

Specialised Commissioning

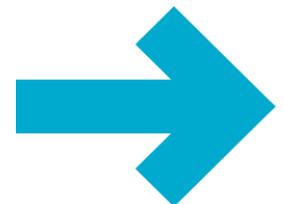
Improving specialised
services for sickle cell,
thalassaemia and other rare
inherited anaemias

What will this mean for
patients and carers?



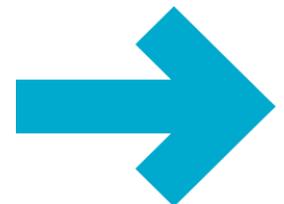
What are the headlines?

- 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.
- Now we have 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 is Specialised Commissioning?

- Most health services are organised locally by clinical commissioning groups (CCGs) but specialised services are managed directly by NHS England
- These are services which are rare, expensive or only provided at a few hospitals.
- 146 services are specialised services and commissioned by NHS England.
- The budget for specialised services – £16.6 billion in 2017-18 – has increased more rapidly than in other parts of the NHS, but it is under pressure.
- The number of patients needing specialised services is rising due to an ageing population and advances in medical technology.



Specialised haemoglobinopathy services

- NHS England are responsible for all in-patient, out-patient and emergency hospital care where the cause of the admission is related to sickle cell, thalassaemia and other rare inherited anaemias.
- NHS England also pays for certain high cost drugs, such as iron chelation.
- This costs roughly £76 million per year.

This service is commissioned by NHS England because:

- the number of individuals requiring the service is small (there are two to three patients with a haemoglobinopathy registered at each GP practice although this varies widely around the country)
- the cost of providing the service is high because of the specialist drugs involved and some patients are in hospitals for long stays.
- the number of doctors and other expert staff trained to deliver the service is small

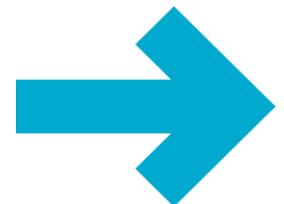


Other care you may receive

This review has only looked at specialised haemoglobinopathy services, so doesn't include all the care patients may need.

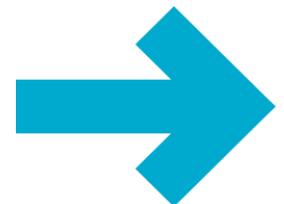
Specialised commissioning does not include GP care, community care or voluntary sector services.

It also doesn't include hospital appointments or admissions where haemoglobinopathy isn't the main reason for being seen.



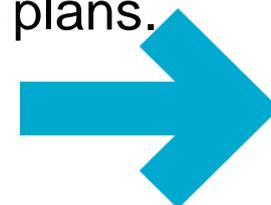
Why are we reviewing services?

- Generally people report services have improved over the past ten years – but **some people still experience poor care** which can vary across the country.
- **Small number** of specialist health professionals, often **overstretched** as colleagues retire with **no new trainees** to take their place.
- Information collected by hospitals suggest **variation in quality** of care across the country.
- Some hospitals seem to have high numbers of **patient admissions**, and that's not always the best way to manage care.
- **Financial pressure** across the NHS. This review won't save money – but as other health services are squeezed, there will not be additional money.



What has been learned during the review (1)?

- **Increasing numbers** of people in England are living with these conditions.
- Feedback from patients and clinicians suggests that services work better for people when **hospitals communicate with each other** and work together in the best interests of patients.
- Some of these **clinical networks** already work well, but that isn't the case everywhere, so there's room for improvement and consistency.
- The **National Haemoglobinopathy Register (NHR)** currently provides high level headcount of patients, treatments and issues. The ambition is to change the way it works so it can be a useful tool for patients and clinicians in the real-time management of care. It will take time, but needs to be part of our long term plans.



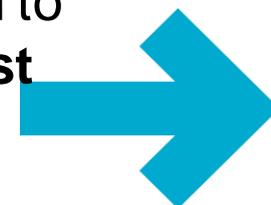
What has been learned during the review (2)?

- The review has looked at **various options** to change the way care is organised, but most ‘radical’ options we tested with patients and clinicians weren’t supported.
- Routine care already makes it difficult for patients to **manage work, education and family life**. It isn’t reasonable to expect people to travel further for treatment.
- Better use of **technology**, such as health apps and video conferencing, could work for some people and should be explored, but aren’t the only solution.
- **New treatments** are on the horizon and they will be very expensive. Transformative treatments will need to be available to appropriately selected patients and the need for very specialist expertise will grow. This can only be achieved through national coordination, and will need to be a fair and transparent process.



