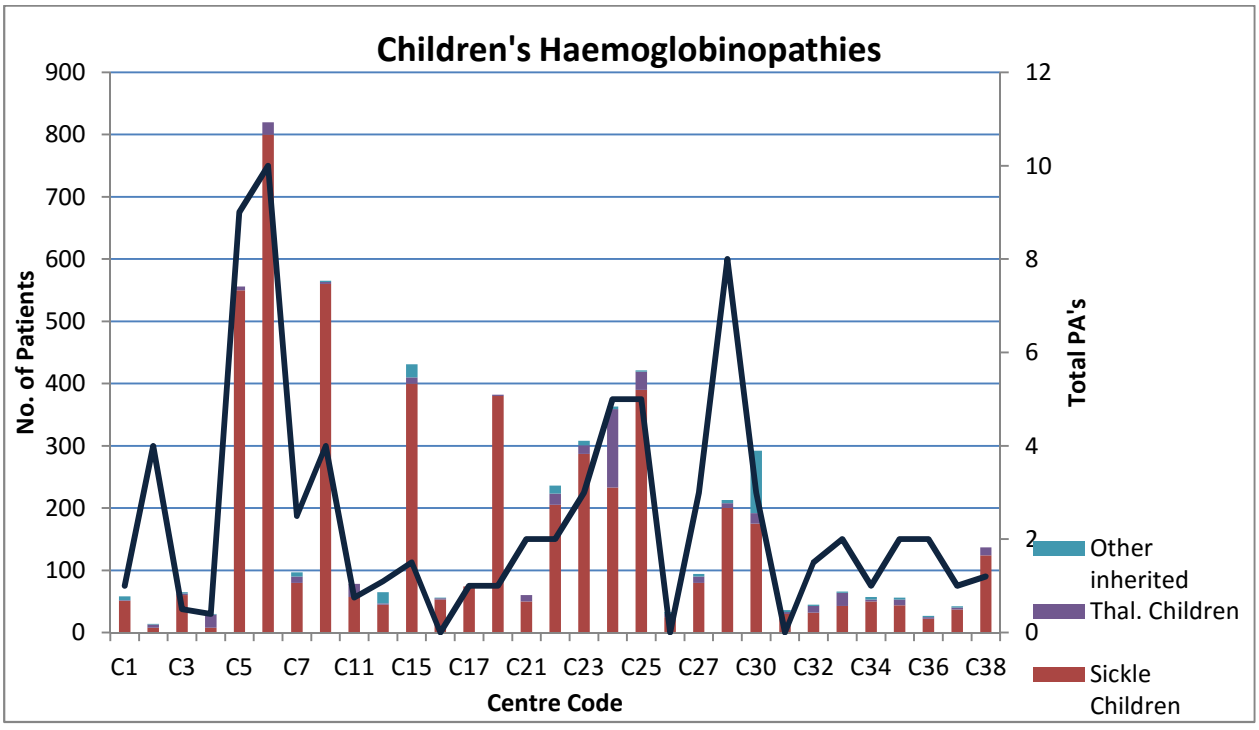


Fig 2: Children's service: allocated Consultant Pas by numbers of patients

b. Non- training grades

Non training grade doctors were involved in the care of children in 4 hospitals: 1 research fellow, 2 Clinical fellows, 1 Staff grade, 1 Specialty Dr. Apart from the research fellow, these doctors also looked after other haematology patients

c. Trainees

Most hospitals delivered some training for haematology and paediatric trainees though experience was very variable and some trainees did not regularly see patients in clinic but managed inpatients. Haematology ST3-7 generally spent 2-4 months in paediatric haematology including Haemoglobinopathy. Paediatric trainees spent 6 months but also saw oncology and other haematology patients. The maximum period for haemoglobinopathy alone was for 6 months for paediatric haematology training

NURSING

A. Adult Clinical Nurse Specialists

21 hospitals gave details of acute clinical nurse specialists for adults (table 4). The other hospitals did not provide any information most of these were smaller centres so it is likely there were no dedicated posts. Results of acute CNS staffing are given in Table 4

Adult Patient numbers	No hospitals	Adult CNS	WTE	Mean WTE /trust
<50	3	3	1.1	0.37
50-100	1	1	0.5	0.5
100-250	5	5	2.9	0.58
250-500	9	10	9.6	1.67
500-750	2	6**	6.9	3.45
>750	1	1*	1.0	1*
Total	**21**	**26**	**22**	

Table 4: Nursing numbers by centre size. *excludes 0.5WTE BMS ** includes one ANP

It can be seen that the majority of services had a single dedicated CNS, even in very large services.

