

The National Haemoglobinopathy Registry (NHR)

What is the National Haemoglobinopathy Registry (NHR)?

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

The NHR only holds information about the patients who have given their 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 at your outpatient clinic visit or clinical nurse specialist. You will be given some written information from the NHR to read, to allow you time to make an informed decision before you give your consent.

If you do not give your consent, then your information will not be sent to the NHR. The decision to be added to the register is your choice and will not affect the care you are given or the treatment you receive.

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

Why do we need a National Haemoglobinopathy Registry?

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

The information held on the NHR helps to make sure better services are in place for people living with these conditions and to help with funding for research to help improve treatments for people with sickle cell disease and thalassaemia.

The UK Haemoglobinopathy Forum is responsible for overseeing developments in treatment and care, and is strongly supportive of the work the NHR is doing to improve care and clinical treatment.

The prevention of infection is a major priority in all healthcare and everyone has a part to play.

- **Please decontaminate your hands frequently for 20 seconds using soap and water or alcohol gel if available**
- **If you have symptoms of diarrhoea and/or vomiting, cough or other respiratory symptoms, a temperature or any loss of taste or smell please do not visit the hospital or any other care facility and seek advice from 111**
- **Keep the environment clean and tidy**
- **Let's work together to keep infections out of our hospitals and care homes.**

What information will the NHR collect?

The NHR need to know:

- Your name
- Your date of birth
- Your gender
- Your NHS number
- Your postcode
- Your GP details
- The condition you have and when you were diagnosed
- The treatment you are having.

For a full list of the details the NHR needs please visit the National Haemoglobinopathy Registry website on www.nhr.nhs.uk

How will the NHR store my information?

The NHR has strict rules about how your information is stored and who can access it. Your details will be stored on a computer system with secure passwords. The information you provide will be strictly confidential and will only be made available to the appropriate staff with secure access to use the NHR.

You will never be contacted by anyone from the NHR directly and if any reports are published, no individual will be identified from the registry.

Further information

You can find out more about the NHR from:

- Visiting the NHR website <https://nhr.mdas.com>
- Asking your hospital doctor or clinical nurse specialist for more information
- Read the patient information leaflet available on the NHR website.

References

The National Haemoglobinopathy Registry, <https://nhr.mdas.com> (accessed online April 2021)

English

If you need information in another way like easy read or a different language please let us know.

If you need an interpreter or assistance please let us know.

Lithuanian

Jeigu norėtumėte, kad informacija jums būtų pateikta kitu būdu, pavyzdžiui, supaprastinta forma ar kita kalba, prašome mums apie tai pranešti.

Jeigu jums reikia vertėjo ar kitos pagalbos, prašome mums apie tai pranešti.

Polish

Jeżeli chcieliby Państwo otrzymać te informacje w innej postaci, na przykład w wersji łatwej do czytania lub w innym języku, prosimy powiedzieć nam o tym.

Prosimy poinformować nas również, jeżeli potrzebowaliby Państwo usługi tłumaczenia ustnego lub innej pomocy.

Punjabi

ਜੇ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਰੂਪ ਵਿਚ, ਜਿਵੇਂ ਪੜ੍ਹਨ ਵਿਚ ਆਸਾਨ ਰੂਪ ਜਾਂ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ, ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

ਜੇ ਤੁਹਾਨੂੰ ਦੁਭਾਸ਼ੀਏ ਦੀ ਜਾਂ ਸਹਾਇਤਾ ਦੀ ਲੋੜ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸਾਨੂੰ ਦੱਸੋ।

Romanian

Dacă aveți nevoie de informații în alt format, ca de exemplu caractere ușor de citit sau altă limbă, vă rugăm să ne informați.

Dacă aveți nevoie de un interpret sau de asistență, vă rugăm să ne informați.

Traditional Chinese

如果您需要以其他方式了解信息，如易读或其他语种，请告诉我们。

如果您需要口译人员或帮助，请告诉我们。