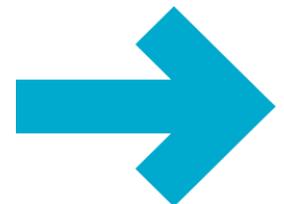
What are we proposing to do differently?

- NHS England proposes we resource a number of centres to lead local networks in each area called **Haemoglobinopathy Coordinating Centres** (HCCs) with responsibility for leadership and education.
- 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.
- There are likely to be around **10 – 14 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.
- No major changes are being proposed to the existing specialist haemoglobinopathy centres, and we fully expect all of them to continue providing care. These will now be called **Specialist Haemoglobinopathy Teams**.



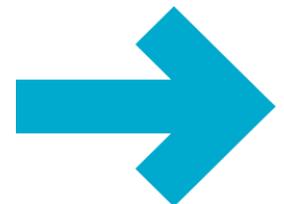
What are we proposing to do differently? (2)

- NHS England are planning to introduce new standards to ensure all patients can expect the same high quality care and find new ways to measure whether services work well for patients.
- Institute a **National Haemoglobinopathy Panel (NHP)**, which will accept referrals from SHTs with complex clinical problems. In the future this will be the group that consider individuals who may benefit from new commissioned treatments, such as gene therapy.
- Continue to develop the **National Haemoglobinopathy Registry (NHR)** to improve functionality and to create a repository of patient information



How will the plans be funded?

- Over the past year new money was introduced to the NHS that was intended to reward the specialised element of haemoglobinopathy care.
- This has amounted to £5.8 million, with relatively small amounts spread to over 150 hospitals – anywhere where patients are seen.
- We don't believe this has worked well for patients or specialised care.
- NHS England proposes this money could be spent to provide a strengthened network model, with a centre in each area of the country to co-ordinate it.



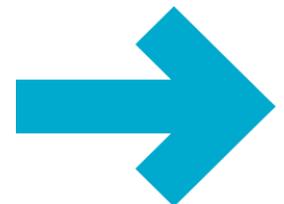
How would the new Haemoglobinopathy Co-ordinating Centres (HCCs) work?

- They would host a regional MDT (multidisciplinary team) which would mean patients could get better access to expert advice if their condition is complex.
- They would develop and oversee clinical pathways in their region, to make sure all patients are getting access to the care they need.
- They would be responsible for education and training in their area, so that hospitals with less experience of these conditions can get the advice they need. This would include better information for patients and carers.
- They would need to show that they are involving people and learning from patient experience to make sure the network works well for everyone.
- They will work with the National Haemoglobinopathy Panel to contribute the expertise of clinicians in the area, and ensure people with the most complex cases get the best possible clinical oversight and advice.



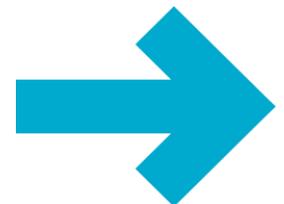
How would the Haemoglobinopathy National Panel work?

- Membership would consist of a range of health professionals, drawn from the local HCCs and beyond.
- The panel will advise on approaches, but not deliver care.
- It's likely that one of the HCCs will be funded to provide administrative support.
- The panel will have two main roles:
 - to act as a national multidisciplinary team offering advice to clinicians for patients with the most complex needs.
 - to act as a nationwide point of referral and advice on new innovative treatments and therapies, as they become available.



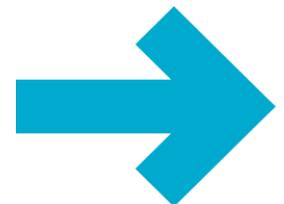
What could this mean for patients?

- 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 care as locally as you would like.
- 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.



Next steps

- Engaging with patients, carers and clinicians on the new proposed model and what's needed for it to work well.
- We plan to hear views from June to August, before we know that there's support to progress these plans, and make any changes based on the feedback received.
- We would need to start the process for selecting HCCs from September 2018 – this needs to be a procurement process.
- The plan is for HCCs to be in place for April 2019.
- Continue to develop the NHR, with increasing engagement opportunities for patients over the next year.



Please give us your views

- Register as a stakeholder of the Haemoglobinopathies Clinical Reference Group (Blood & Infection Programme of Care) and receive info and invitations to get involved

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