Retirements: Adult Acute Clinical Nurse Specialists

	Planned retirement in 5 years	Planned retirement in 5-10 years	Overall loss in nursing capacity
Funded Posts in Acute Setting = 26*	6	1	7
WTE of the funded posts = 22	6.0	1.0	7.0
% of lost post	23%	4%	27%
% of WTE loss	27%	4.5%	31.5%
*Business case is currently in place for 2 posts @ 2WTE			

Retirements: Community adult Clinical Nurse Specialists

	Planned retirement in 5 years	Planned retirement in 5-10 years	Overall loss in nursing capacity
Funded posts) = 34**	9	5	14
WTE of the funded posts = 32.5	7.5	5.0	12.5
% of lost posts	26%	15%	41%
% of lost WTE	23%	15%	38%
** Business case underway for 1 post @ 1.0 WTE NB: One Trust reducing nursing posts to save costs			

B Children's Nurse Clinical Nurse Specialists

Children's acute nurse specialists are shown below. A total of 17 posts were identified, mainly in the centres. It was notable that some large centres, including two hospitals treating in excess of 600 patients had no acute nurse provision.

Children's numbers	No hospitals	Paed CNS	WTE	Mean WTE/trust
<50	2	2	1	0.5
50-100	4	5	4.2	1.05
100-250	3	3	2.5	0.83
250-500	6	8	5.3	0.88
500-750	1	2	1.8	1.8
>750	1	1	1	1
Total	**17**	**21**	**15.8**	

Retirements: Paediatric Acute Clinical Nurse Specialists

	Planned retirement in 5 years	Planned retirement in 5-10years	Overall loss in nursing capacity
Funded posts = 21*	3	1	4
Funded WTE = 15.8	2.6	0.5	3.1
% of lost posts	14%	5%	19%
% of lost WTE	16%	3%	20%
* Business case being progressed for 'several'			

Retirements: Paediatric Community Clinical Nurse Specialists

	Planned retirement in 5 years	Planned retirement in 5-10years	Overall loss in nursing capacity
Funded posts = 25	2	-	2
Funded WTE = 23.3	2.0	-	2.0
% of lost posts	8%	-	8%
% of lost WTE	9%	-	9%

Conclusions

A. Medical and Nursing workforce

The survey confirmed the findings of the peer review programs:

1. Many consultants were single-handed in terms of the haemoglobinopathy service and cover arrangements for leave and other absence was by consultant colleagues with no specialist interest or training.
2. Most consultants had other responsibilities, even in larger centres.
3. Allocated PAs varied greatly between hospitals, even between those with similar numbers of patients. Some large London centres, in particular, were very poorly staffed. It should be noted that some large services didn't submit data
4. Paediatric haematologists and paediatricians deliver care for children across the UK with adult colleagues providing input in hospitals with no dedicated paediatric haematologists. There were some examples of cross working and cover between adult and paediatric services but this was restricted to a few centres only.

5. The haemoglobinopathy workforce is ageing: 8/37 adult consultants (21%) and 8/29 (28%) paediatric consultants intend to retire within 5 years, and 3/37 and 6/29 within 5-10years respectively.
6. Most intended retirements are outside London where less training can be delivered within local training programs. This therefore presents a significant concern for succession planning
7. There were very low numbers of dedicated clinical nurse specialists, particularly for paediatric patients. Some of the largest centres surveyed had no acute nurse provision
8. Haematology specialist nurses, where present were mostly working in isolation.
9. The specialist nursing workforce is also ageing with a number of retirements within the next 10years. Of acute nurse specialists; 30% adult and 16% paediatric nurses were due to retire within 5 years.
10. A significant number of community nurses were due to retire within the next 5 years. In some areas community nurse posts were being lost as a cost saving exercise. Loss of posts will impact on the acute sector and have implications for effective delivery of national haemoglobinopathy screening programmes.

B. Trainees

1. Most of the larger centres had ST3-7 trainees attached to the adult haemoglobinopathy service although the time allocated was generally short. Many trainees did not participate in the outpatient aspects of care. Particularly in smaller services /low prevalence areas it is difficult to see how all the core competencies and skills for haemoglobinopathies in the haematology curriculum (2010) can be achieved. This level of experience does not equip consultants to undertake the highly specialised work required for some patients such as iron chelation and hydroxycarbamide treatment, the management of chronic complications and overseeing pregnancy and surgery.

2. Paediatric haematology training was restricted to fewer centres and not all paediatric trainees will have exposure to haemoglobinopathies during their general paediatric rotations. Furthermore there are no core competencies in the curriculum. It is therefore possible that Paediatricians, who have no specific training or experience in the care of children with sickle cell or thalassaemia, will be appointed to consultant posts.

Recommendations

1. **Hospitals should review their medical and nursing staffing to take into account the current and projected numbers of patients. This should recognise the medical and nursing**

supervision of patients requiring regular blood transfusion and iron chelation and reflect, for adult services, the numbers transferring over from paediatric care and the older patients at risk of developing chronic complications.

