

Supporting the National Haemoglobinopathy Registry (NHR)

Information and advice for patients

Sickle Cell & Thalassaemia

What is the National Haemoglobinopathy Registry (NHR)?

The NHR is a national database of patients living in the UK with sickle cell disease and thalassaemia major. The registry contains information about these people and their condition.

The NHR only contains information about people who have given their consent to be added to the registry.

Why do we need a National Haemoglobinopathy Registry (NHR)?

The information that the NHR collects is used to find out:

- How many people have sickle cell and thalassaemia.
- How people with these conditions are responding to their treatment.

This information helps to:

- Plan services for people with these conditions, making sure that the right services and staff are available in the right place.
- Get funds for research to help improve treatments.

Because of this, we strongly encourage you to give your consent to be added to the registry.

Giving consent to be added to the registry

You can give consent for your information to be added to the registry by speaking to your hospital doctor and completing an NHR consent form. After you have completed the consent form the hospital will pass on information about you to the NHR.

If you do not give consent, then your information will not be passed on to the NHR.

Whether you choose to give consent or not will not affect how you are cared for or the treatment you are given.

Can I change my mind?

You can change your mind at any time and ask your hospital doctor to remove your information from the registry, or ask to be added to the registry.

What information does the NHR need about me?

The NHR need to know:

- your name
- your date of birth
- your gender
- your NHS number

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- your postcode
- the condition you have and when you were diagnosed
- the treatment you are having
- how well you are doing on this treatment
- your GP's details

For a full list of the details the NHR needs, visit www.nhr.nhs.uk/dataset.aspx.

How will the NHR store my information?

The NHR follows strict rules about how they store your information and who can access it. Your details will be stored on computers with secure passwords. Your information will be kept strictly confidential and only made available to the appropriate staff.

When the NHR publish a report, they will never identify a particular person from the registry. No-one from the NHR will ever contact you directly.

Further information

For more information about the NHR you can:

- read the leaflet from the NHR
- speak to your hospital doctor
- visit the NHR website www.nhr.nhs.uk

For more information about our hospitals and services please see our websites www.swbh.nhs.uk and www.swbhengage.com, follow us on Twitter @SWBHnhs and like us on Facebook www.facebook.com/SWBHnhs.

Sources used for the information in this leaflet

The National Haemoglobinopathy Registry, www.nhr.nhs.uk, accessed online May 2013

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5420 or email: swb-tr.swbh-gm-patient-information@nhs.net



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