NHS

East Midlands Specialised Commissioning Group

The National Haemoglobinopathies Project

a guide to effectively commissioning high quality sickle cell and thalassaemia services

July 2011

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Contents

Commissioned by the Department of Health
Delivered by the East Midlands Specialised Commissioning Group

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1

Foreword and endorsements

Foreword

It has been a privilege to serve as chairman of the National Haemoglobinopathies Project Board and I am delighted to be able to introduce the project outputs.

The project was established by the Department of Health to produce a set of documents for commissioners to enable the delivery of high quality, equitable and patient centred lifespan care for all haemoglobinopathy patients using the NHS in England. An Expert Working Party, chaired by Dr Phil Darbyshire, has provided the major input, supplemented by available published clinical guidance. Extensive consultation has been undertaken with stakeholders including patients, patient groups, clinicians and commissioners. The project outputs have been reviewed by members of the Project Board.

The project documents are intended primarily as a toolkit to assist commissioners but they have been produced in a way to make them useful to anyone with an interest in haemoglobinopathies either as a complete set or as individual documents. With this in mind core information is repeated in each document.

All those involved with the project have worked tirelessly to deliver a comprehensive set of documents to a very demanding timetable. I would like to pay tribute to the dedication and professionalism of the project manager, the Expert Working Party and the Project Board, and to thank them all for their contributions and also the many others who have responded to the consultation processes.

Lee Bartholomew
July 2011

Endorsements

"This is a very timely document which should help to mainstream sickle-cell and Thalassaemia care within NHS commissioning. The inclusion of a dedicated section on Community Care offers a most welcome opportunity to responsively address key concerns that came from my nationwide itinerary during the development – that until a cure is routinely available, people would rather live with sickle-cell disease in the community, if a meaningfully wider public health approach were adopted by those commissioning services."

Dr Asa'ah Nkohkwo FRSPH, Clinical Scientist, Nationwide Comprehensive Care Adviser, Sickle Cell Society

"The UK Thalassaemia Society is proud to have been a part of the National Haemoglobinopathies Project; and we welcome this document which will be invaluable to commissioners and all those involved in the commissioning of integrated and comprehensive services for thalassaemia and sickle cell patients. We share the vision outlined in the document; in particular the principles that people living with thalassaemia should be active partners in their care management and should have access to a high quality of care regardless of where they live. We are profoundly encouraged by the statement that care will be designed in a manner which will allow patients to engage with education and employment so that they can become fully integrated, functioning members of society. Our thanks to all who have given such dedication and commitment to this project."

Gabriel Theophanous
President, UK Thalassaemia Society

"I am delighted to endorse these guidelines which I believe are doubly important.

Firstly, they provide a sound foundation for developing quality services. Secondly, they represent a formal recognition from both the Department of Health and specialised commissioners that haemoglobinopathy services are a mainstream responsibility of the NHS.

I have always believed strongly that quality care is fundamental to delivering an ethical and effective screening programme. In particular, I have emphasised that one of the key National Screening Committee criteria for the introduction of a screening programme is that treatment and "clinical management of the condition and patient outcomes should be optimised by all health care providers prior to participation in a screening programme."

I welcome the report and applaud its aim to ensure that there is a seamless interface from screening into care. As the report makes clear, it is important to develop specialist centres which can provide expert advice. Also important is the requirement that services provide data to the Programme. This will enable evaluation of outcomes, scrutiny of how well services are working and information to enable any problems to be addressed.

Many have contributed to this report including committed professionals, users who speak out about their experiences, the voluntary sector, the Screening programme team and more recently the All Party Parliamentary Group. It is striking that across the spectrum of voices, there has been strong collaboration and a clear shared view about the importance of mainstreaming these services within the NHS so that they are fairly available to all in need.

There is widespread recognition that the haemoglobinopathies have traditionally been a neglected area and now needs to be taken more seriously. These are lifelong conditions with significant impact on service users – they need fair resources within the NHS in line with provision for other similar conditions.

In articulating the needs of users and a framework for services to meet them, this report is an important step forward. Of course, it is not an end in itself. In addition to putting the framework in place there still remains an important education and awareness raising challenge. Primary care and front line professionals still need to understand that sickle cell disease can kill quickly from preventable causes such as infection and stroke. There remains misunderstanding and stigma about all the conditions and the way they are genetically inherited.

I would like to personally thank Jon Currington and Binal Nathwani for their hard work in the face of many challenges in developing this work and to say "very well done – thus far."

Dr Allison Streetly OBE
Programme Director,
NHS Sickle Cell and Thalassaemia Screening Programme

"On behalf of members of The UK Forum on Haemoglobin Disorders, I would like to welcome the publication of the comprehensive commissioning guidance documents which are the output of the National Haemoglobinopathies Project. They are the result of a year's very intensive hard work, on which their authors are to be congratulated. A great deal of effort has gone into ensuring that the views of stakeholders are represented. We know, from our round of peer review visits to centres of networks providing care for children with sickle cell disease and thalassaemia during 2010 -11, that commissioning arrangements for these important services have, to date, been erratic and opaque. Now that we have the Specialised Services National Definition Set (38) for Haemoglobinopathy Services outlining the key elements required at this end of the spectrum of care by people with these life long-conditions, we very much hope that specialised commissioners will avail themselves of this very useful and practical guidance as to how they might best work with providers to offer equitable and high quality specialist care to children and adults with sickle cell disease or thalassaemia. We look forward to working with our commissioning colleagues at both local and specialised levels to monitor and improve care standards."

Dr Anne Yardumian
Chair, The UK Forum on Haemoglobin Disorders

"The Royal College of Nursing welcomes the documents published by the National Haemoglobinopathies Project. We believe these documents will be of great benefit to commissioners, providers and patients alike outlining as they do what effective sickle cell and thalassaemia care looks like.

We commend the direct involvement of users, carers and user organisations to inform this work. We also endorse the explicit aspiration of the Project to reduce health inequalities, by improving access for all patients irrespective of where they live, and by promoting the consistent delivery of high quality care to all patients.

We are particularly pleased to see senior nurses participating in the successful delivery of the Project, and the importance of nursing being acknowledged in the effective long-term management of these clinical conditions. The outputs in this Project will support the recently published clinical competencies framework for haemoglobinopathy nurses."

Dr Peter Carter
Chief Executive,
Royal College of Nursing

Cecilia Anim
Deputy President,
Royal College of Nursing

2

The vision for integrated, equitable and effective haemoglobinopathy lifespan care

Introduction

The national haemoglobinopathies project was tasked to produce the following set of guidance documents for specialised and non-specialised commissioners:

The vision for integrated, equitable and effective haemoglobinopathy lifespan care.*
Designation standards for specialised haemoglobinopathy services.
Model service specification for community haemoglobinopathy care.
Model service specification for specialised / tertiary (acute) haemoglobinopathy services.
Equality impact assessment.*
(*These papers were agreed by the Project Board)

The project structure and membership is outlined in Appendix 1.

Project specific glossary

The project's understanding of a clinical network of care is informed by the definition developed by the Scottish Executive – it is linked groups of health professionals and organisations from primary, community, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality clinically effective services.

Designated providers / lead acute providers – these are the hospitals that will deliver the specialised standards, one of which is clinical leadership of the clinical network of care. Designation of specialised services is undertaken by specialised commissioners.

Accredited providers – these are hospitals with a lot of experience in managing haemoglobinopathy patients that go through a form of partial designation so that they can deliver some specialised functions. Accreditation will also be undertaken by specialised commissioners in conjunction with the designated provider.

Linked providers – these are other acute hospitals within the geographical boundaries of the haemoglobinopathy clinical network. They will deliver no specialised haemoglobinopathy care, i.e. they will treat haemoglobinopathy patients with fewer clinical complications. Any non-specialised acute care is commissioned by non-specialised commissioners.

Community care – a set of clinical activities organised and delivered within community care services usually take place outside the hospital setting.

The vision for haemoglobinopathy services

The national haemoglobinopathies project presents the following as its vision for optimal and effective, lifespan haemoglobinopathy services.

Every sickle cell disease (SCD) and thalassaemia patient has the right to receive clinical care that is of high quality and consistently delivered. Care will be delivered by experts or by healthcare professionals supported by experts under commissioned network arrangements. In turn, SCD and thalassaemia patients and their carers are urged to engage fully with healthcare and to become partners in their own care management.

Any care delivered will meet the specific clinical needs of patients and respect their rights and dignity as individuals. All care will be delivered in a non-judgmental manner, free from any stereotyping.

Every SCD and thalassaemia patient irrespective of where they live and local prevalence, has equal rights of access to consistently high-quality care. The project acknowledges that the geographical distribution of clinical expertise may require patients to travel to access the care they need. The location of service provision should be reviewed to ensure that it does not adversely affect the take-up of care. Patient feedback into the development of these documents stressed the value of the local provision of care.

There will be consistency in the commissioning and designating of specialised care across the country to deliver the necessary collaborative and network arrangements required to provide access to expert care for all patients.

Care will be delivered in a way that maximises autonomy, supports engagement in education and employment and allows patients to lead fully functioning lives. This can only be achieved if commissioners at local level actively engage and include public sector and other agencies in the development of care pathways. This should include voluntary sector, schools and social care.

Irrespective of the number of providers and professionals involved in the delivery of care, care planning will support seamless transition across services and the patient will be encouraged to play an active part in planning their own care. Care plans will be reviewed at least annually with the patient and will form the basis of any patient hand-held record.

The care delivered on these pathways will, where possible, be evidence based. Where there is no independent evidence in place, care will be based on nationally agreed clinical consensus as demonstrated in the published clinical guidelines.

Every patient will have the assurance of being under the overall responsibility of their local designated centre. The project acknowledges that for practical purposes lead acute providers will delegate some of the day-to-day management of care to accredited and linked acute providers under transparent commissioned arrangements.

All care will meet the specific clinical needs of patients and respect their rights and dignity as individuals

The delivery of that vision

Effective haemoglobinopathy care is more than its clinical component parts of primary, community, acute and tertiary care. The view of the clinical experts informing the project is that care is most effective when it is integrated between providers, and when it can meet patients' emergency and long-term care needs throughout their life. Care also has to be sufficiently responsive to meet the clinical needs of patients as they get older and experience the clinical impact of a life-long condition.

Effective care can only be achieved by the development of the following:

1. A national approach to commissioning the specialised element of care i.e. all the regions across NHS England will commission specialised haemoglobinopathy care concurrently and in consultation with each other to allow for the required collaborative arrangements within the designation standards to be achieved across England.
2. Via the designation process, the further development of haemoglobinopathy clinical networks of care that will build on existing arrangements and relationships already in place. As part of this designation process commissioners will engage with all providers in the region to apprise them of their role and responsibility in relation to the existing national guidelines.
3. As part of the designation process, lead acute providers will take on the clinical leadership function of the clinical networks of care, which will include the development of consistent guidelines and protocols across all network providers to better deliver integrated and consistent high-quality care. Lead acute providers will also have responsibility for clinical governance, audit and training on behalf of the network.
4. As part of the designation process, all haemoglobinopathy clinical networks of care will have a Clinical Services Improvement Group (CSIG) with some consistent terms of reference between networks, to support regional and national benchmarking. Benchmarking should be undertaken to reduce variation in care and improve standards overall. At network level, benchmarking could be overseen by specialised commissioners. Whilst at present there is no organisation in place that could oversee national benchmarking, this responsibility could possibly be managed by the UK Forum of Haemoglobin Disorders, given the lead this organisation has already taken in improving care.
5. Despite differing commissioning arrangements, community based haemoglobinopathy care is an integral part of the pathway and must be included in clinical networks of care. This will support integrated seamless pathways with clear referral criteria to acute care and support for patients following a hospital episode (either as an outpatient or inpatient as required). There should be joint outcome and performance measures to support such integrated working. Experienced community healthcare professionals will formally support clinical colleagues with less expertise within their own network and in other networks. (This may require commissioners to agree remuneration or reciprocal agreements within other clinical areas to offset any cost pressures).
6. Patients will be educated how to manage their own pathways primarily by community professionals. Patients will be advised of the key milestones within a lifespan pathway for instance, regular transcranial doppler (TCD) scanning for children. Attention will be given to educating patients and carers on the long-term nature of their disorder. Direct user engagement suggests that many SCD patients define their condition largely in terms of crises and therefore may not be aware of the national guidelines related to scheduled care, such as the annual review.
7. Commissioners will use the designation and commissioning process to collect a consistent dataset across the country to allow for regional and national benchmarking, which will support continuous service improvement. This dataset should be submitted to the existing National Haemoglobinopathy Registry (NHR – see http://www.nhr.nhs.uk/). This data collection will also inform the development of clinical and cost effectiveness evaluations of service provision across the country.

Aims

The project has two aims:

Aim one – the redress of present inequalities:

The first aim is to redress the present clinical inequalities outlined powerfully in a report by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), A Sickle Crisis? (2008). Present inequalities are:

- Unequal haemoglobinopathy service provision throughout the country.
- Undue variation in the quality of clinical outcomes.

The NCEPOD report provided independent evidence that such inequalities are leading to unnecessary morbidity and even avoidable deaths.

The redress of both of these inequalities can partially be achieved through the designation process. Designation, if adopted nationally, will see greater equality in the provision of tertiary services, which will improve access to clinicians most experienced in managing complex care.

Also as part of designation, specialised commissioners and lead acute providers will work together to promote further the existing networks of care. By developing and disseminating consistent clinical guidelines and protocols to all providers, networks of care have the potential to support all providers to deliver a consistent baseline of care in accordance with the published standards.

Care also has to be sufficiently responsive to meet the clinical needs of patients as they get older and experience the clinical impact of a life-long condition

Aim two – to improve care overall:

The second aim is to improve the overall quality of care through a model of care based on designation of lead acute provider and development of clinical networks of care. The designation process explicitly develops the role and responsibility of the clinical network of care to standardise and raise the quality of clinical care overall delivered by providers, irrespective of how those services are commissioned. Networks can also support service innovations and the development of integrated pathways that overcome different commissioning arrangements. Improved quality of care can be furthered by auditing outcomes against the consistent guidelines and protocols mentioned above. This has the potential to improve care in a number of ways:

- Designation in the way described will enable commissioners to collaborate with all providers in the network area to secure integrated pathways.
- Clinical networks of care promoting collaborative working can mitigate against any possible risk of fracture points occurring in pathways that may arise from different commissioning arrangements for specialised and non-specialised services.
- Regional benchmarking of clinical outcomes against the network wide clinical guidelines and protocols.
- The national benchmarking of all haemoglobinopathy clinical networks against an agreed range of indicators, for example serious incidents and deaths.

The project's model of care can only be delivered if it is led by commissioners using all the levers and influences available to them to engage with providers and drive change.

Commissioners will support this network of care approach by designating specific acute provider(s) to deliver expert oversight of patients' needs and care as well as care for the patients experiencing the most complex clinical complications. Under the authority of the specialised commissioners the designated provider(s) will adopt the clinical leadership function of the designated clinical network of care. The model of care will be dependent on enthusiastic clinicians willing to exercise leadership on clinical matters.

The project acknowledges the work of the paediatric and adult peer review programme led by the UK Forum on Haemoglobin Disorders.

Whilst the scope of the national haemoglobinopathies project is limited to producing guidance documents for healthcare commissioners, the project further acknowledges the importance of the wider determinants of health. Many haemoglobinopathy patients may also experience a range of other inequalities which have the potential to adversely affect their health. Non-specialised commissioners are particularly urged to ensure that pathways and policies are in place to refer patients to social care and voluntary organisations that may be able to assist in supporting wider public health matters.

The second aim is to improve the overall quality of care through a model of care based on designation of lead acute provider and development of clinical networks of care

The two principles underpinning the model service specifications

Principle one – the designated provider will, via the clinical network, provide oversight on the organisation of services to patients. Working closely with commissioners they will ensure effective governance arrangements exist across the network.

The NHS Sickle Cell and Thalassaemia Screening programme has formally requested that in line with other screening programmes, all newborns identified as screen positive for SCD or thalassaemia will be assigned to the overall responsibility of a designated provider wherever their day to day management occurs. This designated provider will be responsible for ensuring provision of data on programme standards to the screening programme. The National Haemoglobinopathies Project has accepted this request.

Furthermore, to promote equity of care for all patients, the project recommends that as part of designation of specialised care all haemoglobinopathy patients, children and adults will be under the overall responsibility of the designated provider. For practical purposes and dependent on the clinical expertise in place, this responsibility may be delegated to other acute providers under a commissioner led formalised accreditation process.

In support of the leadership responsibility of the designated provider(s), the National Haemoglobinopathies Project Board has concluded that there should be only two model service specifications:

- **A model service specification for community care.**
- **A model service specification for specialised (designated) acute care.**

The Project Board concluded there should be no dedicated model service specification for non-specialised acute care as any care commissioned from accredited or linked acute providers must be delegated from the lead acute provider as part of transparent network arrangements. The degree of delegation from the designated to the accredited or linked provider will vary across each network based on local expertise in place.

- Linked acute providers may provide care in the following ways:
  - Emergency care for acute symptom management – this would not be specifically commissioned, as it would be included within any generic A&E bundle. However, ensuring effective pain management protocols are in place and regular audit of the painful episode pathway will be the responsibility of designated provider(s).
  - Scheduled care – this is care that is delegated down from the designated lead acute provider.
- Accredited acute providers will also provide the above two elements of care; in addition, they will provide some agreed elements of specialised care. Depending on local expertise, linked and accredited acute providers will have clear escalation policies to secure specialised input as required.
- Designated providers in lower prevalence areas are also likely to require clear escalation policies to larger designated providers for the most complex / rarer aspects of care.

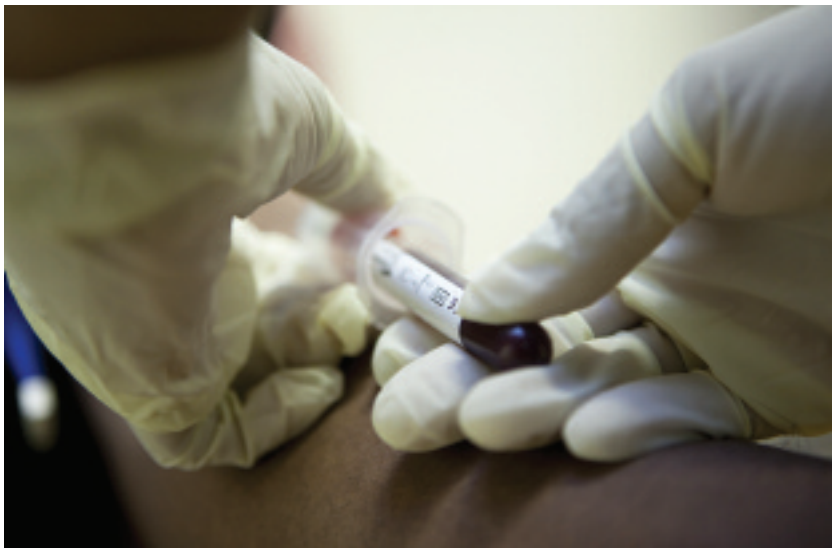
To secure optimal haemoglobinopathy care, community services must also be linked into all networked arrangements. This will require the co-operation of non-specialised commissioners.

As part of their leadership function of the clinical network, the designated provider(s) will oversee the development of all clinical guidelines and protocols across their network including those used in a community setting relating to clinical care, even though community services will be separately commissioned. This is to ensure consistency of care and seamless pathways; it will also support shared governance and audit. Training and clinical professional development opportunities should be made available to community staff via the network.

Principle two – care provision must reflect clinical need and not prevalence. Ethically, the project has as its starting point that an individual patient's clinical need for care exists independently of any issues relating to geography or prevalence. In other words any patient with SCD or thalassaemia has the right to high quality care irrespective of the numbers of other haemoglobinopathy patients within the locality.

Therefore the project has concluded that both model service specifications will be generic and not linked to prevalence i.e. the documents describe the components of care required to meet clinical need. Please note the term used is "care" not "services". The project recognises that given resource constraints and the issue of prevalence, services may be configured differently across the country. However, irrespective of how services are configured, they need to deliver the components of care outlined in the service specifications.

The project acknowledges that affordability must inform the commissioning process and that prevalence is an important factor in determining affordability. Therefore, where it is possible to do so, commissioners of non-specialised services in low prevalence areas may wish to explore other methods of securing care, for instance joint commissioning of care between different areas to optimise resources.



Additional contextual information

- Sickle cell disease and thalassaemia (SCD&T) are complex lifelong conditions that can affect every part of the body. Throughout their lifetime patients, especially SCD patients, will present for emergency care, which can be complex and life threatening; the geographical prevalence of the condition means that patients can present for care anywhere in the country. Effective emergency management will require formal escalation to expert acute care. Community services also have a critical role in actively case managing those patients with the greatest frequency of hospital attendances.
- As this is a lifespan condition, patients also require all the elements of scheduled care common to all long-term conditions. Effective long-term care will include following components:
  - Community care that clinically supports patients within agreed parameters particularly relating to acute and long-term pain management of SCD and appropriate long-term conditions management and support with clear escalation criteria to acute and specialised providers. Community care should support patient self-management within clinically safe parameters, promoting healthy lifestyle choices.
  - Regular access to specialised acute care (this may be delivered by non-specialised acute providers under agreed network arrangements).
  - In addition, many patients will also require the support of social care and other key agencies that can assist with education, housing and other such issues.
  - Commissioners of non-specialised services are encouraged to integrate these pathways and referral processes where possible to maximise the impact of care and reduce the duplication of resources. This is consistent with the QIPP approach to optimising the use of resources. Quality, Innovation, Productivity and Prevention (QIPP) is a national initiative to optimise the use of financial resources to secure maximum benefit for patients.
- Historically, haemoglobinopathy patients have experienced a significantly reduced lifespan due to their condition, often dying from acute complications of their disorder. This is now beginning to change, albeit slowly, with patients living longer and morbidities arising from the chronic nature of their condition likewise increasing. Patients are likely to survive into their 40s and 50s; however, they are more likely to experience physical impairment and organ damage; (such impairments can also occur at a much younger age in some patients). Commissioners are advised that care for older patients is a relatively new development and therefore they should work closely with clinicians in the development of any services.
- Clinicians in low prevalence areas may be unfamiliar with haemoglobinopathies and some of the clinical complications associated with it. Therefore transparent networked arrangements between linked acute providers and the designated lead acute provider are essential to deliver a national failsafe level of care.
- Presently, commissioning of haemoglobinopathy care is divided between the regional specialised commissioning groups which have responsibility for commissioning specialised (tertiary) care, and primary care trusts (PCTs) which have responsibility for commissioning any community and non-specialised acute care. A comparable division in commissioning arrangements is likely to remain under anticipated health reforms.
- Presently, there are no specific tariffs for haemoglobinopathy specialised care. Acute providers delivering specialised care will also deliver non-specialised care; commissioners will need to work with providers to agree how best to separate out specialised and non-specialised clinical activity.
- As community care and acute care are commissioned separately to specialised services, there are increased risks of creating fracture points within care pathways compromising integrated care. By strengthening the role of the designated provider and clinical network to promote collaborative working, such fracture points can be overcome.

