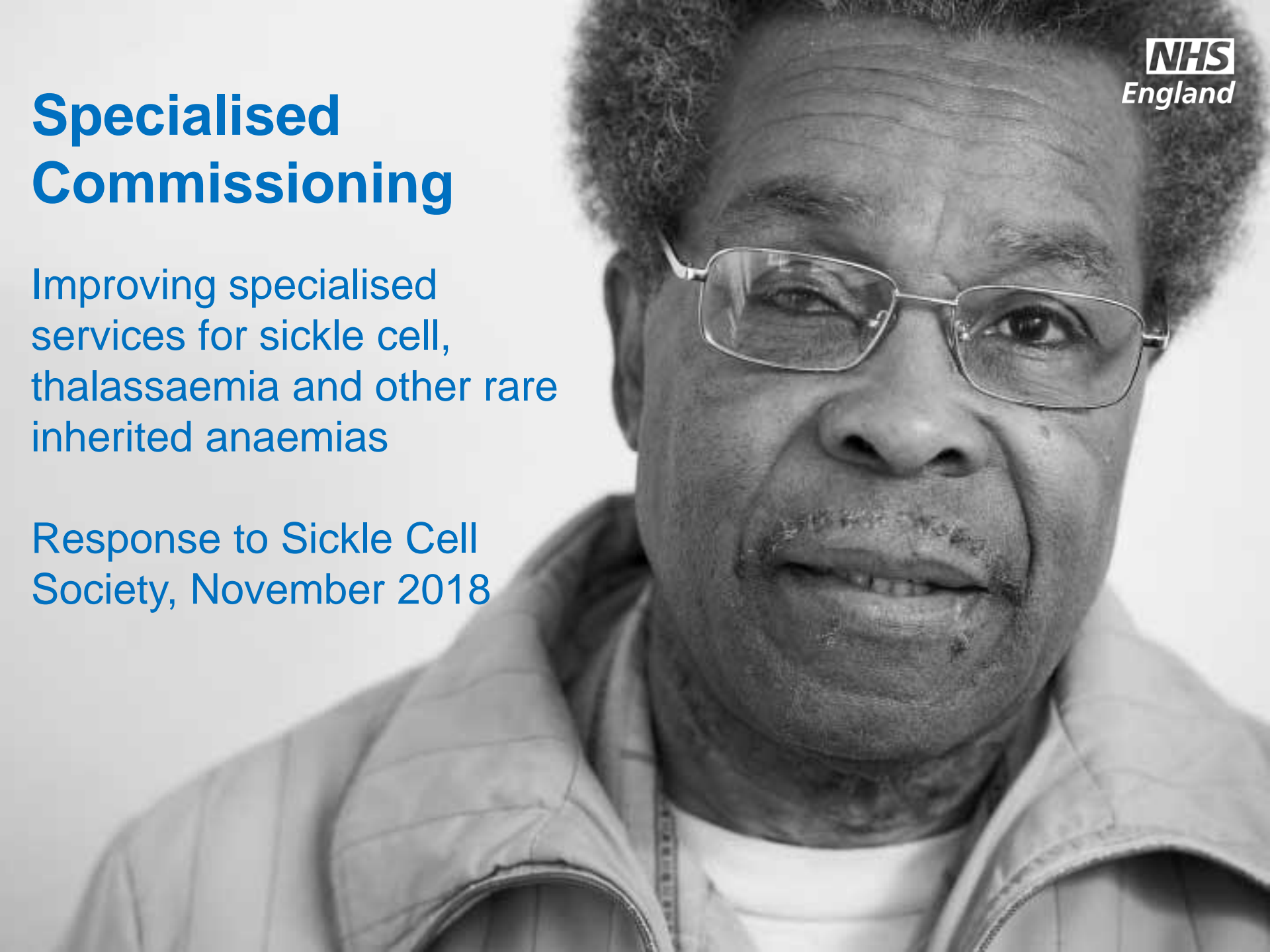


Specialised Commissioning

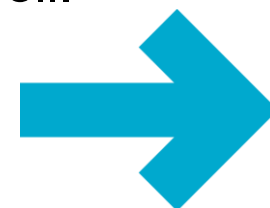
Improving specialised
services for sickle cell,
thalassaemia and other rare
inherited anaemias

Response to Sickle Cell
Society, November 2018



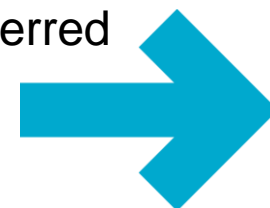
What are the headlines?

- NHS England is responsible for planning and buying **specialised services for sickle cell disease, thalassaemia (known as haemoglobinopathies) and other rare inherited anaemias**
- Over the past year we've been reviewing how these are organised and paid for, to ensure services work well for patients.
- Specialised services mainly covers care received in hospital. It doesn't include GP care or community care.
- Between June – August 2018 we spoke to people about some proposals to make changes to the way these services are commissioned.
- These changes won't disrupt the care patients currently receive, but we hope that over time everyone will see improvements and find it easier to let us know when services aren't working well.