2. **For calculating consultant requirements it is suggested that consultant PAs are allocated as follows:**
   - **0.25PA CPD per consultant**
   - **1.5 PA for every 50 patients for direct clinical duties* made up as:**
     - **Clinics including specialist annual review (2.0 hours/week)**
     - **Ward rounds (1.5 hours/week)**
     - **Day unit attendance and ad hoc consultations, on call (1.0 hour/week)**
     - **Clinical administration and MDT meetings (1.5 hours/week)**
   - **0.25 PA for every 50 patients for supporting activities- NHR and data collection, audit, teaching, patient liaison, network participation)**
   - **1PA for geographical area clinical lead**
   - **Additional PAs as required (e.g. for specialist training, laboratory work, research, outreach clinics).**

     Some of these duties may be delegated to clinical nurse specialist or specialty doctors, with the appropriate training: this must be recognised in their job plans

3. **For centres with fewer than 50 patients job plans will need to be determined locally. However, such centres should consider joint working with other hospitals in the geographical region or with specialist centres**

4. **Robust arrangements should be in place to provide expert consultant advice at all times. Hospitals with single-handed consultants should consider new appointments, and all should consider the need to make formal arrangements with other centres to cover out of hours periods when the haemoglobinopathy consultant is not on call, and for times they are on leave or other absence.**

5. **Training programmes must ensure that all haematology consultants are able, at appointment, to deliver essential and emergency care for haemoglobinopathy patients. For trainees in low prevalence areas, with little exposure to haemoglobinopathy patients, this might involve secondment to larger centres or undertaking specific learning modules.**

6. **Curriculum requirements for adult and paediatric haematologists in training should be reviewed to ensure they are able to deliver care at local and specialist level as set out in the Specialised Teams National Definition Set Definition No. 38 Specialised**

Haemoglobinopathy Teams (see appendix 2). These requirements should be assessed appropriately within training portfolios as well as by examination.

7. **Additional training should be provided for consultants intending to undertake a specialist role including those responsible for care in smaller centres. It is suggested that a 6-12 months specific training, to undertake defined roles is undertaken. This could be in the form of out of programme experience or as post CCST training.**

8. **Curriculum requirements for general paediatrics should be reviewed to include core competencies for the acute care of children with haemoglobinopathies.**

9. **Additional training requirements for specialist paediatric care should be identified and sites identified which can deliver these either to paediatric haematology or paediatric trainees. As above, this may be delivered with training rotations or necessitate out of programme or post CCST training.**

10. **The key contribution of hospital and community based nurses to the acute and chronic disease management of sickle cell and thalassaemia patients should be acknowledged and numbers should be brought into line with those of other long term condition.**

11. **Job planning for specialist nurses must include adequate time to deliver RCN training competencies for hospital staff and to undertake audit and service development.**

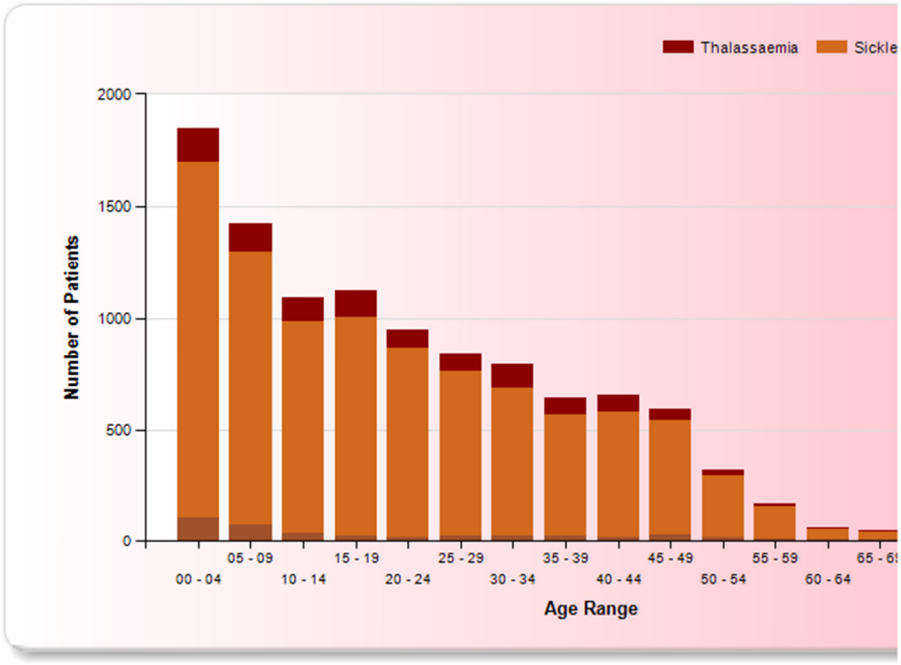
12. **Local arrangements for delivery of the national screening programmes must ensure that specialist haemoglobinopathy counselling is available to all individuals at risk**

13. **A registrable training programme for haemoglobinopathy specialist nursing and an outline of career progression opportunities is required to attract junior nurses into the specialty.**

Acknowledgements

I would like to thank all those who participated in this survey. Thanks also to committee members of the UK Forum: Anne Yardumian, Lola Oni, Collis Rochester-Peart, Jo Howard, Neil Westerdale, Banu Kaya, Elaine Miller (UK Thalassaemia Society) and John James (Sickle Cell Society) for reviewing the report, and to Christopher Ardern for help with data analysis and graphs.

Appendix 1: Age breakdown of sickle cell and thalassaemia patients: NHR June 2015



Appendix 2: 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 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 (eg 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.