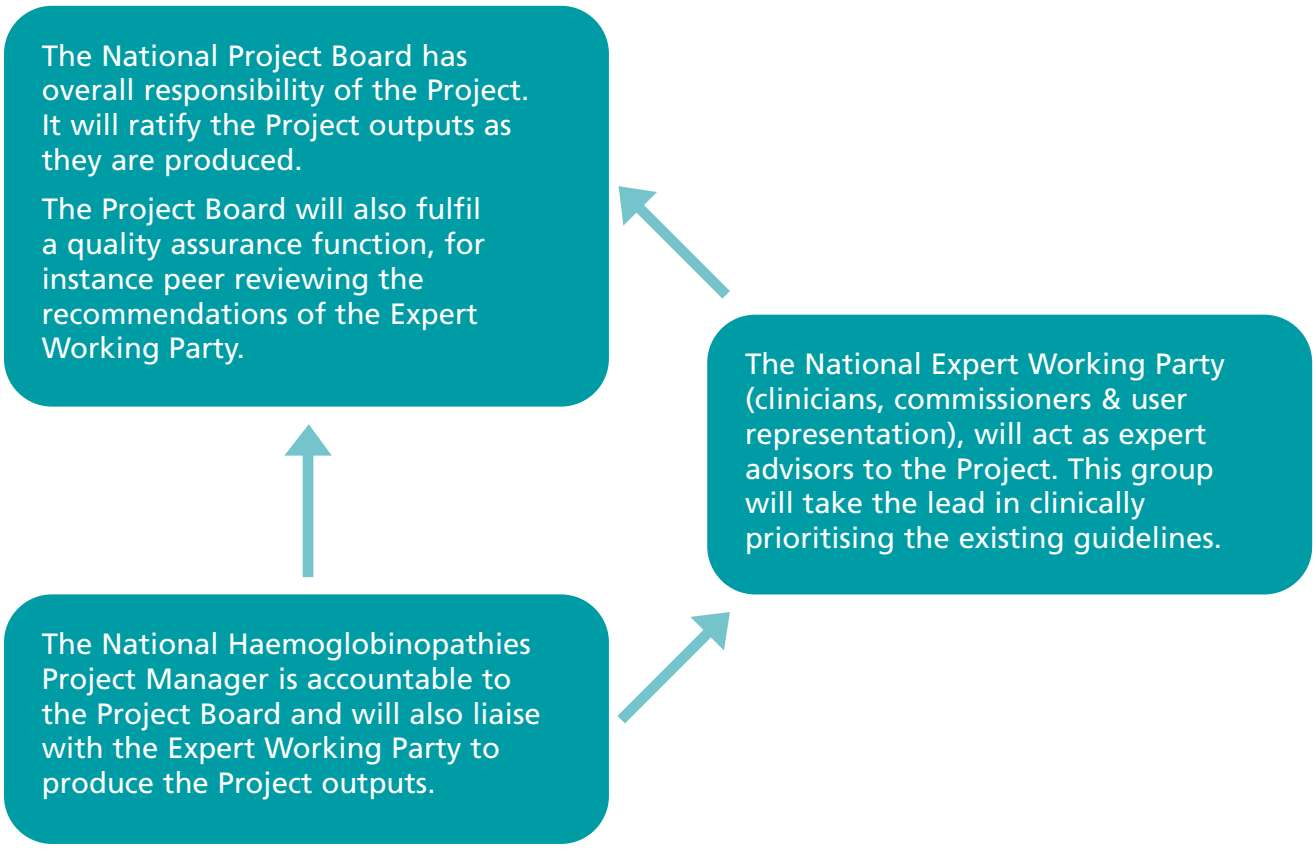
Additional information related to the guidance documents

- The model service specification for specialised acute care (i.e. designated centres) is written using Schedule 2 (Service Specification) of the NHS standard contract for acute hospitals 2011–12 (effective from April 2011).
- The model service specification for community care is written using Section 1 – Specification of the NHS standard multi-lateral community contract for 2010 – 11 (valid April 2010 – March 2011 only). The new community contract for 2011 has yet to be issued.
- Any information contained in these model service specifications is written to be transferable to future specifications templates.
- The specifications are written to reflect core elements of the lifespan pathway and make no assumptions about who the provider of that care may be.
- To date, there has been no national consensus on the core elements of community care and the role of the lead nurse in that service provision. The model service specification reflects:
  - Examples of best practice from across the country (as agreed by members of the project's Expert Working Party).
  - Areas of current activity that perhaps could be delivered by other providers e.g. the third sector – these have been identified by nurses presently leading community haemoglobinopathy services.
  - Areas of possible service development to improve care and secure efficiencies across the pathway. These have been identified by community professionals in recognition of the need to continually innovate new models of care in line with the QIPP agenda.
  - Where clinical and cost effectiveness data exists, these will be made available to commissioners as part of the project deliverables. Commissioners may wish to use the commissioning process to secure additional cost and clinical effectiveness data.

Appendix 1 – The national haemoglobinopathies project structure and membership

The project structure benefited from in-built peer review as distinct and autonomous groups were set up to guide and scrutinise the project.

Figure 1 – Headline Illustration of the national haemoglobinopathies project structure.



Terms of reference were established clarifying the differing roles and responsibilities of the two groups. The Project Board also had a dedicated governance lead with delegated authority from the Board, to offer advice and guide the project.

In addition, the deliberations of the project were assisted by an Integrated Governance Framework. Under Prince 2 project management, it is usual to have a range of documents outlining various project processes. However, to aid the transparent and effective working of the project, it was seen as helpful to merge these processes and approaches into an Integrated Governance Framework (IGF).

The IGF outlined the project's approach to the following areas:

A. Quality (The project used Lord Darzi's definition of Quality as Clinically Effective, Personal and Safe).

B. Stakeholder Engagement.

C. Communication.

D. Equality, Diversity and Human Rights (not specifically defined in Prince 2 methodology but this was included within the IGF to reflect the needs of the healthcare context).

Project Membership

Project Manager

Binal Nathwani – National Haemoglobinopathies Project Manager, East Midlands Specialised Commissioning Group

Project Board Members

Mr Lee Bartholomew – independent lay Chair of the Project Board

Dr Lorna Bennett – Clinical Service Manager, NHS Islington's Sickle Cell & Thalassaemia Centre – Governance Lead for Project

Jon Currington – Senior Strategy & Planning Manager, East Midlands Specialised Commissioning Group

Lorraine Gregory – Senior Policy Manager, Department of Health's Screening & Specialised Services Team

Professor Joe Kai – Professor of Primary Care, University of Nottingham & General Practitioner, Derby Family Medical Centre

Dr Kate Ryan – Consultant Haematologist, Central Manchester University Hospitals NHS Foundation Trust (Manchester Royal Infirmary)

Dr Allison Streetly OBE – Programme Director, NHS Sickle Cell and Thalassaemia Programme

Expert Working Party Members

Dr Edwina Affie – Senior Lecturer and Consultant in Public Health, University of Birmingham

Dr Kofi Anie – Consultant Clinical Psychologist, Central Middlesex Hospital

Dr Claire Chapman – Consultant Haematologist, University Hospitals of Leicester

Verna Davis – Service Manager, Manchester Sickle Cell & Thalassaemia Centre

Dr Moira Dick – Consultant Community Paediatrician, King's College Hospital, London

Dr Phil Darbyshire – Consultant Paediatric Haematologist, Birmingham Children's Hospital. Clinical lead for national haemoglobinopathies project; Chair of the Expert Working Party

Dr Elizabeth Dormandy – Deputy Programme Director, NHS Sickle Cell & Thalassaemia Screening Programme

Daksha Elliott – Lead Sickle Cell & Thalassaemia Nurse, Leicester Community Health Services

Nick Haslem – Commissioning Manager, South East Coast Specialised Commissioning Group

Nicola Howe – Senior Commissioning Manager, London Specialised Commissioning Group

Dr Jane Logan – GP, Mawbey Brough Health Centre, London

Sue Mather – Specialised Commissioner – North West Specialised Commissioning Team

Dr Priyanka Mehta – Consultant Haematologist, University Hospitals Bristol

Elaine Miller and / or Dr Christos Sotirelis, UK Thalassaemia Society

Dr Asa'ah Nkohkwo – Sickle Cell Society

Dr Dianne Plews – Consultant Haematologist, James Cook University Hospital, Middlesbrough

Professor John Porter – Consultant Haematologist, University College Hospital; Professor of Haematology, University College, London

Collis Rochester-Peart – Service Manager / Clinical Lead, South East London SCD&T Centre. Sickle Cell and Thalassaemia Association of Counsellors (STAC)

Maureen Scarlett – Community Nurse Specialist for Haemoglobinopathies, Luton Community Health Services

Helen Tilly – Assistant Director South East London Specialised Commissioning Group

Dr Anne Yardumian – Consultant Haematologist, North Middlesex Hospital

Additional acknowledgments

The project would formally like to acknowledge with thanks, the contributions of the following:

- All the patients, carers and user representatives that attended the User Workshop that took place in London on 30th March 2011.
- Members of the Sickle Cell Disorder and Thalassaemia Association of Counsellors (STAC).
- Members of the UK Forum for Haemoglobin Disorders.

Personal thanks are given to:

- Mrs Belinda Taylor – Head of IT & ECIP Programme Manager, Milton Keynes Community Health Services – for project management mentorship.
- Mrs Cecilia Shoetan for kindly sharing her family's very moving experience of healthcare.

3

Designation standards for specialised haemoglobinopathy services

Part 1 – Executive summary

The national haemoglobinopathies project was tasked by the Department of Health to produce the following set of guidance documents for specialised and non-specialised commissioners:

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Accredited providers – these are hospitals with a lot of experience in managing haemoglobinopathy patients that go through a form of partial designation so that they can deliver some specialised functions. Accreditation will also be undertaken by specialised commissioners in conjunction with the designated provider.

Linked providers – these are other acute hospitals within the geographical boundaries of the haemoglobinopathy clinical network. They will deliver no specialised haemoglobinopathy care, i.e. they will treat haemoglobinopathy patients with fewer clinical complications. Any non-specialised acute care is commissioned by non-specialised commissioners.

Community care – a set of clinical activities organised and delivered within community care services and usually takes place outside the hospital setting.

Any references to patients encompass all users and carers engaging with haemoglobinopathy services.

Introduction

This document presents the designation standards for acute providers (hospitals) seeking specialised status for the delivery of haemoglobinopathy care. (Please note, in this document, the terms designated providers and specialised providers will be used interchangeably).

Specialised care in some clinical areas can be easily defined by specific interventions like paediatric cardiac surgery or bariatric surgery. In haemoglobinopathies, specialised care is much harder to define as it is less focused on specific interventions in the context of these standards. It focuses on care delivered by acute providers in secondary / tertiary care.

Specialised haemoglobinopathy care is defined by the complexity of the patient's clinical condition which can be life-threatening in nature; therefore, specialised care is delivered by acute providers only. Consequently, this document only makes limited reference to other key haemoglobinopathy services delivered in primary care and community care.

This document presents a set of mandatory and non-mandatory standards for the designation of specialised haemoglobinopathy centres spanning NHS England. It is written for both commissioners and providers; the document will also be of interest to users and carers.

The aims informing the designation standards

There are two aims underpinning the designation standards contained in this document. They specifically endeavour to redress the two fundamental inequalities outlined in the report by the National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD), A Sickle Crisis? (2008) http://www.ncepod.org.uk/2008sc.htm. The report outlined variable service provision across the country; it also provided evidence on inappropriate levels of variation in the quality of care provided to sickle cell patients. The aims underpinning the project:

1. Equity of access – all sickle cell and thalassaemia patients must have equal access to high quality specialised care irrespective of where they live and irrespective of where they present for care. For instance, a patient that presents for care in Cumbria, an area of low prevalence for haemoglobinopathies, must have equal access to the same level of specialised care that is available to patients in London, a high prevalence area. This document acknowledges that for some patients such access will require them to travel to a designated provider. It is the principle of equal entitlement to expert care irrespective of location that this document embeds throughout all the Project guidance documents. Designation if delivered nationally will make certain that all patients, irrespective of where they live, will have equal rights and access to the most expert care.
2. Equity in the quality of outcomes – the Project stresses the rights of all haemoglobinopathy patients to have consistent high quality care, irrespective of where they live and where they present for care. The Project has concluded that equity and indeed improvement in the quality of clinical outcomes can only be secured by developing further clinical (haemoglobinopathy) networks of care. This development will be done under the clinical leadership of lead acute providers that will support other providers within their network for the effective management of haemoglobinopathy patients.

These two aims can only be achieved by a national and concurrent approach to commissioning specialised services across NHS England. Improving the quality of care has the potential to reduce costs overall, notably by reducing emergency admissions.

The evidence base for the designation standards

All the guidance documents including the designation standards draw on the following evidence base:

Standards, guidelines and quality requirements	
1	Quality requirements for health services for adults with haemoglobinopathies (likely to be rolled out 2012) – (adult peer review).
2	Royal College of Nursing – Caring for people with sickle cell disease and thalassaemia syndromes – a framework for nursing staff (2011).
3	Sickle Cell Disease in Childhood – standards and guidelines for clinical care – second edition (2010). First edition 2006.
4	Transcranial Doppler Scanning for Children with Sickle Cell Disease – standards and guidance (2009).
5	Quality requirements for health services caring for children and young people with haemoglobinopathies (2009) – (paediatric peer review).
6	Specialised Services National Definitions Set (SSNDS) 3rd edition – specialised haemoglobinopathy services (all ages) – Definition No. 38 (2009).
7	Sickle Cell and Thalassaemia – Handbook for Laboratories (2009).
8	Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2008) – second edition. First edition, 2005.
9	Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (2008).
10	NHS Sickle Cell and Thalassaemia Screening Programme, Standards for the linked Antenatal and Newborn Screening Programme. Second Edition, 2011.
11	Health Technology Assessments (HTAs) – there are a number of HTAs underway with direct relevance to SCD&T. These HTAs have been sponsored by the National Institute for Health Research (NIHR) and also by the NHS Sickle Cell and Thalassaemia Screening Programme.
12	The National Institute of Clinical Excellence (NICE) is currently developing a short clinical guideline on the management of sickle cell crisis in hospital.
Additional evidence	
13	The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report, A Sickle Crisis? (2008).
14	Published literature and grey literature – the project has also taken learning from a range of published documents e.g. documents published by the Department of Health and Social Care. The project has also taken extensive learning from grey literature, i.e. unpublished documents, for instance service specifications and designation documents for other clinical conditions.
Additional expert guidance	
15	The designation standards have also been informed by a comprehensive range of experts that have guided the National haemoglobinopathies project. These experts include consultants, nurses, GPs and specialised commissioners. The project has also been strongly informed by the NHS Sickle Cell and Thalassaemia Screening Programme.

This table is repeated at the end of the document as part of the self-evaluation matrix, to allow the matrix to be used practically, independently of the rest of the document.

In addition, the designation standards are informed by the input and feedback of the following groups:

- The Expert Working Party (EWP) of the National Haemoglobinopathies Project, chaired by Dr Phil Darbyshire, Consultant Paediatric Haematologist, Birmingham Children's Hospital. Dr Darbyshire is the former head of the UK Forum on Haemoglobin Disorders and a recognised expert on clinical services for haemoglobinopathies. The EWP includes the main user groups, the Sickle Cell Society and the UK Thalassaemia Society; it also includes clinicians and commissioners from across NHS England. In addition, the deliberations of this group were supplemented by consultation with the UK Forum for Haemoglobin Disorders and the NHS Sickle Cell and Thalassaemia Screening Programme.
- The Project Board of the National Haemoglobinopathies Project is chaired by an independent lay chair, Mr Lee Bartholomew. Mr Bartholomew is a Chartered Mechanical Engineer with considerable experience in industry. This Project Board includes Department of Health representation and different clinicians and commissioners to those represented on the EWP.
- The lead commissioners with responsibility for haemoglobinopathies in all ten SCGs in NHS England.
- Direct user feedback via a user workshop. The project has also taken the generic learning from user feedback secured by the Pan London Review of Haemophilia Services.

Readers are signed to appendix 1 of guidance document The Vision for Integrated, Equitable and Effective Haemoglobinopathy Lifespan Care, which outlines the project structure, membership and acknowledgments of others that have informed the work undertaken.

The designation standards for specialised haemoglobinopathy services

The designation standards are divided into three sections:

- Section A – the core standards (mandatory) – these are standards that acute providers must meet directly i.e. they must have the clinical expertise and facilities on-site.
- Section B – the collaborative standards (mandatory) – these are standards that acute providers can meet in collaboration with other designated providers.
- Section C – additional quality standards (non-mandatory). Although not mandatory they are in line with best practice. Commissioners are requested to use the designation process to promote such quality developments.

Figure 1 – Headline designation standards for specialised haemoglobinopathy care.

Section A – Core standards (mandatory)	
A1	Clinical leadership (medical and nursing).
A2	Newborn screening.
A3	Prevention and management of neurological complications of SCD through transcranial doppler (TCD) scanning in childhood; specialised neuro-radiology, neurology and neuropsychology services.
A4	Expert multi-disciplinary care for complex patients including complex annual reviews.
A5	Initiation, modification and cessation of long-term transfusion regimes and preventative therapy in SCD.
A6	Initiation, modification and cessation of long-term iron chelation. The monitoring of the complications of iron chelation.
A7	Acute management of severe and life-threatening complications of SCD and thalassaemia.
A8	Long-term specific therapy for severe and complicated SCD cases.
A9	Peri-operative management of SCD&T patients requiring surgery.
A10	Management of pregnant women with SCD and thalassaemia.
A11	Clinical governance and audit.
A12	Patient and carer engagement.
A13	Data collection, management and submission.
A14	Education and research.
A15	Timely access to critical care (adults).
Section B – Collaborative standards (mandatory)	
B1	Timely access to critical care (paediatric).
B2	Access to a comprehensive range of clinical specialists experienced in treating haemoglobinopathy patients.
B3	Access to bone marrow transplantation and stem cell transplantation.
Section C – Additional quality standards (non-mandatory)	
C1	Appropriate adolescent in-patient facilities.
C2	Development of a network wide patient hand-held record.

Commissioners are advised that designated providers will also continue to deliver routine haemoglobinopathy care to their local patients.

The model of care required to deliver the specialised standards and optimal integrated care

The Project's model of care is reliant on the designation process being implemented across all the regions of NHS England concurrently and in collaboration with each other to allow for the standards outlined in the document to be fulfilled.

The model of care is based on the designation of a number of lead acute providers across the country; these providers will then adopt the clinical leadership of the clinical (haemoglobinopathy) networks of care, building on arrangements in place.

Designated providers will at individual patient level offer oversight and direct care for the most complex care. At macro level, these providers will offer leadership of their respective networks. The project recommends the further development of the clinical networks of care with the intention of formalising collaborative working arrangements between all providers of care. The purpose of this is to secure integrated pathways that may arise from differential commissioning arrangements.

The project is also looking for the networks of care to redress inequalities in clinical outcomes by standardising clinical guidelines and protocols across all providers both acute and community and to support the improvement of care overall. These networks also have a role in improving care by providing a forum for service improvements and supporting audits of clinical outcomes and network wide benchmarking. There is also a need for national benchmarking and for a national strategic overview of haemoglobinopathy services. This latter function could potentially be undertaken by a group bringing together network leads and commissioners, the benchmarking function being fulfilled by the UK Forum on Haemoglobin Disorders.

It will be for specialised commissioners to take the lead in initiating and influencing all providers to collaborate and support the clinical network of care. This should not be left to individual clinicians as they will not have the levers available to them as commissioners do to influence the services of other providers.

Clinical leadership of the networks of care can only be achieved if the clinicians from the lead acute providers are able to dedicate appropriate time and support to deliver this responsibility.

The national haemoglobinopathies project and the East Midlands Specialised Commissioning Group

This document is produced under the authority of both the East Midlands Specialised Commissioning Group (EMSCG) and the national haemoglobinopathies project.

The national haemoglobinopathies project (June 2010 – July 2011) was commissioned to deliver the following set of guidance documents for commissioners.

The vision for integrated, equitable and effective haemoglobinopathy lifespan care*
Designation standards for specialised haemoglobinopathy services
Model service specification for community haemoglobinopathy care
Model service specification for specialised / tertiary (acute) haemoglobinopathy services
Equality impact assessment*

(*These papers were agreed by the Project Board)

The national haemoglobinopathies project is hosted by the East Midlands Specialised Commissioning Group, which has delegated responsibility from the National Specialised Commissioning Group (NSCG) for producing the designation standards for haemoglobinopathies. Further information about EMSCG can be found at http://www.emscg.nhs.uk.

Part 2 – Information for providers and users

What is commissioning?

Commissioning is the process by which health needs are identified and services bought to meet those needs. Where possible, commissioners use an evidence based approach in procuring services and in monitoring their delivery.

Ideally, commissioning is an ongoing cyclical process. Service monitoring and the evolving evidence base mean that commissioners and providers should work together to continually improve services to meet need.

Nationally, current commissioning arrangements exist in several tiers; see Appendix 1 for a diagram of these arrangements.

For haemoglobinopathies services commissioning is currently divided into two tiers – between non-specialised commissioners (PCTs) and specialised commissioners (SCGs):

- PCTs commission primary, community and general acute care (both emergency and scheduled care).
- SCGs commission specialised care.

What are specialised services?

Specialised services are a nationally agreed set of services (for example paediatric HIV) that are low volume and high cost to deliver or very complex to deliver. These services are listed in the Specialised Services National Definitions Set (SSNDS), which includes No. 38 relating to Haemoglobinopathies. This document can be accessed via the link below: http://www.specialisedcommissioning.nhs.uk/index.php/key-documents/specialised-services-national-definitions-set/ Please note the definitions do not constitute a service specification, or present an outline of best practice / evidence base. Rather they outline the rationale for why aspects of haemoglobinopathy care need to be commissioned by specialised commissioning arrangements.

PCTs do not commission specialised services individually; instead they pool their resources and commissioning responsibility to allow such services to be managed by commissioners of specialised services. Presently, this specialised commissioning function is delivered by the ten SCGs spanning NHS England.

Haemoglobinopathies are complex lifespan conditions that require expert care from multi-disciplinary clinical teams. It is deemed appropriate that the most clinically complex element of haemoglobinopathies be commissioned under the specialised commissioning approach. Complexity rather than cost is the specialised defining element of haemoglobinopathies.

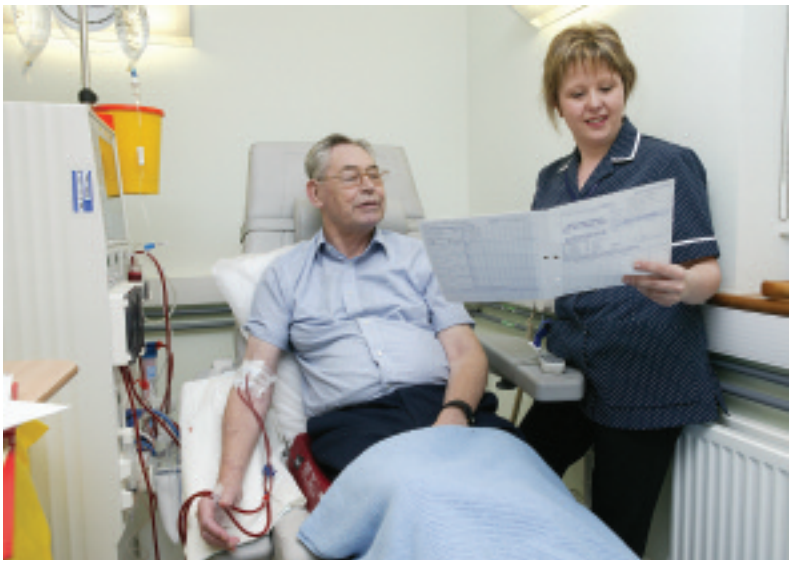
Focusing specialised services within large acute Trusts also reflects the clinical requirement that patients have access to comprehensive medical input for example, cardiology, endocrinology and neurology services. Patients will also require specialised surgical care, for instance orthopaedic care as well as specialised support during pregnancy.

