

## **Stakeholder Update - Reviewing services for people living with sickle cell, thalassaemia and other rare inherited anaemias**

Thanks to everyone who contributed to the engagement events held over the summer to update people about the review into specialised services for sickle cell, thalassaemia and other inherited anaemias, and hear views on the plans proposed by NHS England.

We spoke to hundreds of people through June to August, at a range of events and webinars across the country, as well as by people sharing their views via our online survey and on social media. Many thanks to the Sickle Cell Society who organised several of these meetings, and set up an independent online feedback form for people to share their views on their website. We received a huge range of helpful questions and valuable feedback, and are planning to respond to some of the specific issues raised over the next few weeks. Some of the concerns we heard didn't directly relate to the review, but still provided very useful general feedback and we plan to address as many of the queries received as possible.

We believe that our proposals will help to better co-ordinate access to specialist care and advice, and make it easier for patients to give feedback about services – particularly when they've experienced problems. Although our proposals won't disrupt the way that people receive their care or the range of services available, we wanted to take time to speak to people and let them know what we learned through the review, explain what will be changing and hear views on how to make these new plans work well for people.

We were pleased to hear that broadly our proposals to introduce new Haemoglobinopathy Co-ordinating Centres (HCCs) in each area of the country were supported, and we will be proceeding with those plans over the next few months, in order to get the new centres in place for next year. The HCCs will have new responsibilities to support all the hospitals in their area by ensuring there is access to the right expertise and advice, especially when people develop complications, and providing support and training to healthcare staff to address issues such as managing a sickle crisis in A&E.

We'll also be sharing more information about the work to improve the NHR (National Haemoglobinopathy Register) and set up the new National Haemoglobinopathy Panel as this work develops, but these are longer term plans. Our immediate priority will be to set up the 10 HCCs across England as this will be subject to a procurement process to select which hospitals will take on this new co-ordination role.

In the next few weeks we will be sharing more detailed information about the feedback we've heard, outlining next steps and explaining how people can continue to be involved.

We will also share the links to the new published service specifications, which are the technical documents that set out the roles of Haemoglobinopathy Co-ordinating Centres and Specialist Haemoglobinopathy Teams.

If you would like to receive updates directly, you can register as a stakeholder on our website. You need to sign up to the Haemoglobinopathies CRG (clinical reference group) which comes under the Blood & Infection Programme of Care.

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

If you have registered as a stakeholder, we have your name, contact details and your interest areas on file. We may also have a record of a health condition or disability that you have told us about. This information is used by the Specialised Commissioning team to enable us to communicate with you and invite you to be involved in our work. Should you want us to remove your details from the stakeholder register, please contact the membership team: [england.voice-crg@nhs.net](mailto:england.voice-crg@nhs.net).

For more information about how NHS England processes your personal data please see our [privacy notice](#).

### **Haemoglobinopathies CRG, Specialised Commissioning, NHS England**

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