What could this mean for patients?

- We hope these plans will mean that you see improvements over time, but this will not disrupt the care you currently receive.
- You are able to access routine care as close to home as possible.
- You can have confidence that the people caring for you day to day are supported by specialists.
- That no matter where you live, you will benefit from specialist advice – you won't have to travel to see them to benefit.
- You know those planning and paying for services have invested more in the network arrangements and will be measuring how they are working.
- You can be more involved with the networks to flag up incidences of poor care and highlight where hospitals may need additional training & support.
- Networks are made up of hospitals in your area who work together to ensure you get access to the care you need – including being referred to specialists if your health needs are complex.

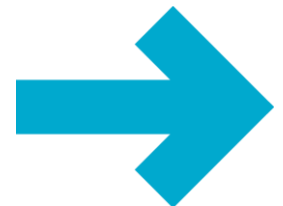


What did we talk to people about? England

Thanks to the support of the Sickle Cell Society, who helped us to organise a number of events and social media activity, we were able to speak to hundreds of people about our proposals.

We talked to people about the findings of the review from June to August 2018 to talk about three main areas:

- Plans to introduce a number of centres to lead local networks in each area called **Haemoglobinopathy Coordinating Centres (HCCs)** with responsibility for leadership and education.
- Plans to develop a **National Haemoglobinopathy Panel** to review the care of people with the most complex needs and oversee the introduction of new treatments, as they become available.
- Plans to review the **National Haemoglobinopathy Register (NHR)** to expand how it is used.



Haemoglobinopathy Co-ordinating Centres

One of the key proposals of the review is to introduce new Haemoglobinopathy Co-ordinating Centres to strengthen local networks using existing money more effectively:

- HCCs will support hospitals in their area who have less expertise in these conditions, to make sure all patients have access to specialist advice when needed. This will involve offering training and advice to less experienced hospitals.
- Patients will continue to be seen at their own hospital – there's no reason that patients would need to go to the HCCs, although people may still be referred to another hospital for specific complications.
- There are likely to be around **10 HCCs** across the country. Although the tasks will be different for sickle cell and thalassaemia, it is possible an organisation may be able to host HCCs for both.
- We will commission around **24 Specialist Haemoglobinopathy Teams (SHTs)**. These are likely to be the existing specialist haemoglobinopathy centres. They will have to meet improved standards.
- At the moment, networks are informal: it's not always been clear as to which trusts are connected and who is responsible for the network. HCCs will take on that responsibility, freeing up time for the SHTs to focus on providing care. HCCs work with SHTs to standardise care and ensure that advice is readily available throughout the network.



What did people think about HCCs?

- Some people commented that of the information seemed complicated – especially in understanding some of the changes about how the money will be used differently.
- It's true that the way that the NHS works can be complicated, and while we wanted to be honest about the changes being proposed, we appreciate that many people didn't feel they needed such detailed financial information. Except to be clear that resources for these services are not reducing.
- Although the review did initially consider more radical solutions – these could have involved people travelling further for routine care. We hope people can be reassured that our plans are intended to minimize disruption or unnecessary changes.
- People wanted to make sure that patients will continue to be listened to and involved – and this will be a key responsibility of each HCC who will need to demonstrate how they intend to involve local people.
- People were particularly keen to understand how HCCs will improve emergency care when speedy access to pain relief is needed. HCCs will have a key role in supporting hospitals in their area with training and advice on how to manage sickle crises.



Institute a National Haemoglobinopathy Panel (NHP)

This new panel will have two key roles:

- to advise clinicians about patients who have complex or more rare health problems.
- In the future this will be the group that considers individuals who may benefit from new commissioned treatments, such as gene therapy.

In general people felt this was a good idea – and commented that they want to see fairness and transparency as decisions need to be made about new treatments. Although these are still some way from being available, we want to make sure we have thought through what will be required in advance.

People wanted reassurance that we will involve patients as much as possible in this process, and we will keep people informed as these plans progress next year.



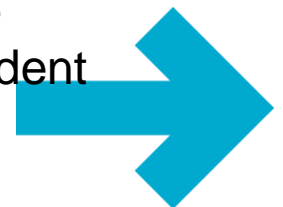
Develop the National Haemoglobinopathy Register

Although the NHR has been running for some time, it is effectively only a 'headcount' and we believe that it could be a more useful tool for clinicians and patients, to better manage care and access essential information when required.

This is also something that we are not changing immediately as more work is needed to understand how the NHR can develop to safely share information.