What is designation?

Designation is the process by which commissioners assess acute providers against a set of criteria to assess their clinical capability to deliver specialised care. Commissioners will adopt a number of measures to designate, for example the extent to which the acute provider promotes user engagement and the development of a comprehensive communication strategy that outlines clinical and user engagement. User involvement is an integral part in any designation process.

Commissioners of specialised services are obliged to re-evaluate the designated Trust every at least every five-years or more frequently to make certain designated providers continue to meet the standards and / or to assess the Trust against updated standards.

There is no specialised tariff in place for specialised haemoglobinopathy care and no clinical coding in place to easily support such tariffs. It will be left to specialised commissioners to agree locally what, if any, specialised payments will be made. This will inevitably be informed by the current resource constraints in NHS England.



Part 3 – Information for commissioners

What are haemoglobinopathies?

Haemoglobinopathies is an umbrella term covering the inherited red blood cell disorders, sickle cell disorders (SCD) and thalassaemia (major and intermedia). Certain other very rare transfusion-dependant red cell disorders for example Blackfan Diamond anaemia are also included within the SSNDS definition. These are inherited forms of anaemia and together they form the most common inherited condition in the country, exceeding numerically conditions such as cystic fibrosis.

Although SCD and thalassaemia are grouped together and are treated by the same specialised teams, the clinical manifestations of the conditions are very different. Treatments for the conditions also vary significantly from paediatric and adolescent to adult care. These differences must be reflected in commissioning arrangements that meet local and regional need.

Patients living with these chronic conditions can have every aspect of their quality of life affected (both medical and psychosocial), including their growth, organ and musculo-skeletal health and fertility and reproductive choices.

Children with SCD are at risk of strokes with associated cognitive impairment, adversely affecting their education, academic achievement and future life choices. The detection of children at risk of stroke at a pre-symptomatic stage is an important component of paediatric practice.

One of the main clinical problems associated with SCD is the acute painful crisis which strikes quickly and unpredictably. Such crises must initially at least be dealt with by local health teams; it is neither possible nor appropriate to deliver all care for this aspect of SCD solely within a specialised setting.

Most patients with thalassaemia major require lifelong transfusions and an increasing number with SCD will require blood transfusions for many years. In parallel with transfusions is the need for chelation therapy to maintain a negative iron balance and remove excess iron from their system caused by the transfusions.

SCD and thalassaemia are seen in a wide variety of minority ethnic groups in England. SCD predominantly affects the African-Caribbean and African population, whilst thalassaemia tend to affects South Asian and Mediterranean people. The conditions are however seen in many other communities.

As black and minority ethnic (BAME) population groups are more likely to live in large urban areas, the distribution of haemoglobinopathies across England is extremely variable leading to high and low prevalence areas, with the highest concentration of patients being in London.

Why commissioners should designate and commission specialised haemoglobinopathy services

In 2008, the National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD) published A Sickle Crisis? The report stated that both the provision of care for SCD patients as well as clinical outcomes were unduly variable across the country. The report cited the management of acute pain as a cause of particular concern. Overall, the report concluded that inadequacies and inconsistencies in provision were causing avoidable morbidity and mortality in SCD patients.

SCD is now the most common serious inherited genetic disorder in England affecting 1:2000 births. Approximately 350 newborn babies are detected with SCD annually by the linked Antenatal and Newborn Screening Programme. Approximately 20 – 30 babies are born each year with a significant thalassaemia condition.

Cases of affected births are occurring in all regions and haemoglobinopathy patients can be found throughout England, albeit that most patients are concentrated in London and other cities. London has approximately 70% of adult patients and data from the NHS Sickle Cell and Thalassaemia Screening Programme reveals that approximately 80% of births detected with SCD are in London.

Areas around London also have high prevalence but only a national solution can meet the varying prevalence across the country.

There is also a financial imperative for commissioners to effectively commission and manage service provision. The rate of admissions (hospital stays) in England where one of the diagnoses relates to sickle cell disorders (ICD10 code D57) has risen substantially faster in the last decade than the overall number of admissions. In 2007/08 there were 19,900 sickle cell disorder admissions, over 70% more than in 1997/98; total admissions rose by only 28% over a similar period.

These hospital stays accounted for 60,600 bed days in 2007/08 compared with 55,600 in 1997/98, a rise of 9%; total bed days rose by only 3% over this period.

Hospital episode statistics on admission rates of children and adolescents gives a national snapshot of the scale of this issue.

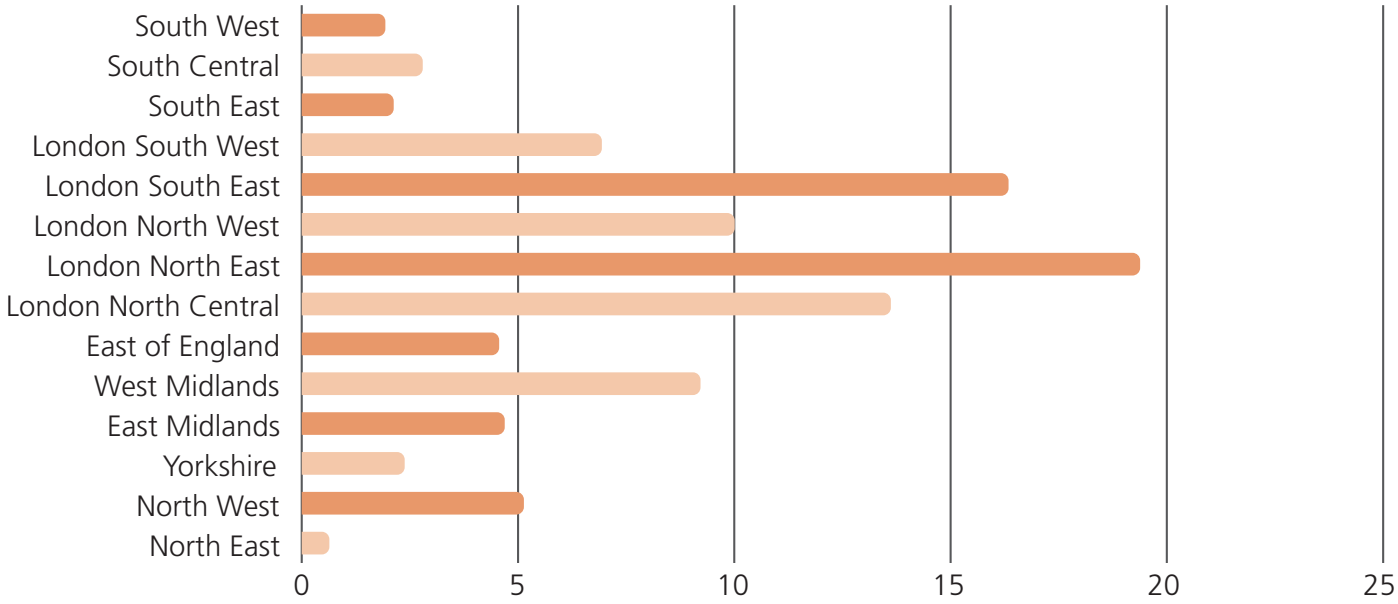
Figure 2 – Hospital admissions of under-20s for sickle-cell disease and thalassaemia per 1000 population, by Region and Strategic Health Authority.

Average annual admissions 2003-04 to 2007-08 related to mid-2005 population			
		Sickle Cell age 0-19	Thalassaemia age 0-19
	England	0.57	0.49
EA	East	0.25	0.28
EM	East Midlands	0.33	0.31
LO	London	2.62	0.97
NE	North East	0.08	0.05
NW	North West	0.21	0.47
SE	South East	0.15	0.18
SW	South West	0.10	0.06
WM	West Midlands	0.40	1.10
YH	Yorkshire & The Humber	0.14	0.69

Figure 2 looks specifically at children and adolescents. It indicates the variability in prevalence and illustrates that admissions occur throughout the country and that therefore all acute providers must be sufficiently supported to manage these admissions.

National aggregated data for SCD (provided by the NHS Sickle Cell and Thalassaemia Screening Programme and including paediatric, adolescent and adult admissions) gives an indication of the scale of the issue. This will allow commissioners to start considering the financial costs associated with such admissions. The data contradicts any perception that may be held that SCD care is a marginal issue.

Hospital admissions of persons with sickle cell disorders, percentage of England total by Region, 2007/08.



There was not much difference between regions in 2007/08 in the proportion of admissions which were emergency – figures ranged from 51% in Yorkshire and West Midlands regions to 61% in South East region. Maternity admissions formed a lower proportion in London (5%) and the South West (3%) with most other regions having 10% or more. The number of admissions per individual was highest in London, particularly in London North Central (2.5) and London North East (2.0); in regions outside London the ratio was between 1.3 and 1.5.

In 2007/08, the use of day case rather than overnight patient treatment for sickle cell disorders was more prevalent in London (24% of episodes) and in South West region (23%); in North East, North West, Yorkshire and South East regions the proportion was 15% or lower. The mean length-of-stay for patients other than day case patients ranged from 2.5 days in North East region to 4.3 days in Yorkshire.

Whilst the data does not indicate whether patients required specialised care, the designation standards outline the responsibility of lead acute providers to support other providers within their region. This leadership function includes advocating for community support to manage these diseases as long-term conditions and ensuring that appropriate training of clinical medical and nursing staff.

The standards also stress the role of the network in standardising clinical guidelines and protocols which have the potential to positively affect the emergency management of SCD&T patients.

If specialised services remain un-commissioned for large parts of England, as is presently the case, haemoglobinopathy patients will continue to access healthcare in a random and ad-hoc way. This care is already being paid for although much of it will not be monitored for clinical efficacy and value for money. Furthermore, as indicated by the NCEPOD report, some of this care will be sub-optimal.

Commissioners are urged to prioritise the designation of specialised haemoglobinopathy providers for their region to enable care to be delivered in a structured and integrated way to achieve better clinical outcomes and financial efficiencies. The high prevalence of SCD in some London areas has led to some acute providers having expertise in managing clinical complexities. The commissioning approach outlined allows for such acute providers to be 'accredited'; to undertake some specific and agreed elements of specialised care. This approach makes best use of clinical expertise already in place.

This document recommends universal coverage and that designation occurs concurrently across the country to allow for the collaborative and integrated approach to be secured. It is believed that such concurrent designation will optimise the use of resources and create a national, clinical 'safety net' of expert care for SCD&T patients. To have only partial designation coverage would maintain the current inequitable arrangements and it would compromise fundamentally the concept of a national safety net and the principles of equity outlined at the start of this document.

Provider designation

Guidance for commissioners and providers on the effective designation of specialised haemoglobinopathy centres

- All SCGs should designate acute provider(s) to deliver specialised care for their region or formally work with other regions for the delivery of specialised haemoglobinopathy care. Designation may require SCGs in low prevalence areas to work proactively with a local provider to develop haemoglobinopathy services sufficiently to enable designation.
- Specialised commissioners should make certain that robust pathway and network solutions are in place, to allow for all patients to access care anywhere in the country depending on where that clinical expertise is located. Any cost pressures may need to be realised through efficiency savings by reducing avoidable admissions.
- Commissioners are urged to recognise in their designation process the very different needs of SCD and thalassaemia patients and the different needs of paediatric, adolescent and adult patients.
- Complications arising from iron overload (particularly cardiac, endocrine and fertility problems) may require clinical management by a few experienced centres as not all designated providers may be able to manage such complications (i.e. super-specialised functions). This introduces the principle of super-specialist designated provider for specific aspects of care. This will not require different commissioning arrangements although robust collaborative arrangements will need to be in place.
- To ensure effective pathways, commissioners of specialised services should work with their local providers to develop pathways to allow haemoglobinopathy patients to access appropriate care provided as close to home as possible. For instance post-discharge follow-up care at home by appropriately trained and supervised community healthcare professionals. Such follow up care may require a degree of clinical supervision from the designated provider; this is particularly important in low prevalence areas where there may not be any dedicated community or acute provision.
- Commissioners in high prevalence areas (primarily London where there are currently many providers in close proximity) might consider whether emergency admissions can safely be managed by designated and accredited providers. In other regions where transfers are geographically more challenging, designated providers should develop robust policies and protocols to support other Trusts to effectively manage emergency episodes, especially the management of painful episodes as any delays could pose a clinical risk.
- As designated providers will also be delivering general haemoglobinopathy care for example routine follow-up appointments, commissioners may need to work with Trusts to capture specialised activity (paid for by SCGs) and non-specialised activity (presently paid for by PCTs and in future by non-specialised clinical commissioning groups). In addition, some preliminary tests may be done in local centres before the patient attends the designated provider.
- It is not expected that all designated providers will offer all the elements of specialised care identified in this document, for instance stem cell transplantation, as it would not be safe or efficient to do so. However, it is essential that between all the designated providers nationally all the specialised elements identified are delivered somewhere. This requires a national oversight which is not presently formalised, although it is to a degree in place via the UK Forum on Haemoglobin Disorders which currently supervises the peer review programme.

- The small number of patients in low prevalence areas should not preclude designation.
- Structural reforms and changes to the provider landscape including moves to foundation trust status and vertical integration should not prevent or unduly delay SCGs from designating specialised providers.

To facilitate universal coverage of designation, this document encourages commissioners to adopt a flexible approach to designation. For instance:

- In low prevalence areas, an SCG may consider joint designation between two or more providers to secure the expertise required to deliver the standards or to deliver paediatric and adult care.
- Alternatively, two SCGs may wish to pursue the designation process together – also to jointly designate Trusts.

A lifespan pathway

Haemoglobinopathies are lifespan conditions and patients will access both ongoing routine care as well as specialised care throughout their lifetime. The key steps of a linear pathway are outlined below.

Key steps in a the care pathway

- Screening and diagnosis – the pathway for most haemoglobinopathy patients commences with the Antenatal and Newborn Screening Programme. The Programme's standards make clear recommendations on how to support at risk couples with Pegasus trained practitioners or, from 2012, a counselling course for at risk couples based at King's College London. The standards also outline what steps should be taken at the point of diagnosis in newborns. Pegasus trained professionals also have responsibility for 'breaking the news home visits' to inform parents of infants born with a haemoglobin disorder and facilitate the referral of these children to named hospital consultants for clinical follow-up.
- The key screening standards are:
  - The results of positively diagnosed babies communicated to parents by four weeks of age.
  - All babies with the condition to be registered with a designated provider / named clinic by eight weeks of age.
  - All babies to attend for an acute provider appointment by three months of age.
  - All babies offered prophylaxis penicillin / antibiotics by three months of age.
  - All confirmed results to be added to the patient notes by six months of age.
  - The completion of Prevenar course by six months of age.
- Primary care and community care – newly diagnosed newborns will be transitioned into primary and community care. There is little in the national guidelines to indicate the specific responsibilities of general practitioners. There is however more clarity about the role of community teams; in particular there are standards from the screening programme regarding the timeliness of making initial contact with parents, enrolling infants into care and commencing prophylaxis penicillin (a screening standard).

- Key components of community care undertaken by community healthcare professionals, involve the initiation of care (both designated and community providers will be informed of all newborn screen positive results). Other aspects of community care include genetic haemoglobinopathy counselling of carriers; counselling of at risk couples and families with positively diagnosed newborns; education and health promotion and long-term case management of patients. In low prevalence areas there may be no dedicated community provision for haemoglobinopathy patients and community staff may need support from designated staff in the provision of counselling.
- General acute care – any haemoglobinopathy patient can present to any acute Trust in the country for emergency care. Patients will also access scheduled outpatient care as well as ongoing therapy, for instance regular blood transfusions. Designated providers will continue to offer non-specialised, general acute care for their local population.
- Specialised care – all haemoglobinopathy patients will require specialised care at points in their life. This specialised care is likely to be emergency as well as scheduled. Specialised care will be high level care delivered by clinical experts able to recognise and manage the most complex aspect of haemoglobinopathies. Care will be delivered using a multi-disciplinary team (MDT) approach for instance, complex annual reviews and managing neurological complications detected by TCD scanning.
- Not all patients will be identified at birth by the NHS Sickle Cell and Thalassaemia Screening Programme; both children and adults can arrive from another region, or indeed through migration from another country, and present for care. Care pathways must be sufficiently flexible to accommodate all patients irrespective of what point they join the lifespan pathway.

Patient access / egress criteria

Some specialised services have clear entry and exit criteria. For example, bariatric surgery will use strict weight thresholds to control access to surgery.

However, reflecting the lifespan nature of haemoglobinopathy care required from birth, there are no 'entry and exit' criteria for haemoglobinopathies. It is clinically appropriate that all haemoglobinopathy patients access specialised services to minimise the morbidities and risk of mortality associated with their condition.

Commissioners are advised that designated providers will also be delivering general acute care i.e. non-specialised acute care. Therefore a form of access and egress criteria will be determined by having very clearly defined pathways differentiating between specialised and non-specialised care.

Some of the key learning from service improvement tools and models is that routine care should not be managed through the most complex (specialised) pathways even if delivered by the same team to the same patients.

Commissioners may wish to assess how designated providers will discharge patients back into non-specialised care (when clinically appropriate to do so), as part of the designation evaluation.

Currencies, diagnostic codes and costings

(This section is based on information included in the SSND No. 38).

Figure 1 below lists the International Classification of Diseases (ICD) codes for SCD and thalassaemia.

Figure 3 – ICD 10 Codes Relevant to Haemoglobinopathies.

D560	Thalassaemia
D561	Thalassaemia
D562	Thalassaemia
D563	Thalassaemia
D564	Thalassaemia
D568	Thalassaemia
D569	Thalassaemia
D570	Sickle-cell disorders
D571	Sickle-cell disorders
D572	Sickle-cell disorders
D573	Sickle-cell disorders
D578	Sickle-cell disorders
D582	Other hereditary haemolytic anaemias

At present, there are no codes for specialised care with the exception of transcranial doppler scanning; the OPCS 4.6 code for TCD scanning of children with SCD is U35.3. This code was authorised for use from April 2011. It has been mapped to the payment grouper for ultrasound HRG RA23 and RA24. TCD scanning in itself is not a specialised function but the provision of TCD services must be to national standards; however, the management of any neurological complications identified, is specialised. Potentially, annual reviews undertaken by designated provider can use an enhanced multi-disciplinary code to reflect the complex nature of care delivered i.e. multiple codes can be inputted.

Health resource groups (HRGs) are used to describe the following clinical activities:

- Out-patient attendances.
- Out-patient procedures – for instance a TCD scan.
- Non face to face out-patient attendances – for instance a review at a specialised multi-disciplinary teams.
- Day cases – for instance regular blood transfusions.
- In-patients.

The designation standards and self evaluation matrix

The following section presents the designation standards within a self evaluation matrix to be completed by providers.

As a minimum, providers will demonstrate compliance with the mandatory standards in the self-evaluation matrix. The self evaluation matrix will inform but not solely determine the designation process. Commissioners will make decisions on designation by examining the entire pathway and existing service configuration.

The matrix outlines the core elements that all designated providers must meet as well those that can be met collaboratively with other designated providers.

Providers may secure designation without meeting all the elements outlined as long as they can demonstrate robust plans that will deliver all the elements within an agreed timeframe.

In reflection of the clinical experience in place particularly in London some acute providers may wish to pursue accredited status by demonstrating compliance with specific specialised standards. They will be accredited for delivery of those specialised functions only and will be monitored by specialised commissioners in the same way as the designated provider. Any provider that secures accreditation for a specialised function identified as generating a specialised tariff will be awarded that payment.

It is assumed that in the development of the self-evaluation matrix that all Trusts seeking designation will already be demonstrating compliance with data protection, Caldecott standards on patient confidentiality, health and safety etc as part of their compliance with the Care Quality Commission regulatory framework.

Designation standards for specialised haemoglobinopathy care – self evaluation matrix. All the designation standards are applicable to children and adults unless otherwise indicated.

1.	Name of haemoglobinopathy clinical network of care.
2a.	Name of acute provider seeking designated status i.e. to become the designated provider within the network. Providers must demonstrate compliance with all the sub-sections in the Core Standards and either direct compliance or formal relationships to comply with the Collaborative Standards. NB – any paediatric provider seeking designation is encouraged to make a joint application with another acute provider able to deliver adult care.
2b.	OR Name of acute provider seeking accreditation for the delivery of specific specialised functions (such providers will have their delivery of such specialised functions also monitored by specialised commissioners as with the designated provider).
3.	Any provider seeking designation or accreditation must demonstrate a successful peer review – please attach report (adult peer review likely to be rolled out 2012 – reports are likely to be available 1-2 years thereafter).
4.	The provider seeking designation must provide the contact details for the following: • Lead physician (will become the named network medical lead). • Lead nurse (will become the named network nursing lead. This individual may be employed by the acute provider or community care. This can be locally determined based on the expertise in place). • The service manager for haemoglobinopathies. Any provider seeking accreditation must provide the contact details for the following: • Lead physician. • Lead nurse. • The service manager for haemoglobinopathies.

Key

- Section A – presents the mandatory core standards that designated providers must in principle meet directly – i.e. they must be able to deliver that aspect of care on site with their own professional teams. In instances of joint designation, the core standards can be divided between the two Trusts. It is recognised that designated providers in low prevalence areas may need a degree of liaison to deliver all the sub-standards.
- Section B – outlines the mandatory standards that can be delivered collaboratively i.e. providers must demonstrate formal collaborative relationships with other designated providers.
- Section C – outlines additional non-mandatory quality indicators. Although these are not mandatory they are in line with national best practice.
- The elements of specialised care underlined in red are those that will incur a specialised tariff. The value of that specialised tariff will be left to commissioners and providers to locally determine. Commissioners are advised that there is no coding in place to support any specialised tariffs; local mechanisms will need to be agreed to capture such activity. Any accredited provider that delivers a specialised function will then be awarded the specialised tariff.
- The term designated provider and lead acute provider are used interchangeably. Other acute providers in the network may also be described as linked providers. Those acute providers that secure accreditation to deliver specific specialised functions are referred to as accredited providers.
- Some of the collaborative standards are super-specialised functions, for instance bone marrow transplantation. Such super-specialised functions will inevitably be limited to a few centres nationally; the other designated providers will need to demonstrate that they have formal relationships in place to access such care for their patients.

Indicators	Explanation
Activity	This is a numeric indicator – for instance the numbers of annual reviews conducted. It can be linked to performance insofar as it aids commissioners to assess provider compliance with any service contract.
Outcomes	This can both be a qualitative or quantitative indicator to assess the impact of certain actions for instance the initiation of long-term blood transfusion regimes.
Quality	This can be related to outcomes to assess the impact of specific interventions. Commissioners and providers may wish to agree in advance specific quality indicators, ideally those already assessed by the Peer Review Programme to avoid any duplication of work. Examples of indicators include the numbers of young people successfully transitioning to adult care by 18 and the degree to which providers use patient and carers to inform service development.
Performance	This is largely a commissioner driven indicator to assess providers delivery against any contract and service specification. For instance, commissioners may have performance thresholds related to DNA rates.

Evidence base used in the development of the haemoglobinopathy designation standards.

Standards, guidelines and quality requirements	
1	Quality requirements for health services for adults with haemoglobinopathies (likely to be rolled out 2012) – (adult peer review).
2	Royal College of Nursing – Caring for people with sickle cell disease and thalassaemia syndromes – a framework for nursing staff (2011).
3	Sickle Cell Disease in Childhood – standards and guidelines for clinical care – second edition (2010). First edition 2006.
4	Transcranial Doppler Scanning for Children with Sickle Cell Disease – standards and guidance (2009).
5	Quality requirements for health services caring for children and young people with haemoglobinopathies (2009) – (paediatric peer review).
6	Specialised Services National Definitions Set (SSNDS) 3rd edition – specialised haemoglobinopathy services (all ages) – Definition No. 38 (2009).
7	Sickle Cell and Thalassaemia – Handbook for Laboratories (2009).
8	Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2008) – second edition. First edition, 2005.
9	Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (2008).
10	NHS Sickle Cell and Thalassaemia Screening Programme, Standards for the linked Antenatal and Newborn Screening Programme. Second Edition, 2011.
11	Health Technology Assessments (HTAs) – there are a number of HTAs underway with direct relevance to SCD&T. These HTAs have been sponsored by the National Institute for Health Research (NIHR) and also by the NHS Sickle Cell and Thalassaemia Screening Programme.
12	The National Institute of Clinical Excellence (NICE) is currently developing a short clinical guideline on the management of sickle cell crisis in hospital.
Additional evidence	
13	The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report, A Sickle Crisis? (2008).
14	Published literature and grey literature – the project has also taken learning from a range of published documents e.g. documents published by the Department of Health and Social Care. The project has also taken extensive learning from grey literature, i.e. unpublished documents, for instance service specifications and designation documents for other clinical conditions.
Additional expert guidance	
15	The designation standards have also been informed by a comprehensive range of experts that have guided the National haemoglobinopathies project. These experts include consultants, nurses, GPs and specialised commissioners. The project has also been strongly informed by the NHS Sickle Cell and Thalassaemia Screening Programme.

Designation standard – core and collaborative	Rationale for standard – i.e. what is the intended outcome and additional information for commissioners
Section A – Core standards (mandatory) – these are the standards that designated providers must meet directly i.e. they must have the clinical expertise and facilities on-site	
A1 Clinical Leadership a) Medical Leadership – the designated acute Trust must have a named medical lead at consultant level. This must be a haematologist / paediatric haematologist or a paediatrician with expertise in haemoglobinopathies. NB dependent on configuration of acute care within a network, there may be two medical leads to cover paediatric and adult care. b) All designated acute providers to have a named medical deputy at consultant level. NB there may be two deputies i.e. one each for paediatric and adult care. c) Nursing leadership – each designated provider must identify a lead nurse either within the acute or community setting (to be locally agreed based on expertise in place). Lead nurse to support all nurses and all allied health professionals across network and also take responsibility on governance matters for the clinical network. d) Responsibility for data, audit and outcome monitoring - see A13.	• The designated provider to be a source of clinical advice and guidance to other health care professionals. • Medical and nursing leads to provide dedicated clinical network leadership. This will involve: • Medical lead(s) to develop and chair multi-professional, network wide Clinical Services Improvement Group (CSIG), which will review and ratify all protocols and guidelines across the network. • The CSIG to the lead in developing consistent clinical guidelines and guidelines across the clinical network. • The CSIG to lead in developing integrated pathways across the network – even when the clinical services are commissioned separately. • The CSIG to lead in developing escalation thresholds across the clinical network which outline access to expert 24-hour emergency care. Based on local expertise, such escalation should clarify the thresholds between linked and specialised providers and the thresholds between community and acute care. • CSIG to the lead on clinical network governance and data collection arrangements across the network. • To liaise with specialised commissioners on ongoing service development. • To be a source of expert advice and guidance to specialised and non-specialised commissioners on haemoglobinopathy services. • The CSIG to support any local peer review taking place within the network. Commissioners will need to work with designated provider and the provider that employs the lead nurse, should it be different – to agree the number of PAs/hours needed to undertake this leadership role effectively. This will vary based on prevalence and the size of the network.
A2 Newborn Screening The current system of reporting screen positive newborn bloodspot results to for example to SCD&T specialist nurses where they exist, and other local staff elsewhere should be maintained. However, there is no robust failsafe system to ensure these babies enter care. An additional failsafe is to ensure that all positive screen babies are notified and care provided overseen by a designated provider even if much of the care is provided locally. Positively screened babies will be registered with a designated provider. a) In line with other newborn screening programmes, the designated provider for the clinical network to be informed of all positively diagnosed babies. NB. Arrangements for laboratories to report to community care must continue to allow immediate contact by community staff and the process of enrolment in care. Informing the designated provider is a quality addition and not a replacement of current processes. b) Designated providers have responsibility for collating and submitting a comprehensive range of data to the screening programme in a manner that is timely, accurate and comprehensive. Details on data collection can be found in appendices 7 and 8 of Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care. 2010. – See A13.	• All SCD&T patients within the network to be under the nominal responsibility of the designated provider. For practical purposes this may be delegated to acute linked providers. However, it is recommended that the notification of positive newborn screening results will remain with the designated provider who is responsible for oversight of enrolment of care and outcome of all positive cases. This oversight must link with the NHS Sickle Cell and Thalassaemia Screening Programme, and providers must record specified data to support the screening programme standards; this data to be returned to the NHS Sickle Cell and Thalassaemia Programme to allow evaluation of programme outcomes. Commissioners and designated providers are signed to appendix 7 – 'Data collection by clinical networks to support monitoring of newborn screening outcomes'. – from Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care. 2010. Not all children(and adults) with SCD&T come via the screening programme – there should be network mechanisms to ensure that children and adults are placed on lifespan pathways.
A3 Prevention and management of neurological complications of SCD through transcranial doppler (TCD) scanning in childhood; specialised neuro-radiology, neurology and neuropsychology services. The supervision of the TCD scanning programme and the management of identified complex neurological abnormalities is a specialised function. a) The expert clinical management of those children and adults identified at risk of stroke and other neurological impairment to minimise the risk. b) The MDT management of complex neurological abnormalities. c) Compliance with any national quality assurance schemes established to support continuous quality improvement.	• To identify those at risk of strokes and minimise that risk. • To offer effective and expert MDT neurological care to those that have already suffered a stroke to reduce the risk of further events and cognitive impairment. Effective neurological care will require integrated pathways between specialised providers, community services and social care. See Quality Innovation, Productivity and Prevention (QIPP) workstream on long-term conditions. See also Transforming Community Services Guides on Long-Term Conditions, and the guide for Rehabilitation Services. Commissioners may also wish to refer back to the NSF on long-term conditions, which also focused on neurological impairment. This standard is also consistent with the principles of the National Stroke Strategy (2007).

	Indicators: Activity (A) Outcomes (O) Quality (Q) Performance (P)	Delegation to accredited organisations & the parameters of that accreditation	Responsibility of other providers within network to support integrated care
	(P) The formation of a network-wide CSIG within 6-months of designated provider securing designation status. The CSIG must meet at least twice a year. (O) The CSIG to demonstrate progress against development of consistent network wide protocols and guidelines.	None.	All providers to share all relevant guidelines, protocols and pathways with the CSIG for review and ratification.
	(P) The lead and community providers are informed of all positive newborn diagnoses by the screening laboratories. Commissioners are urged to work with the Screening Programme for the monitoring of this.	None.	• All acute and community providers to advise the designated provider of all new patients joining the network area. • All providers to advise designated provider of any patients leaving the network area.
	(A) The numbers of children screened across the network. (P) All children aged 2 and above to be offered an annual screening. (Q) Evidence of TCD programme participating in any national quality assurance scheme established.	• Management of complex neurological conditions can be delegated to accredited providers if they have the necessary clinical expertise in place as identified in the TCD standards.	• It is recommended that community providers formally liaise with all schools/ education providers in any instance of a silent stroke or neurological impairment. • It is recommended that the network work with community providers to oversee the development of a network wide information leaflet for school nurses and other education professionals on SCD and stroke. • It is recommended that community providers identify the range of long-term condition support in their area that may benefit SCD&T patients for example clinical input from community matrons for stroke, any support groups for stroke patients – even if they are not SCD specific.

Designation standard – core and collaborative	Rationale for standard – i.e. what is the intended outcome and additional information for commissioners
Section A – Core standards (mandatory) – these are the standards that designated providers must meet directly i.e. they must have the clinical expertise and facilities on-site	
A4 Expert Multidisciplinary Care for Complex Patients Indicators of complexity include but are not limited to: • Multi-system disease including organ damage. • Mono system disease for example renal disease. • Abnormal neurology (see standard A3). • Severe psychological issues. • Pregnancy (see standard A10). • Surgery (see standard A9). • Orthopaedic issues. • Endocrine complications. • Cardiac complications especially related to iron overload. • An MDT should include the following professionals: medical lead, nursing representation (acute and community), psychology input. Larger designated providers should also secure for a complex MDT (as required), neurology, cardiology, radiographer and sonographer input. a) Multidisciplinary teams (MDT) and complex annual reviews. All patients with clinical complexity to be reviewed at least annually by designated provider. If patients are unable to travel, reviews may be undertaken remotely. The clinical experts informing these standards have advised that some patients may require a greater frequency of reviews to best manage the complexity of their condition. b) MDT teams will review and oversee the overall progress of all patients with clinical complexities to optimise overall care.	• The provision of an MDT annual review for all complex patients in the network is consistent with key national clinical standards. • To optimise the care given to complex patients to: • Reduce morbidity for example physical impairment. • Reduce mortality. • To improve equity of access to expert MDT reviews for complex patients i.e. each network via the designated provider must provide MDT care. This has the potential to start redressing the variations in care outlined in the NCEPOD report. The clinical guidelines indicate that all annual reviews should be carried out by experts. It has been agreed nationally that this is neither clinically required nor is it practical. Non-complex reviews should be undertaken by linked acute providers. Commissioners are advised that designated providers will continue to offer non-complex annual reviews to their local patients. Providers and commissioners will need to agree a mechanism to differentiate between specialised and non-specialised reviews as they will generate differential tariffs. Where complex reviews take place, commissioners should scope a range of MDT approaches for instance, outreach clinics or MDT by phone or letter. Direct user feedback stated that any appointment that requires the patient to travel may adversely affect the take-up of care. User feedback also stressed the need for care to adopt a 1-stop approach where possible to minimise the requirement to travel. Commissioners are advised that not all dedicated designated providers across the country will be able to provide all the clinical expertise to manage every aspect of clinical complications – for example cardiac complications from iron overload. All designated providers must be able to provide MDT care, this may need to be supported by formal liaison / referral with other experts. See Collaborative Standard B2.
A5 Initiation, Modification and Cessation of Long-Term Transfusion Regimes and Preventative Therapy in SCD This standard is associated with standard A6. a) It has been clinically agreed that the initiation, modification and cessation of long-term blood transfusion regimes is a specialised function. Regular administration and monitoring of transfusions is not a specialised function but any amendment that is required as an outcome of monitoring is a specialised function.	• To minimise the complications associated with long-term transfusion regimes by centralising this function to specialised and accredited centres that adhere to consistent policies across the country. • To further equity of care by making certain that all patients placed on such care regimes are done so by designated providers or accredited providers which have the required expertise. Commissioners to encourage providers to deliver transfusions in day-case setting to avoid admissions. Commissioners to encourage providers to provide transfusions at flexible times to allow patients to maintain normal school and work patterns. This was raised as a particular issue by patients and carers. Any flexible provision has to be balanced against clinical safety issues.
A6 Initiation, Modification and Cessation of Long-Term Iron Chelation. Monitoring of Complications of Chelation This standard is associated with standard A5. a) The initiation and amendment of long-term iron chelation regime is a specialised function. The regular administration of iron chelation regime can be carried out by linked providers i.e. they do not need to be accredited. b) Specialised and accredited providers must have access to cardiac and liver scanning. c) Specialised and accredited providers must have access to neuro-psychological support and social worker support for patients that struggle with adherence.	• To reduce the risk of complications due to iron overload from long-term transfusion. • To ensure equity of access to expert care with regards to long-term chelation. • The effective clinical support for patients struggling to adhere to long-term chelation regimes.

	Indicators: Activity (A) Outcomes (O) Quality (Q) Performance (P)	Delegation to accredited organisations & the parameters of that accreditation	Responsibility of other providers within network to support integrated care
	(Q) The numbers and clinical outcomes of patients managed by MDT approach. Acute providers may not have electronic methods to capture this and commissioners may wish to use quality audits to record outcomes. (Q) All GPs and patients to be given a copy of the letter summarising the annual review [to form part of the patient held record].	• This specialised function can be delegated to accredited providers if they comply with the components of this standard. • The degree of this delegation may be limited to the management of specific aspects of clinical complexity – again based on expertise in place.	• Ideally, community providers will identify those most at risk of admission and actively case-manage these patients to reduce avoidable admissions. • Community providers are encouraged to look at the development of a community matron type role consistent with the long-terms conditions agenda.
	(Q) The existence of consistent, network wide transfusion guidelines and protocols. (A) The numbers of patients on long-term transfusion regimes. (A) The numbers of patients receiving transfusions in day-case setting. (Q) The numbers of patients offered transfusions at flexible times.	This standard can be delegated to accredited providers based on their clinical expertise in place.	Regular transfusions can be delivered by linked providers in line with network guidelines and protocols.
	(Q) The existence of consistent network wide protocols / guidelines for iron chelation. (A) The numbers of patients on long-term chelation regimes. (O) The numbers of patients referred for psycho-social support.	This standard can be delegated to accredited providers based on their clinical expertise in place.	• Regular chelation can be delivered by linked providers in line with network guidelines and protocols. • Any community provider supporting patients not adhering to chelation regimes must have escalation processes in place to refer the patient for expert psychological support.

Designation standard – core and collaborative	Rationale for standard – i.e. what is the intended outcome and additional information for commissioners
Section A – Core standards (mandatory) – these are the standards that designated providers must meet directly i.e. they must have the clinical expertise and facilities on-site	
A7 Acute Management of Severe and Life Threatening Complications of SCD and Thalassaemia a) The management of painful episodes is not specifically a specialised function. However, the CSIG will develop a network guideline on the management of painful episodes. b) Designated provider must be able to clinically manage the following range of complications for SCD: • Fulminant sepsis. • Acute sickle lung syndrome. • Acute splenic or hepatic sequestration. • Ischaemic and haemorrhagic stroke. • Subarachnoid haemorrhage. • Acute renal failure. • Multi-organ failure. • Biliary obstruction. • Fulminant priapism. • Post-transfusion hyperhaemolysis. • Acute ophthalmological complications (for example complications of sickle retinopathy/central retinal artery occlusion). • Osteonecrosis of major joints (for example hip, shoulder). c) Designated provider must be able to manage the following complications for thalassaemia: • Heart failure and cardiac arrhythmias. • Post-splenectomy sepsis. • Iron chelator therapy-associated sepsis. • Acute endocrine disturbances (for example hypocalcaemic tetany). • Acute hepatic decompensation. d) If patients are unable to be transferred to a specialised centre, that centre will offer formal liaison support to the acute provider.	Commissioners are advised that NICE is presently producing a short guideline on the management of sickle cell crisis in hospital. • To promote the early recognition and appropriate clinical management of life threatening complications. • Nationally, this standard aims to reduce the undue variations in morbidity and mortality as highlighted in the NCEPOD report. Commissioners will need to work closely with all the acute providers within their network to agree local escalation thresholds. This may be a complex process as non-designated provider may not have sufficient experience / expertise to recognise underlying complications beyond the presenting symptom. Verbal evidence from clinicians suggests that transfers of critically ill patients to appropriate centres require clinicians to secure senior management approval. It is the opinion of the clinical experts that any such delays could adversely affect morbidity and even mortality. Commissioners are recommended to expedite any such processes should they exist, as part of the designation process. Commissioners are advised that super-specialised renal and cardiac clinics may not be available in every designated provider / every network and therefore formal referral will be required to relevant expert clinics. See standard B2.
A8 Long-Term Specific Therapy for Severe and Complicated SCD and Thalassaemia (Complex Long-Term Conditions Management) This standard links to standard A3 relating to annual reviews and MDT management of complex patients. a) Specialised providers must be able to clinically manage a range of progressive and often irreversible complications in both outpatient and in-patient settings. In SCD, these include: • Stroke. • Chronic sickle lung syndrome. • Pulmonary hypertension. • Chronic renal impairment. • Avascular necrosis of the hips, spine and shoulders. • Retinopathy. • Chronic ankle ulceration. In thalassaemia major and intermedia, these complications include: • Endocrine dysfunction (growth hormone deficiency), hypogonadotrophic, hypogonadism, hypothyroidism, hypoparathyroidism, diabetes (which may require insulin treatment). • Cardiac dysfunction. • Chronic liver disease (cirrhosis, portal hypertension, hepatic failure, hepatocellular carcinoma, often associated with transfusion-transmitted hepatitis B or C). • Bone problems (avascular necrosis, osteoporotic fractures of the hips and spine, disc disease). • Gallstones. • Ankle ulceration. • Iron overload. • Pulmonary hypertension. • Thrombosis. • Retinal damage. • Pseudoxanthoma. • Chronic pain. b) Specialised providers must be able to initiate, modify and cease long-term medication regimes. For instance, to prevent or mitigate against sickle painful episodes. The monitoring of such drug regimes is not a specialised function but any modification based on the outcomes of that monitoring remains specialised. c) Specialised providers must be able to provide psycho-social / psycho-neurological support to complex patients struggling to manage their condition.	• Verbal evidence from clinicians informing these standards suggests the clinical burden and risk of death are increasingly shifting from emergency crises to chronic care. The aim of this standard is to optimise the chronic care given to complex patients by making it a specialised (MDT) function. • To mitigate against chronic complications where possible. • To slow down any irreversible chronic damage through effective medication and other treatment regimes.

	Indicators: Activity (A) Outcomes (O) Quality (Q) Performance (P)	Delegation to accredited organisations & the parameters of that accreditation	Responsibility of other providers within network to support integrated care
	• Adverse event reporting via the NHR. • A network-wide guideline on the management of painful episodes until NICE produces its short guideline on the management of sickle cell crisis in hospital. • The numbers of transfers to designated provider / critical care transfers.	• The management of life-threatening complications of SCD can be delegated to accredited providers that can demonstrate they can effectively clinically manage the listed complications. • Most life-threatening complications for thalassaemia patients will be associated with iron-overload. Any delegation of such clinical management to accredited centres must include formal liaison with the specialised provider.	a) Any acute provider unable to transfer a patient with a life-threatening complication must request the formal support of their specialised centre. b) The physicians informing these standards have specified that any thalassaemia complicated admissions must be managed in liaison with a specialised centre because of the risk of mortality from possible iron overload.
	(A) The numbers of patients receiving specialised chronic care. (A) The numbers of admissions. (A) The lengths of stay.	The long-term management of complex SCD&T patients can be delegated to accredited providers dependent on whether they have secured accreditation for standard A4 related to annual reviews and MDT care.	• See standard A4. Specialised commissioners should work with their non-specialised commissioner colleagues to encourage community providers to actively identify and case manage chronic patients most at risk of admission. • Where the clinical expertise is in place, community providers should be encouraged to develop early supported discharge processes for chronic patients or other comparative models like 'hospital at home'. Any such developments must be managed through the clinical network's CSIG. • Community and third sector providers should signpost patients to the Expert Patient Programme.

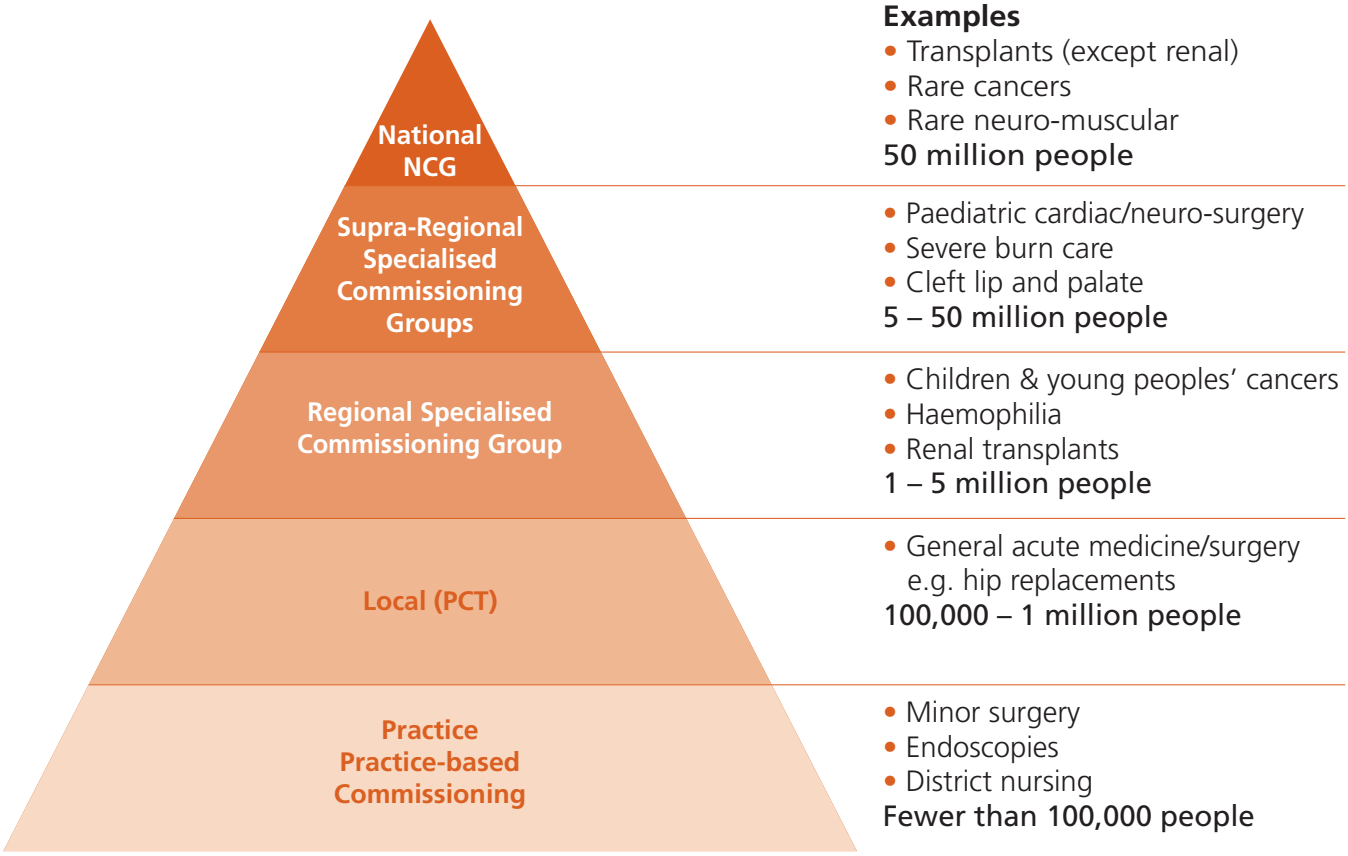
Designation standard – core and collaborative	Rationale for standard – i.e. what is the intended outcome and additional information for commissioners
Section A – Core standards (mandatory) – these are the standards that designated providers must meet directly i.e. they must have the clinical expertise and facilities on-site	
A9 The Peri-Operative Management of Sickle Cell and Thalassaemia Patients Requiring Surgery a) In principle, all elective surgery and where possible, all emergency surgery should be carried out in a specialised centre. For practical purposes, it may not be feasible or even clinically necessary for all surgery to be a specialised function. It will be for commissioners and each network lead provider based on local expertise to agree surgical levels of escalation to specialised care. b) Specialised providers will demonstrate close liaison between haematologists, paediatricians, surgeons and anaesthetists. Surgeons and anaesthetists will have experience in the effective peri-operative management of SCD&T patients. c) Where a local acute provider is required to deliver an emergency operation, they should liaise with the specialised provider. d) All surgical care must be consultant-led.	• To improve clinical outcomes by ensuring that all complex surgery is delivered by specialised or accredited providers with experience in managing haemoglobinopathy patients. • To support network and national benchmarking on surgical clinical outcomes.
A10 Management of Pregnant Women with SCD and Thalassaemia • Complex pregnancy refers to any pregnant woman that has SCD or thalassaemia. A high risk carrier couple identified by the Antenatal Screening Programme do not require specialised care during the pregnancy unless a specific complicating factor has been identified. a) Each clinical network to have a named obstetric lead to advise on complex pregnancies. This obstetric lead may or may not be part of the designated provider. b) All networks to have a named midwife to advise on complex pregnancies. The named midwife may or may not be employed by the designated provider. c) All high risk pregnancies to be managed by MDT approach between obstetricians and haematologists. If it is not possible for the woman to travel to the specialised centre, there will be formal liaison between the specialised centre and the local acute provider.	• To ensure that pregnant women with SCD or thalassaemia access the most expert MDT care, irrespective of where they live, to reduce any possible clinical risks to themselves and the baby. • To allow for the consistent and equitable management of all pregnant women across the network. • To support network and national benchmarking on clinical outcomes.
A11 Clinical Governance and Audit a) On behalf of the network, the designated provider will adopt a clinical governance and leadership function, primarily through the CSIG. This will involve: • Reporting all adverse events to commissioners and to NHR. • Undertaking an agreed number of clinical / quality audits as agreed with specialised commissioners. • Participating in existing peer review process. • Reviewing all network wide clinical guidelines and protocols including those produced by community providers. • Reviewing and amending pathways to promote integrated care. • Supporting any network wide and national benchmarking. b) Commissioners and networks will need to agree how they will monitor devolved / accredited arrangements to ensure consistency and equity of clinical standards and outcomes between designated and accredited providers.	• The purpose of this standard is three-fold. • To promote consistency and equity of care across the network by standardising clinical guidelines and protocols where possible. • To improve care and clinical outcomes through the use of audit and benchmarking. • To promote integrated and seamless pathways across all network providers. Commissioners and providers may agree locally that peer review reports be shared with commissioners.
A12 Patient and Carer Engagement a) The network via the CSIG will take the lead on public and patient engagement (PPE). This will involve the following: • User or user group representation on the CSIG. • User involvement in service planning and development. • The CSIG to review and standardise any clinical information contained in patient literature across the network. • To promote user feedback and engagement with healthcare providers.	• To promote access and equity of care by making services more responsive to the needs of patients and carers. • To improve the take-up of care and services by providing user-friendly literature. Commissioners are advised that this standard is specifically focused on patients and carers rather than the general public – to optimise the use of clinical time and expertise. The experts informing this work felt that the third sector had a greater contribution to make regarding wider public education.
A13 Data Collection, Management and Submission a) This is a network standard that should be consistent for all networks across NHS England. This will see the formation of a national dataset via the NHR and the national screening programme. b) Designated providers have responsibility for collating and submitting a range of data to the Screening Programme in a manner that is timely, accurate and comprehensive. Details on data collection can be found in appendix 7 of Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care. 2010. See A2. c) The data collection should represent the clinical pathway and not just the specialised element.	• The aim of this standard is to create a national dataset to support regional and national benchmarking. • A robust and consistent national dataset will support effective planning and commissioning of services – both specialised and non-specialised. Specialised commissioners are encouraged to collaborate with acute providers across the network to secure their participation in this standard. Registration of patients on the NHR is based on patient consent. Any data submitted to the screening programme is 100% anonymous.