Almost everyone agreed that the NHR isn't currently fit for purpose, and so work to improve this will be carrying on. Generally people were supportive of the plans to develop it and explore options.

Some people expressed concerns about how secure confidential information would be, and we will continue to involve people in these plans to make sure that we develop something that people feel confident in.



Other things we heard

As we were talking to people about our plans – people also raised comments and questions about other aspects of the NHS that they wanted to discuss. Some of these are not issues being addressed by this review directly, as they are not covered by specialised commissioning but we wanted to address as many of these concerns as possible.

These included:

- Issues getting speedy and compassionate care in A&E
- Shortage of specialised staff
- Prescription charges
- Access to community care
- Questions about innovative treatments and when they will be available
- Access to psychological support

People also raised some specific medical questions – but unfortunately we can not comment on individual cases, and these issues should be discussed with your health professional.



NHS Prescriptions

- The issue of prescription charges was raised by lots of people, but unfortunately this isn't something that can be addressed by this review.
- NHS prescriptions are currently only free to a small number of working age adults with a medical exemption – this doesn't include all people living with long term conditions. People have told us that having sickle cell means that they need to pay for lots of prescriptions which is an unfair burden.
- Sickle Cell Society are part of a group of charities supporting people with health conditions who are asking the Government to review which conditions are exempt from prescription charges.



Shortage of specialist staff

- People reported that their hospital appears to be struggling to have enough specialist staff who understand their condition, and asked whether more staff can be recruited.
- Staff shortages are a challenge across the NHS, and this isn't something that can be easily fixed by the review.
- Our plans are intended to make best use of the limited specialist expertise of existing staff, in offering advice and training to other NHS colleagues.
- The CRG (clinical reference group) will continue to work with HEE (Health Education England) and professional healthcare bodies, to look at how we can encourage doctors, nurses and other clinicians to consider haemoglobinopathies as a special interest.



GP knowledge and community care

- People have commented that it would be helpful if GPs knew more about their condition. The new networks are focused on hospital care, but networks may try to engage with GPs. However, this is something that is likely to happen only where haemoglobinopathies are a local priority for GPs.
- Lots of people told us that they felt there was a lack of community care – although people meant different things by ‘community care’ including community nursing and support offered by voluntary sector groups.
- NHS England pays hospitals for providing specialist care and makes sure it is delivered to an agreed standard. Some hospitals may employ community staff to provide some aspects of care outside of their hospital if they feel it will benefit patients. This is a decision for the hospital.
- Other local health services are paid for by local clinical commissioning groups (CCGs). Although these services aren’t part of specialised commissioning, HCCs will have a useful role in identifying local issues for people living with sickle cell and thalassaemia and working with local health services to address problems where possible.



Innovative treatments

- Over the next few years we expect that various new, transformational treatments will become available – such as stem cell and gene therapies.
- This is not being led by NHS England. These are being developed by researchers, and when these treatments are ready, NHS England will be looking at how patients can access these services.
- At the moment we don't know who will most benefit from these treatments or what the referral criteria will be.
- Certain treatments, such as bone marrow transplants, are only available to certain groups of patients, including the age of patients. This is decided by NICE and NHS England do not have control over those decisions.
- We are setting up the National Haemoglobinopathy Panel to ensure that when new treatments become available suitable patients can be referred for advice. This is part of NHS England's commitment to making information about who is suitable for new treatments available in an open and transparent way.



Psychological support and transition

- We understand that sometimes accessing specialist psychological support can be difficult, often due to staff shortages.
- NHS England are requesting that trusts provide psychological support as part of the service specification; however specialised services do not pay for that aspect of the service.
- It is important that the transition from paediatric to adult care happens with the minimum of disruption. The changes we are making to the service make it clear that adult and paediatric services are required to work more closely together. This is one of the areas we believe can be improved on by HCCs working with local patients to find better ways to support young people.



Next steps

- The new service specifications for Haemoglobinopathy Co-ordinating Centres (HCCs) and Specialist Haemoglobinopathy Teams (SHTs) will soon be published on the NHS website. These set out what NHS England expects HCCs and SHTs to provide, including quality standards.
- We have now begun the process to choose the 10 HCCs. This will be an open procurement which means all eligible services, including all existing SHTs will be able to apply.
- After hearing your feedback, we will ensure some of our questions for prospective HCCs during the procurement process will cover the issues raised by patients.
- We are hoping to have this new model in place by Spring 2019.
- We will be sharing more information about plans for the new NHP and the development of the NHR next year, and continuing to work with the Sickle Cell Society so that people are involved in this work.



Stay informed

- If you would like to receive ongoing updates about the work of the Haemoglobinopathies CRG (clinical reference group) – please **sign up as a stakeholder**. Haemoglobinopathies comes under the Blood and Infection Programme of Care.

<https://www.engage.england.nhs.uk/application/crg-stakeholder-reg-may-2018/>