	Indicators: Activity (A) Outcomes (O) Quality (Q) Performance (P)	Delegation to accredited organisations & the parameters of that accreditation	Responsibility of other providers within network to support integrated care
	(Q&O) All adverse reporting via NHR. (O) Surgical clinical outcomes. (Q) Network wide peri-operative guidelines.	Accredited providers must demonstrate they have comparable clinical expertise / experience in place as the specialised provider for optimal peri-operative management of SCD&T patients.	Any non-specialised acute provider undertaking emergency surgery on a SCD&T patient must liaise with a specialised centre.
	(O) Adverse events during the pregnancy - reporting via the NHR. (O) The clinical outcomes of the pregnancies.	Management of pregnancies can be delegated to accredited provider if they can demonstrate comparable expertise as the specialised provider.	• All local acute providers to refer any pregnant women with SCD or thalassaemia to a specialised provider. • Any local acute provider to formally liaise with specialised provider if the pregnant woman is unable to travel.
	(Q) Regular audits of transfusion practice. (Q) Regular audits of chelation practice. (Q) Regular audit of pain management (chronic and acute). (A) The numbers of patients undergoing transition to adult care. (O) Any adverse incidents within two-years of transition to adult care. (A&Q) Numbers receiving Penicillin V (or having a/b available if not taken regularly in adults). (P&A) Numbers receiving appropriate immunisations.	None.	• All providers within the network to support the remit of the CSIG by submitting audit data, guidelines and protocols for review and ratification.
	(Q) User representation on the CSIG and evidence that they are contributing to the working of that group. (Q) An annual patient satisfaction survey of the specialised provider. This must be extended to providers that are accredited to deliver specific elements of specialised care. (Q) Evidence that the specialised provider is acting on the findings of any patient satisfaction surveys.	None.	• All providers to support the CSIG in the development of patient and carer literature. • All service development and planning even at non-specialised level should be discussed at CSIG.
	(P) Initial registration of the patient (this includes all patients and not solely the newborns identified by the Screening Programme). (A&P) The numbers of annual reviews undertaken by each provider (see above). (A) The numbers of TCD scans offered and delivered. (A) The numbers of patients on long-term transfusion. (A) The numbers of patients on long-term chelation regimes. (Q&O) All serious incidents.	None.	• All acute providers to submit a consistent dataset to the NHR and Screening Programme.

Designation standard – core and collaborative	Rationale for standard – i.e. what is the intended outcome and additional information for commissioners
Section A – Core standards (mandatory) – these are the standards that designated providers must meet directly i.e. they must have the clinical expertise and facilities on-site	
A14 Education and Research a) The designated provider will oversee any clinical education and training across the network. This training does not need to be delivered by the designated provider. b) Any training will be offered to clinical staff in all providers across the network to support integrated working. c) Designated providers must be able to provide practical training to relevant clinical staff including junior doctors and nurses. d) Any training to nurses must be compliant with the Royal College of Nurses (RCN) Competencies Framework for nursing staff caring for SCD&T patients. e) Any counsellors or healthcare professional that counsels couples at risk of an affected pregnancy should have undertaken the PEGASUS programme or its replacement. f) Designated providers must demonstrate a research portfolio – possibly linked to clinical and cost effectiveness of certain aspects of care.	• The promotion of consistent and evidence based practice across the network by all providers. • The promotion of collaboration between providers to optimise care. • To support the professional development of clinicians working across the network. • To be a source of advice and guidance to other professionals for example school nurses, social workers and any local commissioning groups in the locality. • To promote succession planning of staff.
A15 Timely Access to Critical Care (Adult) a) Unless a Children's Trust, the designated provider must have an adult Intensive Therapy Unit (ITU) on site.	• To reduce the risks of morbidity and mortality by allowing prompt access to critical care facilities. • To improve the clinical outcomes as it is anticipated that designated providers will have anaesthetists / intensivists more experienced in the management of complex SCD&T care.
Section B – Collaborative standards (mandatory) – these are standards that designated providers can deliver in collaboration with other designated providers to ensure clinical and cost effectiveness. In addition, some elements will be super-specialised i.e. they will be limited to a very small number of providers nationally.	
B1 Timely Access to Critical Care (Paediatric) a) If the designated provider does not have a Paediatric Intensive Care Unit (PICU) on site, they must demonstrate formal arrangements with either other designated providers that have PICUs or other acute Trusts with PICUs.	• To reduce the risks of morbidity and mortality by allowing prompt access to PICU facilities – ideally in a centre familiar with SCD&T.
B2 Access to a Comprehensive Range of Clinical Specialists Experienced in Treating Haemoglobinopathy Patients a) All designated providers must have demonstrable arrangements in place that recognise the challenges that patients face in travelling long distances, access to the following specialists: a. Experienced nurse specialising in the conditions. b. Acute and chronic pain team. c. Consultant Cardiologist. d. Consultant Respiratory physician. e. Consultant teams with experience in managing pulmonary hypertension. f. Consultant Nephrologist and access to renal replacement therapy and transplant. g. Consultant Hepatologist h. Consultant Urologist with expertise in managing priapism, erectile dysfunction. i. Consultant Neurologist and acute stroke service. j. Consultant Ophthalmologist. k. Consultant Endocrinologist. l. Contraception and sexual health services. m. Genetic counselling and fertility services. n. Consultant Obstetrician. o. Consultant General Surgeon. p. Consultant Orthopaedic Surgeon. q. Tissue viability service / leg ulcer clinic. r. Psychologist and other. s. Mental-health services.	• The existing guidelines and standards are clear that haemoglobinopathies are complex, lifespan conditions that can affect every single part of the body and therefore optimal care requires access to a comprehensive range of specialists experienced in the complications of SCD&T. Clinicians have indicated that that this standard should not replace informal conversations between consultants across different providers to discuss the most clinically effective way to manage patients.
B3 Access to Bone Marrow Transplantation and Stem Cell Transplantation Both of these interventions are deemed super-specialised and will be available to only a few centres nationally. a) Designated providers must have formal processes in place to refer patients for such clinical interventions.	To reduce the risks of morbidity and mortality by allowing prompt access to PICU facilities – ideally in a centre familiar with SCD&T.
Section C – Additional quality standards (non-mandatory)	
C1 Appropriate Adolescent In-Patient Facilities a) Ideally, designated providers will have appropriate adolescent in-patient facilities in line with national best practice.	• This standard is in line with national best practice. • Direct user feedback was clear that appropriate facilities are fundamental to effective care.
C2 Development of a Network Wide Patient Hand Held Record a) Clinical networks of care are encouraged to develop a single and integrated patient hand held record that covers the entire pathway.	• To support the patient to better manage their condition. • To give the patient a greater role in managing their own treatment and care. • To support the better management of emergency episodes.

	Indicators: Activity (A) Outcomes (O) Quality (Q) Performance (P)	Delegation to accredited organisations & the parameters of that accreditation	Responsibility of other providers within network to support integrated care
	(A) The number of training / development sessions offered to staff across the network. (Q) The findings of any research undertaken. (Q) Usage of the RCN nursing competencies framework. (Q) 80% of counselling episodes to be by PEGASUS trained or equivalent trained counsellors for 'at-risk' couple counselling.	It is expected all providers, acute and community will support the delivery of this standard. No accreditation is required.	• Community and linked providers are encouraged to share any training they offer with the network lead to support an integrated network programme.
	• The numbers of admissions to ITU – reported via the NHR. Any admission of a young adult within 2 years of transition to adult care must specifically be reported. • The clinical outcomes of the ITU admission. • Any acute readmissions within 30 days post-discharge.	Commissioners may wish to consider this standard as part of the accreditation process. For instance, an acute provider may only secure accreditation to conduct surgery if they have an adult ITU on-site.	
	(O) The numbers of admissions to PICU – reported via the NHR. (O) The clinical outcomes of the PICU admission. (Q&O) Any acute readmissions within 30 days post-discharge.	Any accredited providers must also demonstrate formal arrangements with centres with PICU if they do not have one on-site.	
	(A) The numbers of referrals made across the network for specialist input.	Accredited providers should demonstrate formal arrangements to refer their patients for such care.	
	(O&Q) The numbers of admissions to PICU – reported via the NHR. (Q) The clinical outcomes of the PICU admission. (Q&O) Any acute readmissions within 30 days post-discharge.	Any accredited providers must also demonstrate formal arrangements with centres with PICU if they do not have one on-site.	
	(Q) Patient satisfaction surveys	Ideally, accredited providers would also adhere to this standard.	
	(P) The development of a network wide patient hand held record. (Q) The involvement of patients in the development of the hand-held record. (O) Possibly through an audit, assess how the records are being used.	This is a network-wide responsibility.	All providers within the network to contribute and support the development of the patient hand held record.

Appendix 1 – NHS levels of commissioning currently in place (December 2010)



Appendix 7 – Data collection by clinical networks to support monitoring of newborn outcomes

NB – this second appendage is titled 'Appendix 7' as it is extracted from 'Sickle Cell Disease in Childhood – standards and guidelines for clinical care' – 2nd ed. 2010 – where it is listed as Appendix 7.

The NHS Sickle Cell and Thalassaemia Screening Programme assess the outcomes of the linked antenatal and newborn screening programme at a national level. For babies affected with sickle cell or thalassaemia the following are assessed:

- mortality and morbidity in children affected by haemoglobinopathies, up to age 5.
- timely entry of affected babies / children into care.
- a look back at the mother's antenatal screening history.

To obtain reliable data on these outcomes requires named data on all babies with sickle cell disorder or thalassaemia. Collecting named data without consent is a sensitive issue. The Programme has received approval from the Ethics and Confidentiality Committee of the National Information Governance Board (http://www.nigb.nhs.uk/ecc/register-1/ register-of-approved-applications) for this work. We are also working closely with the Sickle Cell Society and the UK Thalassaemia Society to ensure the work addresses users' views. More information about this work is available at http://sct.screening.nhs.uk/evaluation.

The Ethics and Confidentiality Committee of the National Information Governance Board have balanced the autonomy of individuals with the importance of assessing the outcomes of a screening programme. They have given approval for one year in the first instance and have asked the programme to consider how to assess newborn outcomes without named data. Therefore the Programme are setting up two data collection systems on babies with sickle cell disease or thalassaemia: named and anonymous. Both named and anonymous data are based on the programme standards, and are requested as one record per baby. Data will be requested on an annual basis, based on financial years. An Access database to store these results is available on request. The table below lists the anonymised data items required. The table also indicates whether these items are included in the named data collection. Details of named data collection is available at http://sct.screening.nhs.uk/evaluation.

Eligibility: All children requiring long term follow up for sickle cell diseases identified by the age of five years, regardless of screening history will be included.

Sickle cell conditions to include: HbSS, HbSC, HbS beta thalassaemia, Hb S/D Punjab; HbS/Oarab, Hb-S/HPH/HbSE.

Standard and Objective	Minimum Standard	Data to collect	Specific Data items (one record per baby)	Notes
Newborn O1: Best possible survival for infants detected with a sickle cell disorder by the screening programme.	Mortality rate from sickle cell disease and its complications in children under five of less than four per 1,000 person years of life (two deaths per 100 affected children.	Date of Death if applicable Cause of death if applicable.	Patient ID (unique and anonymous) Year of birth Date of Death Cause of Death.	full date full date free text (also in named data collection).
Newborn 2i: Accurate detection of all infants born with major clinically significant haemoglobin disorders.	99% detection for HbSS 98% detection for HbSC 95% detection for other variants.	Screen result, confirmed result and methods used, if available.	Newborn screening result Confirmed result. Methods used to confirm result.	FS, FSC, FS-Other, FE, F-only (also in named data collection) As listed in Tables 1 and 2 of laboratory handbook (also included in named data collection).
Newborn P4: Effective follow up of infants with positive screening results (sickle cell disorder) – all babies to be registered with a local clinic/centre.	90% attend local clinic by three months of age.	Age of baby when first attend local clinic.	Age of baby when confirmed results documented in appropriate notes. Age of baby when first attended local clinic.	Age in weeks, recorded in electronic or paper notes in local or specialist centre Age in weeks (also included in named data collection).
Newborn P5: Timely confirmation of diagnosis for infants with a positive screening result.	90% of cases of Hb SS and Hb SC have confirmation of result documented in clinical notes by six months of age.	Age of baby when confirmed result documented in appropriate notes.		
Newborn P6i: Timely effective treatment and education for: HbSS, HbSC, HbSD – Punjab, Hb-SE, Hb beta Thalassaemia, Hb-SO Arab, Hb-S/HPH.	90% offered and prescribed Penicillin V or alternative by three months.	Age of baby when penicillin prescribed Vaccination status at aged 6 months.	Age of baby when penicillin prescribed Vaccination status. Information offered at first visit with named HP.	Age in weeks (also included in named data collection) (also included in named data collection) 2, 4, 13, 24 months Yes / No.
Newborn P6ii: Communication to parents.	95% of families offered information on condition, follow up, and treatment at first visit with named professionals.	Information offered at first visit with named HP.	Yes / No response.	
Newborn S1ii: Up-to-date registers maintained of babies (cases) for which units are responsible.	Less than 10% of cases on registers who have been lost to follow up within the past year.	Number of babies lost to follow up in past financial year, if available.	Lost to follow up.	Yes / No.

Additional information on conditions to be detected are included in the Laboratory Handbook (listed as reference 7 in your evidence base) and the second edition of the screening programme standards (listed as reference 10 in your evidence base)

There are links between this work and that of the National Haemoglobinopathy Registry (see Appendix 8).

4

Model service specification for community haemoglobinopathy care

NHS standard multi-lateral community contract (2010 – 11) Module B – Performance requirement – specification. Quality and productivity

Section 1 – Specification

Care Pathway/Service	Model service specification for community haemoglobinopathy care.
Commissioner Lead	Commissioners of non-specialised services. Ideally this should be undertaken in liaison with commissioners of specialised services and in collaboration with designated providers.
Provider Lead	To be completed locally.
Name of Clinical Network	To be completed locally.
Name of Designated provider of Clinical Network	To be completed locally.
Period	To allow for effective service and workforce planning, this should be for a minimum 3 years with a contract review at the end of year 1.
Applicability of Module E (Acute Services Requirements)	

Introduction

Background information

This document is part of a series of guidance documents produced by the Department of Health's commissioned national haemoglobinopathies project (June 2010 – July 2011).

The following is one of two model service specifications for commissioning high quality sickle cell and thalassaemia services.

1. Model service specification for community care – this is care organised and delivered within community care services and usually takes place outside the hospital setting.
2. Model service specification for specialised services – this is tertiary acute care for haemoglobinopathy patients i.e. the most expert care for the most complex patients.

Community care will be commissioned locally by non-specialised commissioners and specialised services will be commissioned nationally. This separation in commissioning arrangements has the risk of creating fracture points in the delivery of care impeding integrated care pathways.

The national haemoglobinopathies project has therefore developed a set of standards for specialised care (designation standards). Specialised commissioners will designate acute provider(s), which will then lead the haemoglobinopathy clinical network of care. These network arrangements explicitly encompass all providers of haemoglobinopathy care in that region including community care. The network of care will promote collaborative working across providers and integrated care pathways, clinical guidelines and protocols.

As part of these network arrangements, any clinical guidelines and protocols used in the community setting (as with policies used by acute providers) should be reviewed and ratified by the clinical network of care. Such a review of protocols should include appropriate escalation thresholds to acute and tertiary providers based on local expertise in place.

It is believed the collaborative approach including all providers within the network area will raise the quality of care overall and give assurance to local commissioners that any services they commission will contribute to integrated care pathways.

Executive summary

Community haemoglobinopathy care is not defined by any particular provider, indeed with vertical integration it could be provided by an acute provider. Community care is a set of activities that can take place outside an acute hospital setting; such activities will vary based on the local services and expertise in place.

There is considerable variation in the way different community haemoglobinopathy teams work; this model specification describes the principles upon which services should be based. It is accepted that there will be variation in implementation based on what is presently in place and local prevalence.

This model specification describes the core elements of haemoglobinopathy care that can be delivered in a community setting; it reflects the care required to meet clinical need rather than any issue relating to prevalence. The project acknowledges the importance of prevalence in planning services; however, the clinical lead for the Project, with the support of the community healthcare professionals, agreed that this model specification must describe optimal community care without the constraining influence of prevalence. This decision was reached to respect the right of every patient to have access to the highest quality care; this right exists independently of the numbers of other patients within a given geographic area. However, the way services are provided will vary by prevalence and community. It is unlikely that lower prevalence areas will have specialist nurses in the community setting. Therefore, local commissioners are advised to work with their specialised commissioner colleagues to explore more generic support for patients with formal support from the designated provider. Indeed, the role of the designated provider to support community care in low prevalence areas is considerable.

This document reflects current working examples of best practice from across NHS England (as determined by the experts informing the national haemoglobinopathies project, see – The vision for integrated, equitable and effective haemoglobinopathy lifespan care).

This specification also presents possible service developments for consideration, including service changes with the potential to release either financial efficiencies or staff capacity. Any efficiencies have been informed by experienced community healthcare professionals.

Historically, community based services have been led by sickle cell disease and thalassaemia (SCD&T) nurse counsellors; it is accepted by senior nurses informing the project that the role of the nurse counsellor may not be fully understood. Therefore, it has been agreed this role should be described as a haemoglobinopathy nurse specialist or community matron role. This is consistent with comparable nursing roles for other long-term conditions such as respiratory medicine or stroke.

A haemoglobinopathy nurse specialist role may include counselling for couples identified as at reproductive risk of an affected pregnancy, or for families with newborns with a screen positive or carrier result for SCD identified through the NHS Sickle Cell and Thalassaemia Screening Programme. Commissioners are recommended to refer to the national service specification for the NHS Sickle Cell and Thalassaemia Screening Programme, commissioned by the Department of Health.

The proportion of time nurse specialists dedicate to counselling and direct patient related work will vary according to prevalence and expertise; this will be locally agreed. Any nurse specialist undertaking either role should have clear links with both the screening pathway and the care pathway.

Any roles with counselling responsibilities must be integrated into the screening pathway which includes the adoption of screening governance arrangements and data reporting requirements. Further information on the standards of the screening programme can be found on the NHS Sickle Cell and Thalassaemia Screening website www.sct.screening.nhs.uk

Commissioners are advised that any healthcare professionals delivering genetic couple counselling for the screening programme should have undertaken the PEGASUS training programme or its successor training programme being established at King's College, London. Correspondingly, nurses delivering clinical care to patients should have access to training based on the Royal College of Nursing's nursing competency framework.

SCD&T are chronic, life-long conditions that primarily affect black and minority ethnic communities (BAME); although they are not exclusive to these populations. Management of SCD and thalassaemia are mainstream NHS responsibilities that should concern all NHS providers. The conditions, particularly SCD resulting emergency complications which can be life-threatening. Consistent with all chronic diseases, any monitoring of community arrangements should be comparable to the monitoring of any other long-term conditions.

At present, in some areas, SCD&T community care is delivered as an almost entirely stand-alone service detached from other services. It is essential that any commissioning of community care is placed within the broader context of long-term conditions management and any pain management processes that exist locally; this is consistent with the Quality, Innovation, Productivity and Prevention (QIPP) agenda. Any care commissioned should be part of the commissioners overall approach to managing long-term conditions.

Community haemoglobinopathy staff should benefit from close working arrangements with other healthcare professionals managing other long-term conditions; they should also benefit from the same service development opportunities present in other chronic disease groups.

Given the clinical profile of SCD&T, Community healthcare professionals should link closely with colleagues supporting such patients in an acute setting, particularly in relation to pain management and protocols for referral to hospital.

Commissioners will be aware that many SCD&T patients may experience a range of other inequalities such as poor housing. In particular, commissioners are advised that children with SCD&T can have their education compromised by their conditions. An element of effective community care will be signposting patients to other statutory and voluntary bodies that may be able to assist with these wider determinants of health. Depending on local arrangements, commissioners are advised to consider joint working arrangements with social care if they are also supporting the same group of individuals.

Ideally, the most effective community service will consider a multi-professional team including nurses, social workers and clinical psychologists. The skill mix of any team should match the complexity of the patients' clinical needs and be reviewed at a network wide level to support integrated pathways between providers.

An element of effective community care will be signposting patients to other statutory and voluntary bodies that may be able to assist with these wider determinants of health

Project specific glossary

The Project's understanding of a clinical network of care is informed by the definition developed by the Scottish Executive – it is linked groups of health professionals and organisations from primary, community, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality clinically effective services.

Designated providers / lead acute providers – these are the hospitals that will deliver the specialised standards, one of which is clinical leadership of the clinical network of care. Designation of specialised services is undertaken by specialised commissioners.

Accredited providers – these are hospitals with a lot of experience in managing haemoglobinopathy patients that go through a form of partial designation so that they can deliver some specialised functions. Accreditation will also be undertaken by specialised commissioners in conjunction with the designated provider.

Linked providers – these are other acute hospitals within the geographical boundaries of the haemoglobinopathy clinical network. They will deliver no specialised haemoglobinopathy care, i.e. they will treat haemoglobinopathy patients with fewer clinical complications. Any non-specialised acute care is commissioned by non-specialised commissioners.

Community care – a set of clinical activities organised and delivered within community care services and usually takes place outside the hospital setting.

Any references to **patients** encompass all users and carers engaging with haemoglobinopathy services.

Purpose

Community provision of haemoglobinopathy care is one component part of lifespan care. Commissioners are signposted to the Haemoglobinopathy Designation Standards and the associated model specification for specialist centres to deliver the other key element of lifespan care.

Working closely with both the NHS Sickle Cell and Thalassaemia Screening Programme and local acute and specialist Trusts, appropriately trained community haemoglobinopathy care will provide a range of services that include the following headline areas:

Counselling couples and families identified by the NHS Sickle Cell and Thalassaemia Programme

- Carrier results including partner testing given within five days of the laboratory results.
- Results and counselling to be offered within four-days of results to couples identified by the Antenatal stage of the Screening Programme as having an 'at risk' pregnancy. This will include advising them of the choices available to them about their pregnancy outcomes. All counselling to be undertaken by Pegasus trained professionals.
- Support for the worried well i.e. those that have been screened and found not to have an at-risk pregnancy may be signposted to voluntary agencies where it is possible to do so. Providers may wish to liaise with the local screening co-ordinator as another source of support.
- The project acknowledges that parents with a newborn baby identified as a carrier may also require counselling, support and information. Much of this responsibility presently falls to primary care and community care.
- All families with a newborn diagnosed with a haemoglobinopathy disorder to be notified in person by the time the baby is 4 weeks old. (Please note, under the new haemoglobinopathy designation standards, laboratories will simultaneously advise the designated provider and community care. It will be the responsibility of community care to notify the family and initiate the care pathway).
- All families with a positively diagnosed newborn to be assessed for their psychological ability to manage the condition. Any assessment template used should be approved and consistent across the network (see below).
- Families advised of newborn clinical pathway.
- Community healthcare professionals to ensure babies are registered with a GP.

Support for patients to become experts in managing their own care

- Community healthcare professionals should provide information and other support to enable patients to become experts in their own care so they can fully participate in their own care planning.
- Community healthcare professionals will signpost patients to voluntary and other organisations that may support them to become experts in their own care and live autonomous lives.
- All patients to be signposted to an expert patient programme or self-help groups.

First stage psychological assessment

- As part of their counselling responsibility, appropriately trained community healthcare professionals already undertake psychological assessments of patients and families. At present community services use their own models and templates, it is recommended that community providers, in collaboration with their clinical network of care, develop a standardised network-wide Stage 1 psychological assessment (a number of templates are available nationally). Networks are encouraged to agree escalation thresholds to Child and Adolescent Mental Health Services (CAMHS), adult mental health services like Improving Access to Psychological Therapies (IAPT) or specialist haemoglobinopathy psychologists if available.
- These psychological assessments are to be used proactively as part of ongoing community care, rather than reactively when a patient and / or family is already in a crisis situation. Each network is to agree key milestones when such proactive assessments are to take place e.g. at annual review, at the start of transition to adult care etc.

- Relevant acute provider to be advised of assessment results in advance of annual review of patient.

Initiation and co-ordination of care

- Community healthcare professionals should initiate the start of lifespan care for newly diagnosed infants by referring the baby for the first appointment with the relevant acute provider clinician. They will make certain that responsibility for follow-up is clear. Any handover to an acute provider is completed within specified protocols including those from the screening programme.
- Community healthcare professionals will make onward referrals to other relevant statutory organisations, for instance social care.
- Community care must be able to initiate and co-ordinate care for paediatric patients that arrive from routes other than the newborn screening programme. Likewise, they must be able to initiate care for adult patients that are not on any lifespan pathway.
- As part of patient enablement, community healthcare professionals should support and encourage patients to manage their own care pathway i.e. co-ordinate their own care if they feel confident to do so.

Liaison and collaboration

- Community healthcare professionals are able to act as a key point of liaison between the range of healthcare providers and other agencies that may be supporting the patient / family.
- All community clinical guidelines and protocols used by community care to be approved by the network to agree formal liaison relationships and escalation thresholds.
- Community healthcare professionals should work with local hospitals to support timely discharge planning.
- The project has concluded that integrated and holistic haemoglobinopathy care can best be delivered through a networked approach. Commissioners are asked to consider as part of an effective commissioning process, the resources providers may require to support the clinical network of care's work programme. This can only be locally determined.
- To promote equity and consistency of care across NHS England, community providers should be able to offer formal liaison to community professionals in low prevalence areas that may need guidance on managing any local patients. Commissioners may wish to consider having a standard liaison charge agreed in advance.

Long-term conditions management (LTC) including promoting patient self-management – reflecting the differing needs and requirements of children and adults

- Appropriately trained community healthcare professionals should work proactively with SCD&T patients with specific complications, for instance those with physical disability or organ damage, and also actively support all patients to minimise the negative impact of their condition. This should be done in formal liaison with the acute provider to ensure any clinical support given is consistent with the care plan arising from the annual review. All care plans should be shared with relevant care providers.
- Community healthcare professionals should identify for their patients other community support that is available to them such as the voluntary sector, stroke community support, renal support groups etc.
- Community professionals should work closely with the patients and carers to promote and train patients to self-manage their condition within safe boundaries, which will vary from patient to patient.

- Pain management is a particular area where community professionals can offer patients support, for instance prevention and patient self-management. It is recommended that community care providers liaise with their local acute providers to agree a network-wide approach to develop effective pain management protocols, including escalation to acute providers as required.
- As part of long-term conditions management, community providers have a role to play in supporting adherence to any long-term iron chelation and medication regimes. Again, this should involve clear escalation thresholds to appropriate psychological support for those patients that require this intervention.
- There are some community providers that presently provide emergency support to patients, which has the potential to reduce accident and emergency attendances. Any such developments are best placed within a network-wide strategy for managing emergency care, where clinical parameters, responsibilities and escalation thresholds can be agreed by all providers of care.
- Providers working across the network are urged to collaborate on protocol development for effective discharge planning that makes best use of the comprehensive range of skills and expertise available across all providers. Such an innovation should be considered as a priority by the network for the possible benefits it has to improve patient care and for the potential it has to release efficiency savings by reducing lengths of stay when it is clinically safe to do so.
- Some community providers offer annual (or more frequent) reviews of patients to assess patients' condition and develop care plans. All patients will also be offered an annual review with their acute provider. Local commissioners are encouraged to work with their specialised commissioner colleagues to integrate and streamline the numbers of reviews taking place.

Active case management for high risk patients

- Using existing models from other long-term conditions, community providers can identify those most at risk of hospital admission and offer them additional clinical / psychological support to help them better manage their condition. Again this may require formal liaison with acute providers to best manage this group of patients. Ideally, patients should be stratified using the Kaiser or comparable model (to be ratified by the clinical network). Stratification could represent:
  - Patients that are effectively self-managing their own condition.
  - Patients, who with support and education could better self-manage their own condition. If they have chronic complications e.g. physical impairment, effective self-management may still require ongoing support from community care i.e. self-management is wholly dependent on the severity of their condition.
  - Patients that are at greatest risk of acute attendances and admissions. These patients may benefit from much more clinical support to allow for their issues to be clinically managed within the primary and community setting when clinically safe to do so. They can also be supported to self-manage aspects of their own condition.

End of life care

- Community professionals will sign-post patients, families and carers to end of life care available within the community or voluntary setting, even if it is not SCD&T specific.

Patient and carer education

- A key function of community care is to educate patients, families and carers on the nature of their respective haemoglobin disorder. Evidence from direct user engagement suggests that SCD patients in particular need greater support to understand the chronic nature of the condition rather than solely as a condition that has emergency painful episodes.
- To date, many specialist nurses have undertaken wider public education responsibilities e.g. organising community events to raise awareness of the condition. This function could increasingly be delivered by the voluntary sector with expert support from community healthcare professionals. Commissioners may wish to liaise with voluntary providers on this area of activity.

Professional education and development intra and inter-Networks

- Many community healthcare professionals already support clinical colleagues and other professionals such as health visitors and school nurses out of goodwill. Commissioners are recommended to factor this professional support when planning care and services as it improves patient care and experience overall.
- Specialist haemoglobinopathy nurses to provide formal clinical advice and support to community health professionals in low prevalence areas unfamiliar with haemoglobinopathies. Please note this support would be in terms of phone / email advice or information sharing only. They would not take on responsibility for those patients unless specifically commissioned to do so e.g. through outreach clinics or other means.
- It is recommended that any professional education delivered by community healthcare professionals be developed in liaison with the clinical network of care, so that it is part of an overall network approach to professional training and development. Any education for school nurses or other groups could be managed across the network to have a consistent information pack.

Possible lead nurse role

As part of the designation of specialised services, all designated providers and accredited providers will need to identify a lead named nurse that will fulfil a leadership function for the network. This nurse may be from the designated provider or from the community provider depending on the expertise in place. This will be left to commissioners to determine. The lead nurse(s) will provide clinical leadership to nurses and allied health professionals across the network that treats SCD&T patients. They will also have elements of governance responsibility for the network. The time commitment for this role will vary from network to network and with local prevalence.

Evidence base

Standards, guidelines and quality requirements	
1	Quality requirements for health services for adults with haemoglobinopathies (likely to be rolled out 2012) – (adult peer review).
2	Royal College of Nursing – Caring for people with sickle cell disease and thalassaemia syndromes – a framework for nursing staff (2011).
3	Sickle Cell Disease in Childhood – standards and guidelines for clinical care – second edition (2010). First edition 2006.
4	Transcranial Doppler Scanning for Children with Sickle Cell Disease – standards and guidance (2009).
5	Quality requirements for health services caring for children and young people with haemoglobinopathies (2009) – (paediatric peer review).
6	Specialised Services National Definitions Set (SSNDS) 3rd edition – specialised haemoglobinopathy services (all ages) – Definition No. 38 (2009).
7	Sickle Cell and Thalassaemia – Handbook for Laboratories (2009).
8	Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2008) – second edition. First edition, 2005.
9	Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (2008).
10	NHS Sickle Cell and Thalassaemia Screening Programme, Standards for the linked Antenatal and Newborn Screening Programme. Second Edition, 2011.
11	Health Technology Assessments (HTAs) – there are a number of HTAs underway with direct relevance to SCD&T. These HTAs have been sponsored by the National Institute for Health Research (NIHR) and also by the NHS Sickle Cell and Thalassaemia Screening Programme.
12	The National Institute of Clinical Excellence (NICE) is currently developing a short clinical guideline on the management of sickle cell crisis in hospital.
Additional evidence	
13	The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report, A Sickle Crisis? (2008)
14	Published literature and grey literature – the project has also taken learning from a range of published documents e.g. documents published by the Department of Health and Social Care. The project has also taken extensive learning from grey literature, i.e. unpublished documents, for instance service specifications and designation documents for other clinical conditions.
Additional expert guidance	
15	The designation standards have also been informed by a comprehensive range of experts that have guided the National haemoglobinopathies project. These experts include consultants, nurses, GPs and specialised commissioners. The project has also been strongly informed by the NHS Sickle Cell and Thalassaemia Screening Programme.

General overview

Effective community care is an integrated set of clinical activities that largely take place outside a hospital setting. For community haemoglobinopathy care this will include two key responsibilities.

- Counselling:
  - Of those identified through the antenatal and newborn screening pathway such as counselling women who are carriers, parents of newborn carriers and including expert counselling of at risk couples.
  - Offer of prenatal diagnosis and follow-up counselling of such couples whatever option they accept.
  - Education to carriers and their families.
  - A general role in education of professionals about the genetic aspects of these conditions and basic information about the clinical conditions resulting.
  - Collaboration and integration more generally with the screening and maternity and newborn care pathways more generally.
- Clinical Care:
  - Clinical care as part of a clinical network of care to create integrated and seamless care. This will include active collaboration across the network with other providers of clinical care to develop standardised clinical guidelines and protocols.
  - Active long-term conditions management of children and adults.
  - Active case management for those with specific complications leading to possible risk of admission.
  - Education and empowerment of patients and carers on how best to manage their condition within safe parameters.
  - Offer of education and training to other professionals in either, health or social care or within education that work with SCD&T patients.

Commissioners may wish to add local prevalence information to this section. For example demographic information and any socio-economic factors that may affect clinical need.

Objectives

Effective community care has two core elements outlined above. Primary objectives include:

- Provide high quality counselling to pregnant women and their families about the carrier status and the implications and choices available to them.
- Educating patients and carers to come to terms with their disease and how to best manage their condition.
- Improve health outcomes by stratifying and actively case-managing patients most at risk of complications and hence reducing hospital admission.
- Improving the understanding of the complexity of SCD&T by educating a range of relevant health and other professionals for the specific benefit of patients and carers.
- Contributing to integrated and collaborative pathways by supporting the work of the clinical network.
- Guiding patients and carers to other sources of support that can assist in addressing some of the wider determinants of health.

Provide high quality counselling to pregnant women and their families about the carrier status and the implications and choices available to them

Expected outcomes including improving prevention

- The delivery of key outcomes of the screening programme including (see the standards listed above), including timely contact with women, couples and families and expert non-directive counselling.
- The initiation of lifespan care for newborns and other SCD&T that require care i.e. new patients that have moved to the area.
- Optimising the quality of life for children by advising schools and other relevant professionals on how best to support children with the condition.
- Optimising the support for adults, particularly if their condition becomes more complex by offering them long-term support and active case management.
- Integrated care pathways that allow patients to receive seamless care across providers that does not duplicate any clinical assessments and allows for shared care between providers.
- Improved liaison between providers.
- Reduced admissions by actively supporting those patients who are struggling to self-manage their condition.
- Early detection of complications by having consistent guidelines and protocols across the network, especially transparent escalation thresholds to acute care.
- Aiding the health and independence of patients by guiding them to other long-term conditions management support that may be available in the community or voluntary setting.
- Addressing wider inequalities by referring or guiding patients and carers to social care or the voluntary sector.

Scope

Service description

- Counselling to support the screening programme is likely to be commissioned by the NHS Commissioning Board as part of the screening programme specification. The whole screening pathway needs to be integrated despite the fact that different professionals and organisations are responsible for different aspects of the pathway.
- Community haemoglobinopathy care is commissioned as a component part of integrated, lifespan care. The service is for patients, families and carers with a haemoglobin condition from the end of screening to end of life care to those dying from chronic complications.
- Care will be patient-centred and attempt to meet the cultural needs of SCD&T patients. Care will be delivered in a way that avoids stereotypes especially with regards to pain management.
- Core elements of clinical care should be placed within the long-term conditions agenda and approach.
- Care should also be commissioned and delivered in way that supports the work programme of the clinical network of care. This network of care will support and encourage collaborative working across all providers to ensure there are no gaps in care arising from differential commissioning arrangements.
- Community care may also host outreach acute services to promote access for patients.

Accessibility / acceptability

- Community care is accessible to all patients, carriers, families and carers with a haemoglobin disorder.
- Community care must also be accessible to a range of professionals that may be working with SCD&T patients and may need education and training as a consequence.
- Community care in high prevalence areas should also be able to offer advice and guidance to community healthcare professionals in lower prevalence areas in their management of patients. The experts informing this document were clear that any such support would be that of formal liaison only – staff will not be able to manage out of area patients.

Commissioners and providers should consider and agree mechanisms to advertise any community service to patients, families and carers. Health and social care professionals will also need to be informed of any service development.

Whole system relationships

This section can be completed locally with named providers.

- The NHS Sickle Cell and Thalassaemia Programme.
- The regional haemoglobinopathy clinical network of care.
- Relevant non-specialised commissioners including those in the local authority.
- The designated provider that delivers specialised care.
- Other acute and accredited providers within the clinical network.
- Social care.
- Education service.
- Voluntary and user groups.
- Specialised commissioners.
- User organisations and other voluntary organisations.

Interdependencies

This section can be completed locally with named providers.

- Local / regional screening laboratory.
- Local acute providers including the designated provider delivering specialised care.
- Other community healthcare professionals e.g. community matrons, health visitors.
- Education providers.
- Social care.

Relevant networks and screening programmes

- NHS Sickle Cell and Thalassaemia Screening programme.
- TCD scanning service – commissioners are advised that in line with best practice all children with SCD must be offered annual TCD scanning to screen for stroke. The actual scan may be delivered either in an acute setting or in outreach clinics by specifically trained professionals. The management of any abnormal results must be undertaken by a designated or accredited provider.
- The haemoglobinopathy clinical care network.

Service delivery

Service model

As SCD&T are lifespan conditions, patients and carers needs will change over time and any community care should be able to meet evolving need, including their psychological need.

Effective community care will also be supported by the clinical network of care, which should work with all providers to optimise all the clinical expertise in place. This may involve determining different levels of care between providers including community care. These different levels of care may be presented as:

- Patients that are so complex that they are best managed by specialised and accredited providers and any support from community care should be developed in liaison with these acute providers.
- Patients that have regular hospital interventions like blood transfusions and iron chelation. These patients may benefit from a shared-care approach between the acute provider and community care. Community care could offer comprehensive long-term conditions management support and support discharge planning.
- Patients that have frequent admissions that could benefit from active case-management by community healthcare professionals.
- Patients that are largely self-managing and may access community care to maintain this autonomy.

This is only one illustration; networks of care are encouraged to develop their own models reflecting local need.

Care pathway(s)

To deliver optimal care to haemoglobinopathy patients, pathways need to be integrated between providers, irrespective of how those providers are commissioned. Care pathways will need to be locally determined based on local expertise and services in place; such pathways need to be developed with the support of the clinical network of care.

- The screening care pathway will follow the generic model described by the screening programme and outlined in detail on the Map of Medicine (http://www.mapofmedicine.com/) but adapted to fit with local circumstance and depending on the prevalence of the conditions. All pathways must be integrated with usual maternity and newborn care.

Referral, access and acceptance criteria

Geographic coverage / boundaries

To be locally determined whether it covers the entirety or part of the clinical haemoglobinopathy network.

Location(s) of service delivery

To be locally determined.

Days / hours of operation

To be locally determined. Commissioners are advised that in direct user feedback, patients and carers were not always aware of what community services were available to them and how to access it. Special focus is needed to advertise any community services to the relevant population.The third sector may be able to assist with this.

Referral criteria & sources

- Any patients (children and adults) with SCD&T.
- Any parents of newborns / children with SCD&T.
- At risk couples identified by the NHS Sickle Cell and Thalassaemia Screening Programme.
- All newborns and their families identified by the NHS Sickle Cell and Thalassaemia Screening Programme.
- Any children or adults with SCD&T referred by GPs or other healthcare professionals.
- Patients with SCD&T or their carers should also be able to self-refer to access community care.

Referral route

- The NHS Sickle Cell and Thalassaemia Screening Programme and screening laboratories.
- Acute providers.
- GPs.
- Self-referral.
- Other healthcare professionals e.g. midwives.
- User organisations should also be advised of how to sign-post patients and carers to community care.

Exclusion criteria

This will need to be locally agreed based on the capacity and expertise in place.

- Education of the general public should be undertaken after consideration of the time and resource involved.
- Community providers may wish to set limits to the counselling support available to the worried well. Commissioners and providers may wish to link in with local screening co-ordinator and voluntary sector as part of their considerations.
- Patients that do not live within the agreed geographical boundaries.

Response time and detail and prioritisation

Commissioners and providers are advised to consult the standards of the NHS Sickle Cell and Thalassaemia Screening Programme, which can be found on the programme's website. The specific documents to be accessed are listed in clause 1.2 – Evidence Base.

- Commissioners and providers will need to locally agree response times for any patient self-referrals.
- Depending on capacity and expertise in place, community care may offer drop-in clinics to support any urgent cases. This is left to local determination.

Discharge criteria and planning

SCD&T are lifespan conditions and therefore patients will not be discharged from community care.

Community care has a strong role to play in supporting discharge planning from the acute setting. Commissioners and community providers with the support of the clinical network of care may explore the development of early supported discharge schemes or hospital at home schemes for the most common forms of admission, for instance painful episodes. Such developments are inevitably dependent on clinical expertise and resources in place.

Community providers should 'discharge' patients that leave the area and also advise the relevant acute providers to support accurate data management.

Community care has a strong role to play in supporting discharge planning from the acute setting

Prevention, self-care and patient and carer information

Promoting effective and safe patient self-management is a core function of community care and any clinical approach should be developed with the support of the network of care. Specifically, patient self-management should focus on managing pain, adherence to chelation and other medication regimes and when and how to access emergency care.

Local and specialised commissioners are strongly urged to work together to commission the formation of network-wide patient information literature to avoid duplication of time and resource. Such an approach is consistent with integrated and collaborative care. Literature will be available in a range of relevant languages and according to the standards established by the Care Quality Commission.

Local and specialised commissioners are encouraged to jointly commission a network wide patient hand-held record. Patients should be provided with copies of all clinic letters and outcomes of annual reviews.

Patients and carers should also be advised of what other health, social and voluntary services are available to them.

All relevant clinic letters should be sent to GPs.

Continual service improvement / innovation plan

To be locally agreed based on services presently in place. Commissioners may wish to consider the development of a patient hand-held record as a priority development.

All improvements plans should be managed via the CISG.

Discharge criteria and planning

Description of Scheme	Milestones	Expected Benefit	Timescales	Frequency of Monitoring

To be locally agreed.

Commissioners may also wish to assess community care on how effectively community providers support patients at home to reduce hospital admissions.

Baseline performance targets – quality, performance and productivity

Performance Indicator	Indicator	Threshold	Method of Measurement	Frequency of Monitoring
Quality				
Insert relevant Vital Signs indicators				
Insert relevant indicators from National Indicator Quality Improvement Programme				
Insert selected indicators from Transformation Guides				
Service User Experience Experience Improvement Plan Reducing Inequalities Reducing Barriers Personalised Care Planning				
Outcomes				
[Any additional local indicators]				
Performance & Productivity				
Insert relevant indicators from Transformation Guides				
Improving Productivity				
Unplanned admissions				
Access				
[Any additional local indicators]				
Additional Measures for Block Contracts:-				
Staff turnover rates				
Sickness levels				
Agency and bank spend				
Contacts per FTE				

Activity

Activity Performance Indicators	Method of measurement	Baseline Target	Threshold	Frequency of Monitoring

Activity plan / activity management plan

- Local commissioners are encouraged to agree a minimum dataset as a baseline.
- Commissioners are also encouraged to make any activity plan outcomes based so that it isn't just the numbers of clinical contacts assessed but the value of those contacts for the patient / carer.

Capacity Review

This section to be locally determined; possible suggestions include:

- Ratio of staff to the numbers of patients accessing the service.
- How staff skill-mix is utilised to manage patients that have been stratified i.e. are the most experienced staff supporting the most complex patients.
- As part of any capacity review commissioners are recommended to factor in the senior management time needed for formal liaison and collaboration with the clinical network and other providers.

Currency and prices

Basis of Contract	Currency	Price	Thresholds	Expected Annual Contract Value
Block / cost and volume / cost per case / Other _____*		£		£
Total		£		£

*delete as appropriate.

Cost of Service by Commissioner

Total Cost of Service	Co-ordinating Commissioner Total	Associate Total	Associate Total	Associate Total	Total Annual Expected Cost
£	£	£	£	£	£

5

Model service specification for specialised / tertiary (acute) haemoglobinopathy services

Service	The model service specification for specialised / tertiary (acute) haemoglobinopathy services. This specification should inform any accreditation process.
Commissioner Lead	Nationalised Commissioning.
Name of Clinical Care Network	To be completed locally.
Name of Designated Provider	To be completed locally.
Period	5 year designation period – services can be reviewed at any time within that period.

Purpose

Background information

This document is part of a series of guidance documents produced by the National Haemoglobinopathies Project (June 2010 – July 2011), commissioned by the Department of Health.

This document is one of two model service specifications for commissioning high quality sickle cell and thalassaemia services.

1. Model service specification for community care – this is care organised and delivered within community care services and usually takes place outside the hospital setting.
2. Model service specification for specialised services – this is tertiary acute care for haemoglobinopathy patients i.e. this is the most expert care and oversight of patients experiencing the most significant clinical complications. Specialised services are obliged to deliver a set of nationally agreed standards including leadership of networks of care, annual reviews for the most complex patients; the initiation, amendment and cessation of interventions like long-term blood transfusions and iron chelation. Therefore, this document should be read in conjunction with the designation standards for specialised haemoglobinopathy care.

As this document covers specialised acute care there will be little reference to the care delivered by other providers. For further information on care that may be delivered outside a hospital setting, please consult the model service specification for community care.

Specialised commissioners are advised that designated providers in addition to overseeing and treating the most complex haemoglobinopathy patients from across their region, will also continue to treat routine sickle cell and thalassaemia (SCD&T) patients in their locality.

Project specific glossary

The Project's understanding of a **clinical network of care** is informed by the definition developed by the Scottish Executive i.e. it is linked groups of health professionals and organisations from primary, community, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high quality clinically effective services.

Designated providers / lead acute providers – these are the hospitals that will deliver the specialised standards, one of which is clinical leadership of the clinical network of care. Designation of specialised services is undertaken by specialised commissioners.

Accredited providers – these are hospitals with a lot of experience in managing haemoglobinopathy patients that go through a form of partial designation so that they can deliver some specialised functions. Accreditation will also be undertaken by specialised commissioners in conjunction with the designated provider.

Linked providers – these are other acute hospitals within the geographical boundaries of the haemoglobinopathy clinical network. They will deliver no specialised haemoglobinopathy care; however, they will continue to see less-complex haemoglobinopathy patients. Any non-specialised acute care is commissioned by non-specialised commissioners.

Community care is care organised and delivered within community care services and usually takes place outside the hospital setting.

Any references to **patients** encompass all users and carers engaging with haemoglobinopathy services.

Executive summary

Specialised haemoglobinopathy services are commissioned to deliver expert oversight and care to patients experiencing clinical complexities, as well as clinical leadership of the clinical network of care. Specialised providers will also deliver specific interventions like bone marrow transplantation and stem cell transplantation – although such interventions may be concentrated to a few national centres. Specialised haemoglobinopathy services are also about clinical leadership via a network of care and the management of clinical complexity and complications to reduce morbidity and mortality.

The delivery of specialised care is largely dependent upon all clinical providers recognising the degree and nature of complexity of that care and having appropriate escalation thresholds and policies in place.

Specialised and life-saving care is also entirely dependent on strong collaborative relationships between providers. These are challenging in a number of ways:

- The geographical distribution of haemoglobinopathies is extremely variable with patients presenting for care anywhere in the country. Therefore, any provider must be able to recognise and manage in particular, emergency presentations and know where to get expert advice. All providers should be able to access summary information on individual patients e.g. from the National Haemoglobinopathy Registry (NHR) http://www.nhr.nhs.uk/

- Providers must also recognise when it is necessary to escalate patients to be managed by centres with greater expertise. This can be problematic as it can take a high level of expertise to recognise underlying clinical complications and complexity, which may not be present in general acute hospitals. Instances of inadequate clinical management have resulted in avoidable deaths, (see National Confidential Enquiry into Patient Outcome and Death (NCEPOD), A Sickle Crisis? 2008).
- Community and general acute care are commissioned separately by non-specialised commissioners. Differences in commissioning arrangements can lead to fractured care pathways resulting in either duplicated aspects of care or some people not accessing the full range of care available to them. In some areas collaborative arrangements have been developed either via the clinical network or enthusiastic clinicians working together. Such collaborations are neither universal nor consistent in their clinical outcomes. Appropriate training of all professionals caring for haemoglobinopathy patients is essential to improve clinical outcomes.

Therefore, for specialised care to be effective it is essential that it be delivered in the context of a formalised network of care. Designation will be of individual providers; there should be sufficient providers to deliver tertiary haemoglobinopathy care across NHS England. A key specialised function will be leadership of the clinical care networks to formalise collaborative relationships including community providers to develop integrated care pathways. The network of care could provide oversight and guidance on the clinical training and professional development of all relevant staff within the region.

A national designation process with all designating centres adopting a standardised approach in their leadership of the clinical networks of care will also support national benchmarking of clinical outcomes.

Aims of the service

- To reduce the morbidity and mortality of SCD&T patients by improving consistency and equity of expert care across NHS England. This will be achieved by designating a number of specialised centres across the country that co-ordinate care across the networks.
- To commission a number of acute providers across NHS England to become designated centres that can deliver the specialised standards outlined in the designation standards developed by the National Haemoglobinopathies Project. These standards include leadership of the clinical network of care. Where there is more than one designated provider in the clinical network area, leadership will be shared.
- Much of this leadership function will centre on developing integrated care between providers, overcoming any divisions in pathways created by differential commissioning arrangements.

Commissioners will also have responsibility for accrediting acute providers with considerable expertise in the management of complex SCD&T to deliver specified specialised functions. All of this will be done under the auspices of the clinical care network.

Evidence base

Standards, guidelines and quality requirements	
1	Quality requirements for health services for adults with haemoglobinopathies (likely to be rolled out 2012) – (adult peer review).
2	Royal College of Nursing – Caring for people with sickle cell disease and thalassaemia syndromes – a framework for nursing staff (2011).
3	Sickle Cell Disease in Childhood – standards and guidelines for clinical care – second edition (2010). First edition 2006.
4	Transcranial Doppler Scanning for Children with Sickle Cell Disease – standards and guidance (2009).
5	Quality requirements for health services caring for children and young people with haemoglobinopathies (2009) – (paediatric peer review).
6	Specialised Services National Definitions Set (SSNDS) 3rd edition – specialised haemoglobinopathy services (all ages) – Definition No. 38 (2009).
7	Sickle Cell and Thalassaemia – Handbook for Laboratories (2009).
8	Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK (2008) – second edition. First edition, 2005.
9	Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK (2008).
10	NHS Sickle Cell and Thalassaemia Screening Programme, Standards for the linked Antenatal and Newborn Screening Programme. Second Edition, 2011.
11	Health Technology Assessments (HTAs) – there are a number of HTAs underway with direct relevance to SCD&T. These HTAs have been sponsored by the National Institute for Health Research (NIHR) and also by the NHS Sickle Cell and Thalassaemia Screening Programme.
12	The National Institute of Clinical Excellence (NICE) is currently developing a short clinical guideline on the management of sickle cell crisis in hospital.
Additional evidence	
13	The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report, A Sickle Crisis? (2008).
14	Published literature and grey literature – the project has also taken learning from a range of published documents e.g. documents published by the Department of Health and Social Care. The project has also taken extensive learning from grey literature, i.e. unpublished documents, for instance service specifications and designation documents for other clinical conditions.
Additional expert guidance	
15	The designation standards have also been informed by a comprehensive range of experts that have guided the National haemoglobinopathies project. These experts include consultants, nurses, GPs and specialised commissioners. The project has also been strongly informed by the NHS Sickle Cell and Thalassaemia Screening Programme.

General overview

Thalassaemia major, sickle cell disease (SCD) and other rarer anaemias are known collectively as haemoglobinopathies. All SCD affected children born in England, and the majority with thalassaemia, will be identified by the NHS Sickle Cell and Thalassaemia Screening Programme, now fully implemented in England. The Programme identifies around 350 babies with SCD and 20 – 30 babies with thalassaemia. Taken together these disorders are now the commonest inherited conditions in England (1:2000 births).

SCD and thalassaemia are complex disorders, and although often grouped together and managed by the same specialist team, their clinical manifestations and treatments are different. Treatment for children also differs significantly from adolescent and adult care.

Presently, there are estimated to be 15,000 patients with SCD in England and approximately 1000 patients with thalassaemia. A large number of these patients are under 19 years of age. Children with SCD are at high risk of silent strokes, which if undetected can cause neurological impairment compromising their education and long-term outcomes without extensive social and community care support.

The prevalence varies according to geographical area, being highest in urban ethnic populations, particularly London where about two-thirds of SCD patients and half of thalassaemia patients live. The affected populations can also experience high levels of social and economic deprivation. The combination of their clinical condition, wider socio-economic inequalities and factors like English not always being a primary language, can mean that some patients experience poor health outcomes attributable to difficulty in accessing care and describing their clinical condition.

If not effectively managed, both disorders can result in patients experiencing long term disability. Lack of effective care can also see increasing accident and emergency (A&E) attendances and admissions. Good quality care aims to minimise the risk of physical impairment and encourage patient self-management when safe and appropriate to do so. An example would be stroke prevention programmes in SCD without which some 10% of children would suffer a stroke. Another is cognitive behaviour therapy (CBT) to help cope with a long-term condition and painful episodes.

In general, the disorders most benefit from well organised and integrated care; this includes access both to good quality specialised, local and community services organised on a network of care basis. This model is supported by both professionals and patients.

Objectives of the service

The objective of specialised haemoglobinopathy care is to:

- Reduce avoidable morbidity and mortality through inadequate or inconsistently provided care.
- Reduce morbidity and mortality by improving the standard and quality of specialised care delivered overall by having consistent standards across NHS England. These standards involve designated providers developing further the network of care by producing and cascading key clinical guidelines and protocols to all providers within that network.
- Use designation and the network of care approach to explicitly overcome any fracture points in pathways and service models caused by different commissioning arrangements.

The headline designation standards are:

Figure 1 – Headline Designation Standards for Specialised Haemoglobinopathy Care.

Section A – Core standards (mandatory)	
A1	Clinical leadership (medical and nursing).
A2	Newborn screening.
A3	Prevention and management of neurological complications of SCD through transcranial doppler (TCD) scanning in childhood; specialised neuro-radiology, neurology and neuropsychology services.
A4	Expert multi-disciplinary care for complex patients including complex annual reviews.
A5	Initiation, modification and cessation of long-term transfusion regimes and preventative therapy in SCD.
A6	Initiation, modification and cessation of long-term iron chelation. The monitoring of the complications of iron chelation.
A7	Acute management of severe and life-threatening complications of SCD and thalassaemia.
A8	Long-term specific therapy for severe and complicated SCD cases.
A9	Peri-operative management of SCD&T patients requiring surgery.
A10	Management of pregnant women with SCD and thalassaemia.
A11	Clinical governance and audit.
A12	Patient and carer engagement.
A13	Data collection, management and submission.
A14	Education and research.
A15	Timely access to critical care (adults).
Section B – Collaborative standards (mandatory)	
B1	Timely access to critical care (paediatric).
B2	Access to a comprehensive range of clinical specialists experienced in treating haemoglobinopathy patients.
B3	Access to bone marrow transplantation and stem cell transplantation.
Section C – Additional quality standards (non-mandatory)	
C1	Appropriate adolescent in-patient facilities.
C2	Development of a network wide patient hand-held record.

Specialised commissioners are advised to refer to the designation standards for the detail underpinning the above headline standards.

Expected outcomes

A key principle driving the haemoglobinopathy standards is clinical governance, audit and data collection, which will allow clinicians and commissioners to measure clinical outcomes. Such outcomes include:

- Reduced morbidity and mortality through improved access to expert care.
- Greater equity through ensuring that all clinical networks of care have designated provider(s).
- Each clinical network of care will have a Clinical Service Improvement Group (CSIG) to develop consistent clinical guidelines and protocols across all providers within that network. This will tie in all providers to shared care models, integrated care pathways and appropriate escalation thresholds.
- Reduced hospital admissions and A&E attendance through supporting effective long-term conditions management especially by community providers (via pain management support and psychological support to manage painful episodes).
- The development of consistent datasets and audits across all clinical networks of care, using the National Haemoglobinopathy Registry (NHR), where appropriate, to support national benchmarking of clinical outcomes (see http://www.nhr.nhs.uk). There should also be the development of a dataset to support the evaluation of the outcomes of the NHS Sickle Cell and Thalassaemia Screening Programme and other data required by the screening programme.
- Greater optimisation of healthcare resources by:
  - Integrating pathways and models of care to avoid duplication of assessments and patient encounters.
  - Accrediting providers to deliver specialised functions making best use of expertise already in place.
  - Reduced admissions and shorter lengths of stay by developing a network-wide approach to active long-term conditions management and early supported discharge schemes for the most common reasons for acute admission (based on the expertise in place).
  - Centralising the super-specialised functions, for instance cardiac clinics for iron overload, to a few centres nationally.
  - Consistency of management of annual reviews.

Where possible, the capture and measurement of outcomes should make use of existing resources, e.g. the NHR and the haemoglobinopathy peer review process to support regional and national benchmarking.

Reduced hospital admissions and A&E attendance through supporting effective long-term conditions management especially by community providers

Service scope

Service description

Designation and accreditation of specialised haemoglobinopathy services has the following core components:

- Expert management of the most complex patients. The designation standards provide greater clarity on the clinical complexities that should be managed by specialised centres. Conversely, the designation standards are also explicit about what aspects of care are not specialised, for instance the regular delivery of blood transfusions to patients.
- Of equal importance is the clinical leadership of the haemoglobinopathy care network, most of these networks are already in place although their degree of development will vary. From a national specialised commissioning perspective, specialised commissions should endeavour to achieve the following:
- Consistency and standardisation (to a degree that is appropriate without being too prescriptive) of the haemoglobinopathy care networks across NHS England. This means that there should be some common objectives, audits, datasets for all networks to support national benchmarking to improve standards overall. Having some common terms of reference for the CSIG will support this endeavour.
- Consistency and standardisation (to a degree that is appropriate without being too prescriptive) of clinical guidelines and protocols for the optimal clinical management of SCD&T patients within each care network; this will include escalation to expert centres. This aspect of clinical leadership must encompass all providers within the network for it to be effective. This includes providers that are commissioned by non-specialised commissioners, such as community care. Clinical leadership must also include oversight and support for professional training and development of all relevant healthcare staff. This aspect of clinical leadership can only be secured if facilitated by the specialised commissioners i.e. it will be for the commissioners that work with providers to invite them into these formal collaborative relationships.
- The designation standards already include elements that can and should be delivered collaboratively to optimise the use of resources so it will not be a requirement for each designated provider to fulfil every clinical standard. There are also some functions that are super-specialised and will be limited to a few centres nationally, for instance stem cell transplantation.

Accessibility / acceptability

It is a fundamental right of all haemoglobinopathy patients to have access to expert elective and emergency care irrespective of where they live in the country. Long-standing inequities in access has resulted in avoidable morbidity and mortality (see the report of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) A Sickle Crisis? 2008).

Specialised care is for the management of complex patients and whilst the designation standards assist in defining complexity, each care network will have to agree its clinical parameters of complexity based on the local expertise in place.

Specialised commissioners, designated and accredited providers will need to develop a network-wide communication policy that meets the needs of patients, carers and the needs of other healthcare professionals.

Whole system relationships

- NHS Sickle Cell and Thalassaemia Screening Programme.
- Specialised commissioners.
- The regional haemoglobinopathy clinical network of care.
- The designated provider that delivers specialised care.
- Other acute and accredited providers within the clinical network.
- Social care.
- Education service.
- Voluntary and user groups.
- Local commissioners.
- User organisations and other voluntary organisations.

Interdependencies

This section can be completed locally with named providers.

- Local / antenatal and newborn regional screening laboratories.
- Local acute providers including the designated provider delivering specialised care.
- Other community healthcare professionals e.g. community matrons, health visitors.
- Education providers.
- Social care.

Relevant networks and screening programmes

- NHS Sickle Cell and Thalassaemia Screening Programme.
- TCD scanning service – commissioners are advised that this in line with best practice children with SCD must be offered TCD scanning to screen for stroke. The actual scan may be delivered either in an acute setting or in outreach clinics by specifically trained professionals. The management of any abnormal results must be done by any specialised centre or relevant accredited provider by individuals that have the relevant training and take part in any national quality assurance schemes that may exist.
- The haemoglobinopathy clinical network of care.

Service delivery

Service model

Designated and accredited providers will work with commissioners to deliver the standards outlined in the designation document. This will be done either directly or in collaboration with other designated providers.

All haemoglobinopathy service provision should be overseen by the haemoglobinopathy clinical network of care.

Care pathways

To deliver optimal care to haemoglobinopathy patients, pathways need to be integrated between providers, irrespective of how those providers are commissioned. Care pathways will need to be locally determined based on local expertise and services in place; such pathways need to be developed with the support of the clinical network of care.

Referral, access and acceptance criteria

Geographical coverage / boundaries

To be locally completed and reflecting the clinical care network. The geographical boundaries of the clinical care network are unlikely to be co-terminus with specialised commissioning boundaries.

As specialised haemoglobinopathies are nationally commissioned, specialised commissioners are encouraged to work together to secure national clinical network coverage.

Location(s) of service delivery

To be locally determined. This information must be included in patient information literature and communication documents.

Days / hours of operation

To be locally determined. Commissioners are advised that in direct user feedback, patients and carers were not always aware of what community services were available to them and how to access them. Special focus is needed to advertise any community services to the relevant population. The third sector may be able to assist with this.

Referral criteria and sources

Any SCD&T patient (paediatric and adult) that is clinically complex under locally agreed definitions. Referrals should be accepted from the following (there will need to be a degree of local determination):

Referral route

- NHS Sickle Cell and Thalassaemia Screening Programme.
- Linked acute providers.
- Accredited providers.
- Other designated providers (for the delivery of collaborative or super-specialised functions).
- Community providers.
- GPs.
- Self-referrals.
- Other health and social care professionals.

The voluntary sector may be able to assist in disseminating this information to patients and carers.

Exclusion criteria

Designated providers will continue to see their own routine local patients. Routine patients should not be placed on complex care pathways.

Response time and prioritisation

See designation standards as some standards have response times such as complex annual reviews. The response times and prioritisation of the other designation standards will need to be locally agreed.

Transfer and discharge from care obligations

SCD&T are lifespan conditions. Throughout their lives patients will need regular access to expert, specialised care. Therefore they will be no actual discharge from the specialised provider, which must be available to all patients based on their clinical need.

However, specialised providers will also be providing routine care for their local patients and therefore commissioners and providers are encouraged to jointly develop separate pathways that differentiate routine and complex care.

Self-care and patient and career information

Promoting effective and safe patient self-management is a core function of community care. Any self-management approaches should be shared and ratified by the CSIG. Specifically, patient self-management should focus on managing pain, adherence to chelation and other medication regimes and when and how to access emergency care.

Quality requirements

Performance Indicator	Indicator	Threshold	Method of Measurement	Consequence of breach
Quality				
(For local agreement and insertion)				
Performance & Productivity				
(For local agreement and insertion)				

Any indicators will need to be locally agreed.

NB: Specialised commissioners are strongly encouraged to use the quality requirements already developed and assessed by the Paediatric Peer Review Programme and the Adult Peer Review Programme, to avoid duplication of time and resource. Specialised commissioners should be members of the peer review teams if they are not so already.

Activity

To be locally determined			
Activity performance indicators	Threshold	Method of measurement	Consequence of breach

Activity Plan

To be locally determined.

Capacity Review

To be locally determined.

Prices and costs

Price – to be locally determined

Basis of Contract	Unit of measurement	Price	Thresholds	Expected Annual Contract Value
National Tariff plus Market Forces Factor				
Non-Tariff Price (cost per case/cost and volume/block/other)*				
Total		£		£

*delete as appropriate.

Cost of service by commissioner – to be locally determined

Total Cost of Service	Coordinating PCT Total	Associate PCT Total	Associate PCT Total	Associate PCT Total	Total Annual Expected Cost
£	£	£	£	£	£

6

Equality impact assessment

Organisation	East Midlands Project Commissioning Group (EMSCG).
Project	National Haemoglobinopathies Project (commissioned by the Department of Health).
Name of 'activity' being assessed (if possible hyperlink document)	The project is developing a set of guidance documents for commissioners. This document will screen the project's work for possible impact on the relevant groups identified in the equality legislation.
Person completing this form	Ms Binal Nathwani, National Haemoglobinopathies Project Manager.
Lead Manager	Overall responsibility for the EIA Screening and all governance matters rests with the National Haemoglobinopathies Project Board.
Additional Information	• With the approval of the National Haemoglobinopathies Project Board (280211), this EIA includes learning from the full EIA commissioned by the Pan London Review of Haemophilia Services (April 2009), which included direct user engagement. Much of the user feedback is generic and not disease specific and therefore has value to the National Haemoglobinopathies Project. We gratefully acknowledge the Pan London Review for sharing their work. • This inclusion has also been approved by the local Equality & Diversity Officer at Leicester, Leicestershire & Rutland Integrated Equality Service.
Date screening completed	0 1 0 3 2 0 1 1
Please indicate (P) whether activity is proposed	or Existing — i.e. the project is underway

Step One: What is the aim or intended outcome of the activity?

This headline and national EIA is shared with commissioners as a starting point for any local EIA.

Useful glossary:

- Health inequality – refers to the differences in health experiences and outcomes using different dimension measures e.g. age, gender, geography, socio-economic grading etc.
- Health equity – refers to the equitable / fair distribution of health resources to meet clinical need i.e. equal share of the resources to meet equal need.

Anecdotal evidence suggests that some patients and clinical staff perceive haemoglobinopathy services to be poorly resourced in comparison to other services.

The same anecdotal evidence suggests that some patients' receipt and experience of health care has not been equal with that of other patients.

The Project acknowledges the existence of these perceptions.

1. Aim of the activity being screened:

It is the starting premise of this EIA that many haemoglobinopathy patients presently experience a range of inequalities by the nature of their population status and by the clinical condition they have. It is not believed that any of the project's activities will compound existing issues. Where possible and within scope of the project every endeavour will be made to reduce any inequalities experienced.

A) Patients

The national haemoglobinopathies project is commissioned by the Department of Health with the specific intention of improving patient care for patients diagnosed with haemoglobinopathy disorders. This is seen to be achieved by the development of a set of guidance documents for commissioners (project and non-project) on commissioning high-quality, lifespan sickle cell disease (SCD) and thalassaemia services. These conditions are known under the umbrella term, haemoglobinopathies.

The project will deliver a set of guidance documents (please see Objectives for this list); only one of the documents is obliged to be used by project commissioners when designating specialist centres. However, it will be a working assumption of this EIA that all the documents will be used and therefore affect the whole of lifespan care.

Haemoglobinopathies is a genetic lifespan condition that affects certain groups disproportionately. Therefore, irrespective of the activities undertaken by the Project the following issues are inherent in any considerations about haemoglobinopathies:

- Race.
- Religion.
- Age.
- Pregnancy and reproductive choices.
- Disability (physical and mental).
- Socio-economic inequalities (interpreted more specifically as financial deprivation). This is not normally included in any EIA but has been added to reflect concerns expressed within the project's national Expert Working Party.

Aim continued:

The NHS can only endeavour to redress any socio-political and economic inequalities when they manifest in a healthcare setting. The wider redress of inequalities can only occur at a national, political level.

In addition, it is essential to include in any equity and equality considerations the geographic prevalence of haemoglobinopathies, which is extremely variable across the country. Prevalence tends to be concentrated in large urban areas where many minority ethnic groups live, who are at most risk of these conditions. However, patients can and do present for care anywhere in the country. Access for these patients is more than physical access to an acute healthcare facility; it has to be defined in terms of access to relevant, expert care which will be focused on a few specialist centres nationally.

Therefore, haemoglobinopathy patients can experience clinical inequalities in terms of access to relevant expert care and variation in the quality of outcomes depending on what care they access and where. These inequalities are alluded to in a report by the National Confidential Enquiry into Outcome and Death, A Sickle Cell Crisis? (2008).

The report concludes that such variation in clinical care has led to undue variation in outcomes. Where possible and where the responsibility rests with commissioners, the project will try to positively address the concerns of the NCEPOD report. (Please note the report does not use the phrase inequality).

B) Employees

As the EIA also looks at impact on employees in relation to various groups, it is essential to clarify that the project is not tasked to make recommendations on employment matters. There is no evidence to date that any employee will be adversely affected by the project outputs. Any description of optimal pathways and care models are informed by practicing clinicians themselves; for instance, nurses representing diverse parts of the country have helped define an optimal model of community care and the role of the lead nurse in a community setting.

However, the project takes place with two major contextual factors:

1. The financial challenges to secure major savings across the health economy. Within this context, evidence is emerging from different parts of the country that community sickle cell and thalassaemia nurse roles are at risk. Any reduction in community care has the potential to adversely affect patient care. The impact of any such changes would need to be identified and addressed in any local EIA.
2. The re-structuring of the NHS including new commissioning arrangements and promoting plurality of providers including those from the private sector.

The combination of both changes is arguably already affecting the provider landscape with developments like vertical integration.

Such reforms and changes may affect employees including those providing haemoglobinopathy care; these changes are not in any way associated with the project and are therefore beyond the scope of this EIA.

Outcomes of activity being screened:

The project documents (outputs) are:

1. The vision for integrated, equitable and effective haemoglobinopathy lifespan care.*
2. The designation standards for project haemoglobinopathy services.
3. The model service specification for community haemoglobinopathy care.
4. The model service specification for project / tertiary (acute) haemoglobinopathy services.
5. The national haemoglobinopathies project's equality impact assessment.*

(*These papers were agreed by the project board.)

The outputs, if used have the potential to change for the better how haemoglobinopathy care is commissioned and delivered. It is not possible to quantify the degree of change as it is dependent on what is presently in place at the moment and how far it differs from what is recommended.

The development of new pathways and model service specifications could mean new models of delivery especially for specialised care. Access could be an issue in three ways:

a) Healthcare professionals not understanding new models of care and knowing where and when to make referrals.

b) Patients/carers not knowing where to access the most appropriate care.

c) Patients/users having practical difficulties in accessing care that is not close to home.

As stated previously, the intention of the project is to improve patient care. Where it is possible and appropriate mitigating measures will be suggested to commissioners, although many of these may need to be locally determined.

Outcomes in terms of current and possible project benefits:

- The project will core elements of a lifespan pathway.
- The project outputs will set out for commissioners the core elements of clinical care they should commission for the delivery of effective care.
- The project will set out for the first time a set of designation standards for project services.
- The project will model services specifications for tertiary and community care – these are shaped by experts from across the country.
- The project will provide a set of documents for commissioners that require no clinical knowledge of haemoglobinopathies.
- The project has explicitly stated its aspiration to secure universal coverage of haemoglobinopathy specialised care to allow equity of high quality clinical care.
- The project is attempting to raise and maintain the profile of haemoglobinopathy for the benefit of patients, at a time of great change and upheaval in the NHS. This is being done in a number of ways including engaging with wider stakeholder e.g. public health teams and by securing the goodwill and influence of stakeholders like UK Forum for Haemoglobin Disorders and the Royal College of Nursing.

All of the above is being achieved in an open and transparent way within the existing project scope and resources. All of the outputs are being delivered with the benefit of comprehensive engagement with a range of professionals and stakeholders and this is being supplemented by direct user engagement.

Step Two: Details of Consultation/Involvement – during the development of this activity?

This is a national project and there has been a requirement to represent the many and varied stakeholders. Part of this has been to represent high and low prevalence areas as well as the different elements of the pathway i.e. community and acute care as well as the varied professionals involved in the commissioning and delivery of care. User societies have been involved from the outset.

Representation has been achieved in the following ways:

- Via a comprehensive induction programme where the project manager met a range of stakeholders that were able to share their learning and expertise to inform the formal development of the project approach. They also identified some of the key individuals that are best placed to take the project forward.
- There is an effective project structure to maximise stakeholder involvement and engagement. This consists of a national project board (PB) representing all the key professionals. The board has an independent lay chair, DH representation and a dedicated governance lead. The PB acts as a quality assurance of the works and deliberations of the national expert working party (EWP). The EWP also includes all the key professional groups and user representation via the two most established voluntary groups, the Sickle Cell Society and the UK Thalassaemia Society. The EWP represents all elements of the pathway and high and low prevalence areas. The EWP inform and shape the Project outputs as they are being developed and review them as they are produced. The outputs are then sent to the PB for second stage scrutiny. Timescales can mean that consultation with the two groups can be concurrent but remain independent of each other to retain the quality control.
- The PB has requested that direct user engagement be secured and to that end a user workshop is planned for April 2011. This will capture patient / carer views on what is most important to them and what from their perspective makes a seamless pathway. This workshop will also be an opportunity to explore how socio-economic factors affect patients healthcare choices. To maximise representation, all of the haemoglobinopathy clinical networks across England have been approached to identify patients to attend this workshop; they were asked to identify one SCD patient, one thalassaemia patient and one adolescent of either condition. As responses have been variable, the user groups have been approached to identify users.
- All key documents that are produced by the project are circulated widely for review and amendment. Circulation includes EWP and PB members and other individuals that have expressed an interest in the Project. All project members are encouraged to also secure the feedback of their colleagues. Once documents are ratified, they are available online on the emscg website (http://www.emscg.nhs.uk/_PoliciesandPublications-Haemoglobinopathydocuments.aspx) and also on the NHS Sickle Cell and Thalassaemia Screening website (http://sct.screening.nhs.uk/cms.php?folder=2558).

Step Three: Policy/Service Content: (A) SERVICE USERS (B) EMPLOYEES				
For sections A & B below check whether the 'activity' is likely to have a negative impact to people of different age, ethnicity, gender, disability, religion or belief, sexual orientation & transgender, civil partnership, pregnancy and maternity, gender reassignment or other group listed below? The checklists will help you to identify any strengths and / or highlight improvements required to ensure that the 'activity' is compliant with equality legislation. If in doubt contact the EDHR Team equality@lcr.nhs.uk				
(A) Check for DIRECT/INDIRECT discrimination against any protected characteristic SERVICE USERS:				
Does your 'Activity' have a negative impact on any group or individual service user from accessing or using the services?		Response		Please justify your response for each area and action to be undertaken.
		Yes	No	
A	Age • Both SCD and thalassaemia are inherited lifespan conditions and therefore age is inherent to any considerations as there will be different needs in childhood to adult care. Transition and handover of care in a person's lifespan care pathway is a known issue.		N	
B	Disability including Learning Disability, Mental Health, Sensory Impairment, Physical or other • Neurological impairment is a known clinical complication in children with SCD as they are at risk of silent strokes, which can go undetected – affecting their development and education. • As the diseases progress through a patient's life, physical impairment and disability are common as patients get older. • As SCD and thalassaemia are lifelong conditions, many patients and their carers/ families need psychological (mental health) input to manage the chronic nature of their condition.		N	
C	Gender (Male, Female) • The project outputs are designed to be inclusive.		N	
D	Gypsy/Roma/Traveller • The project outputs are designed to be inclusive.		N	
E	Marriage and Civil Partnership • The project outputs are designed to be inclusive.		N	
F	Offenders and Ex offenders • The Project outputs are designed to be inclusive.		N	
G	Pregnancy and Maternity • In both conditions there are particular issues related to reproductive choices and clinical complexities in managing pregnancy. The NHS Sickle Cell and Thalassaemia Screening Programme addresses many of these issues in the clinical information it provides and counselling it offers. Community haemoglobinopathy healthcare professionals also counsel pregnant women with at risk pregnancies. Further information on this can be found within the model service specification for community care.		N	
H	Race or Ethnicity • Haemoglobinopathies (sickle cell disease [SCD] and thalassaemia) disproportionately affects certain minority ethnic groups. • SCD patients can experience painful episodes and acute pain crises. Anecdotal evidence suggests that some staff attitudes could be interpreted as making stereotyped assumptions about patients based on their ethnicity. Commissioners are encouraged to work with their providers to make certain that appropriate education and training is in place for staff.		N	
I	Religion or Belief (including other belief) • Patients can be from a full range of faiths. This is particularly significant as faith may affect some of the health choices made. For instance, parents allowing their children to be given antibiotic penicillin or some relying on faith healing to deal with clinical incidents like painful episodes.		N	
J	Sexual Orientation (Gay, Lesbian)		N	
K	Transsexual/transgender/gender reassignment		N	
L	Veterans		N	
M	Socio-economic factors (interpreted as financial deprivation). Please note the Coalition Government has not implemented the socio-economic duty in the Equality Act 2010. • As haemoglobinopathies disproportionately affects certain minority, ethnic groups, it is a working assumption (i.e. non-evidence based) that some, not all of these minorities may experience wider socio-economic inequalities.		N	

Summary of actions required to remedy any negative impact(s) identified for service users		
Action	**Lead**	**Target date**
• The project is tasked to guide commissioners to better commission high-quality haemoglobinopathy services. If the Project outputs are used, this should reduce variation in service provision overall and provide services based on optimal models of care, including specialist care. Therefore, overall the project is seen to further the possibility of better care – thereby reducing health inequalities. • Any possible risks around access will be highlighted to commissioners. Where possible, mitigating measures will be offered. However, as this is a national project, some of the mitigating measures can only be determined at a local level reflecting local configuration of care and expertise. • Users / carers will be asked to comment on access and other issues at a national workshop – March 2011. • Advice on this EIA has been and will continue to be sought from the local Equality & Diversity Officer at Leicester. Leicestershire & Rutland Integrated Equality Service. • The project is taking learning from other projects and developments from within and without haemoglobinopathies. For instance, the development of the paediatric and adult SCD standards made strong use of user engagement. The recent Pan London review of Haemophilia Services was in a position to commission two external full impact EIAs. Much of the learning in these reports is generic and not haemophilia specific. This project will take such learning to improve the quality of project outputs. • The national haemoglobinopathies project board has an ongoing responsibility to assess the project outputs using the Darzi definition of quality. This defines quality as care that is safe, clinically effective and personal. The responsibility of the PB in this regard, is clearly outlined in the project's integrated governance framework.	• The lead for this work is Binal Nathwani – national haemoglobinopathies project manager. • She is supported by the project board that has overall responsibility for project governance issues – which includes equality, diversity and human rights. • Ms Nathwani is specifically supported by Dr Lorna Bennett, a member of the PB that has delegated authority on behalf of the board on day to day governance matters.	The national haemoglobinopathies project will cease at the end of July 2011. All EIA related work that is agreed by the project board must be completed by that time and reflected in the final project outputs.

(B) Check for DIRECT/INDIRECT discrimination against any protected characteristic relating to EMPLOYEES:				
Does your 'Activity' have a negative impact on any group or individual employee?		Response		Please justify your response (Y or N) for each area and action to be undertaken
		Yes	No	
A	Age		N	To date there has been no suggestion that any of the project outputs will adversely affect any employees in relation to their equality rights. The project recommends the effective commissioning of services and describing optimal service models. Anecdotal feedback to date from practicing clinicians is they feel this will help them better understand lifespan care and the contributions of all professional involved.
B	Disability including Learning Disability, Mental Health, Sensory Impairment, Physical or other (Check this link for further)		N	As above
C	Gender (Male, Female)		N	As above
D	Gypsy/Roma/Traveller		N	As above
E	Marriage and Civil Partnership		N	As above
F	Offenders and Ex offenders		N	As above
G	Pregnancy and Maternity		N	As above
H	Race or Ethnicity		N	As above
I	Religion or Belief (including other belief)		N	As above
J	Sexual Orientation (Gay, Lesbian)		N	As above
K	Transsexual/transgender/gender reassignment		N	As above
L	Veterans		N	As above

Summary of actions required to remedy any negative impact(s) identified for service employees		
Action	**Lead**	**Target date**
N/A		
Number of 'Yes' answers for Service users (A) 0		
Number of 'Yes' answers for Employees. (B) 0		

Step Five: Details of specific 'activity' outcomes which promote equality and diversity				
• The entire premise of the project is based on the principles of promoting high quality, equitable care for all patients. Independent evidence (a report by the National Confidential Enquiry into Patient Outcome and Death) showed that care has been both variable in its provision and inconsistent in the quality of its outcomes. The project outputs will describe to commissioners what optimal and equitable care looks like – this includes clearly stated aspirations for universal designation of specialist care so that all patients can access the highest quality of care irrespective of where they live. • The project will describe optimal care based on network arrangements that include all providers irrespective of how they are commissioned. • Presently in many parts of the country, there are no commissioned haemoglobinopathy services at all. The project recommends that designation of haemoglobinopathy providers is undertaken across NHS England.				
Step Six: Determination section				
The following section draws together the outcomes from the above assessment and will help to determine whether the impact is H/M or L		Yes	No	Please add supporting statement for each question below
5.1	Is there any evidence that any protected characteristic group is affected differently?		N	
5.2	Is there a need for external or user consultation?		N	
5.3	If you have identified potential discrimination, are any exceptions valid, legal and/or justifiable?		N	
5.4	Is the impact likely to be negative?		N	
5.5	Can we reduce the impact by taking different action?			

IMPACT (Please tick one box)	High		Medium		Low	✔

If you have answered "Yes" to any of the questions in step five the function/activity may require a full EIA. However, if the action/s identified in step three mitigates the impact/s this will reduce the likelihood of a full EIA. It may be reasonable to review the activity in 12 months to determine the overall outcome of the agreed actions. The EDHR team will be more than happy to discuss any concerns.

Step Seven: Send copy of EIA Assessment to EIA Team. Please ensure you also provide a link to the activity being assessed when submitting the completed EIA screening or full assessment template to the EDHR Team.								
Date EIA template referred to EDHR Team	1	4	0	3	2	0	1	
Signatures author/reviewer of activity	Binal Nathwani – 1st March 2011 – this EIA was updated on 29/07/11							
Date for next review								

Additional information

Part 1 – learning from the Pan London Haemophilia Review

Please note:

i) The information outlined below is included both to inform the EIA and for its potential value of commissioners and providers that may be implementing the recommendations of the national haemoglobinopathies project.

ii) Much of the information below is informed by the hub and spoke model that was proposed to best deliver effective haemophilia care within the Pan-London area. The learning is still relevant for the national haemoglobinopathy project as many of the recommendations will be based on collaborative and / or networked care solutions – which are similar to hub and spoke models.

iii) The Haemophilia Review EIA makes little mention of non-acute care and therefore much of its learning is acute specific.

The Equality Impact Assessment of the Redesign of Inherited Bleeding Disorder Services – by Donna Carr and Dr Susan Robinson (April 2009)

Key messages from the report:

- Identifying any trends in relation to inequalities is impossible without robust and accurate service data.
- Vulnerable patients e.g. those with learning difficulties or the elderly should be supported through any changes to their service arrangements.
- Carers, social workers and support agencies should be fully briefed of any changes so they can provide appropriate advice and reassurance as required.
- Commitment to delivering services within a framework of equity, dignity, respect and tolerance needs to be firmly embedded in the aims of services for changes to be sustained.
- If adopting a hub and spoke model of care, spokes should develop expertise to best meet local need.

Recommendations for action:

The following actions were recommended as having the potential to reduce inequality and promote equity in service delivery:

- Data on patients registered and treated should be disaggregated for age, ethnicity, age etc to allow for commissioned services to be monitored for their impact on corresponding population groups.
- Commissioners should develop a comprehensive communications strategy outlining any new service configuration. This should be shared with a comprehensive range of stakeholders including current and future service users, carers and support agencies, GPs and other healthcare providers (acute and community services).
- When commissioning care from spokes, commissioners should consider the needs of that local population – this may be of particular relevance in culturally and ethnically diverse areas.
- Accessibility by public transport should be an important consideration when considering hub and spoke models (within the National Haemoglobinopathies Project there will be a hub and spoke model between specialist and local acute Trusts).
- Examples of good practice should be captured by commissioners and disseminated more widely through the hub and spoke (clinical networks).
- Changing local demographics should be included in any service planning – for instance the needs of older patients.
- To sustain its commitment to equity any consortia commissioning group should consider drafting a set of common principles for the delivery of care, based on existing equality, diversity and human rights legislation and NHS policy. These principles should be developed in partnership with service users and the emerging hub and spoke centres (within haemoglobinopathies this could form part of the designation process).

Appendix A – Report of Focus Groups & Interviews to Inform the EIA for the Pan-London Haemophilia Consortium Redesign – By Dr Susan Robinson (April 2009)

Findings were structured around the following headings:

Changing hospitals

- For some patients, any hub and spoke reconfiguration caused trepidation if it meant they had to change the hospital they were currently attending.
- Patient choice of hospital was a recurrent theme (in the designation standards for specialist haemoglobinopathy centres, it was made clear that patient choice may not always be a feasible option given the location of clinical expertise).
- Patients were concerned that any redesign would require them to go to different hospitals (providers) for different aspects of their care.
- Within haemophilia, there were mixed views on the priority proximity of services took. The elderly were more likely to favour proximity. There was also uncertainty about which aspect of care should be placed more locally e.g. emergency care. Proximity was only considered an advantage if the services were still available. One patient defined access as being able to speak to someone [expert] not about it being your local hospital.
- Patient experience was an important theme. For instance, the labelling of a centre as a spoke (not designated) was often viewed as a downgrading of provision – one attendee saying that she saw it as a diminished service and a diminution of the service quality for patients within that geographical area.
- Hubs and spokes also seen to potentially reduce choice as not all sites may offer all the elements of care (under haemoglobinopathy designation, not all specialist centres will offer the totality of specialist care).

- The provision of information to patients (and other healthcare professionals) was seen as vitally important to enable patients to access the full range of care. Patients should not be left to navigate hub and spoke models by themselves; especially if they are new to care as they will not know what to look for.

Changes in quality of care

A recurrent concern that any redesign or reconfiguration of service might lead to a reduction in the quality of clinical services provided – some likening it to the care they had received in the past. In a hub and spoke model there are two key concerns:

a) At spoke hospitals care might be compromised by a lack of critical mass of patients.

b) Spoke hospitals might not retain or attract staff of the required calibre and therefore care would be of a lower quality.

Receiving appropriate and timely care

- All respondents were anxious whether the care they would receive at a spoke would be correct and timely especially in an emergency within an A&E setting.
- Conversely, there was also concern about receiving timely care from hubs that may not have capacity to meet need as required as they are seeing patients from across a wider region.

Changes to clinical communication

- Good communication within and between hospitals was seen as essential and should not be compromised by any design or built into any redesign or newly commissioned service.
- Links and collaboration between clinicians at different hospitals was also seen as crucial if care were to be delivered in a hub and spoke model.
- Communication between different staff and teams within hospitals was seen as important especially in a surgical setting.
- Communication between hospitals and GPs was seen as vital as was GPs knowing where to refer patients for relevant care in any new service model.
- Communication between hospital staff and patients was highlighted and linked strongly to continuity of care by long-serving staff.

Part 2 – the development of a national equality delivery system

The Equality and Diversity Council (EDC), which was established by the Department of Health in 2009, has commissioned NHS Leicester City to lead on the development of an Equality Delivery System (EDS). The EDS is still in development stage and is subject to amendment by the Department of Health. The information included below is indicative of work to January 2011.

The aim of the EDS is to improve the equality and performance of the NHS and embed equality into the mainstream business planning processes. It is based on examples of best practice and aims to improve equality overall by focusing on what matters to patients, staff and communities.

The EDS applies to both current and planned NHS commissioning organisations including GP consortia and Foundation Trusts. Effective use of the EDS will also allow organisations to meet the obligations of the Equality Act and will support registration with the Care Quality Commission.

The EDS presents twelve equality outcomes under four headings:

1. Better outcomes for all.
2. Improved patient access and experience.
3. Empowered, engaged and included staff.
4. Inclusive leadership at all levels.

Based on evidence, NHS organisations and stakeholders should agree one of four levels of achievement against each of the four outcomes listed above. The four levels of achievement are:

a) Undeveloped.

b) Developing.

c) Achieving.

d) Excelling.

The National Haemoglobinopathies Project will bring the development of the EDS to the attention of commissioners at relevant parts of the Project outputs.

Please see figure 1 opposite for an un-ratified illustration of EDS.

Figure 1 – Draft Equality Delivery System at January 2011.

Objectives Menu	Narrative – the NHS is asked to	Outcome
1. Better Outcomes.	Achieve improvements in patient health, public health and patient safety for all, based on comprehensive evidence of needs and results.	1.1 Services and care pathways are commissioned or decommissioned, designed or re-designed, procured, provided and contractually monitored so that they meet the needs of patients, carers and local communities.
		1.2 Public health outcomes are measurable, substantive and are developed through evidence-based strategies, developed with the involvement of patients, carers and local communities.
		1.3 Patient safety outcomes are demonstrating measurable increases across all equality target groups, with the active participation of staff and managers engaging with patient groups and involving local communities.
2. Improved Patient access and experience.	Improve accessibility and information, and deliver the right services that are targeted, useful, useable and used in order to improve patient experience.	2.1 Patients, carers and communities are effectively accessing services, taking into account barriers that historically hinder equality of access.
		2.2 Patients, carers and communities are provided with appropriate communications support and information about services, so that they can make informed choices and be assured of diagnoses and treatments tailored to their needs.
		2.3 Patients and carers report positive experiences of the NHS, where they are listened to and respected, and the services they receive are safe, effective and personalised to their specific needs.
3. Empowered, engaged and well supported staff.	Increase the diversity and quality of the working lives of the paid and non-paid workforce, supporting all staff to better respond to patients' and communities' needs.	3.1 A workforce that is diverse within all occupations and grade levels through fair and flexible recruitment, development, and retention practices.
		3.2 The workforce is supported to remain healthy, with a focus on addressing major health and lifestyle issues that affect individual staff and the wider population.
		3.4 The workplace is free from actual and potential discrimination – from recruitment to retirement – and all staff are able to fully realise their potential.
4. Inclusive leadership at all levels.	Ensure that throughout the organisation, equality is everyone's business, and everyone is expected to take an active part, supported by the work of specialist equality leaders and champions.	4.1 Corporate leadership demonstrates the commitment and knowledge to assure equality outcomes within the organisation and the local health economy.
		4.2 The organisation develops and supports equality leaders and champions within the workforce to the standards of capability defined by the NHS Competency Framework for Equality and Diversity Leadership.

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