

# The National Haemoglobinopathy Registry (NHR)



## Patient information

### **What is the National Haemoglobinopathy Registry (NHR) and why do we need it?**

The National Haemoglobinopathy Registry (NHR) is a confidential database of patients with red cell disorders living in the UK. All patients with sickle cell disease, thalassaemia and rare inherited anaemias such as Diamond Blackfan anaemia, sideroblastic anaemia, red cell enzyme disorders are included. Patients with these disorders are managed by specialised haemoglobinopathy services and teams.

The aim of the registry is to improve patient care by ensuring clinically important information related to your health, treatment and complications is available to specialist haemoglobinopathy teams who are involved in your clinical care or may become involved in your care. The registry merges clinically important information about your health which is already available on different databases and hospital records into one central database to ensure relevant and important information is in one place. This means that if you need treatment at another centre important parts of your health record are available to the team providing urgent care.

Information from the NHR, helps NHS England understand the specific needs of people with haemoglobin disorders so that they can assess the quality of services and help guide future funding from the commissioners for specialist haemoglobinopathy centres. This is an important process in improving access to treatments in your local haematology centre. This information is also essential for healthcare planning, identifying accurate patient numbers and conducting research into areas such as patient experience, quality of care, timeliness of care etc...

### **How is patient confidentiality maintained?**

We understand how important it is to keep your personal data safe which is why patient confidentiality is a priority to us. Patient information is stored in a secure NHS information centre in accordance with security standards laid down by the General Data Protection regulations (GDPR) 2016 and the Data Protection Act (DPA) of 2018. The NHR is reviewed annually to confirm that it continues to comply with legislation such as the DPA and NHS information governance requirements via the NHS Digital Data Security and Protection Toolkit.

Information is entered electronically on the NHR by your specialist haemoglobinopathy team using passwords, encryption and other security methods to keep your data safe. All information is held within the NHS network which incorporates a number of features to ensure security of the information. This is a more secure than the traditional paper system or the postal service previously used to share patient health records.

It is also important to note that the NHR cannot be used to identify a patient's address or their contact details.

### **What sort of information is collected?**

The NHR collects information such as an individual's name, diagnosis, date of birth, GP code, NHS number and postcode. This is to ensure your records can then be matched with those on other databases and are kept as accurate as possible.

The data collected is also used to identify your records by healthcare professionals looking after you. Clinically important data obtained include information about your blood group, antibodies, frequency of blood transfusions, medications, immunisations, blood results and other monitoring tests and complications you may have developed. The NHR also collects information on causes of death. A list of all information collected can be viewed on the NHR website ([link](#)).

Information for the NHR is collected from haemoglobinopathy treatment centres and other organisations such as NHS Blood and Transplant (NHSBT) and the newborn screening programme.

### **What information will be kept in the future?**

In the future, with advances in treatment and how that care is provided, we will need to continue to keep detailed information on treatment provided to individuals and the outcomes of such treatment.

The on-going collection of this information is vital assessing which treatments work and for securing adequate resources for your treatment and care.

### **What types of information and reports are produced from the NHR data?**

**All reports have fully anonymised data so there is no patient identifiable data in any report published using NHR data.**

There are several types of reports that are produced from data collected from the NHR. Some of these reports are required from the NHR and others requested by organisations and researchers. It is important to note that all reports produced consist of fully anonymised data. This means that your personal, identifiable data will not be published or reported.

The following are a list of the types of reports requested;

#### **Mandatory reports:**

Specialised services looking after patients with inherited anaemias such as sickle cell disease and thalassaemia have to report on quality of services. These are known as quality indicators to ensure that specialist centres are achieving targets on quality of care. The reports are submitted at regular intervals throughout the year from NHR data to NHS England. Figures are reported as percentages of patients or numbers.

**Annual reports:**

The NHR publishes an annual report on fully anonymised data from the NHR about the numbers of patients and where they are receiving care (specialist centres) and types of treatments patients receive in order to inform commissioning teams and health care providers about the provision of services etc.

**Reports to support other NHS organisations:**

The NHR may provide fully anonymised data to other organisations such as the National Blood Service (NHSBT) on the number of patients on regular blood transfusions to support resources and planning of services. Likewise, other organisations such as the National Institute for Health and Care Excellence (NICE) may request anonymised data from the NHR to help support commissioning of new therapies for haemoglobinopathies and rarer inherited anaemias.

**Data to inform commissioning and planning Haemoglobinopathy Services:**

NHS England is responsible for planning and commissioning Haemoglobinopathy Services. NHS England requires data from the NHR to monitor and review how services are provided and to inform changes needed in the future. It only has access to pseudonymised data for this purpose and the data is held in a secure environment.

**Research:**

Researchers may request data from the NHR database for specific research projects, but this data will be subject to a separate formal process and will be governed by research ethics and complying to the requirements outlined by the Health Research Authority.

These data requests will be overseen by the NHR data analysis and research group and will require approval from the UK Forum on Haemoglobin Disorders (UKFHD) and NHS England as being clinically relevant and useful.

Separate groups of patient representatives from the NHR and from UKFHD will be involved in the approval process. Only data from patients who have provided informed consent for the research part of the NHR database will be utilised in this way and all data provided will be fully anonymised and have no identifiable or personal data. Examples of this type of research requests could be from a university team wanting to find out how common diabetes and kidney complications are in patients with haemoglobinopathies in the UK.

In rare situations there will be a need for a piece of research to address an issue of such importance to people living with either Sickle Cell, Thalassaemia or a rare anaemia, that there will be a need to access data from everyone. In order to get permission to access the NHR data in this situation, the researchers will need to obtain approval for the research from the NHS Health Research Authority. As part of this they will need to demonstrate that the data will be held securely, the minimum amount of data necessary to carry out the research is used and that this is anonymised.

**Statement from the UK Forum for Haemoglobin Disorders (UKFHD):**

The UK Forum for haemoglobin disorders (UKFHD) is a multi-professional voluntary organisation that has supported the development of services for patients living with haemoglobinopathies and rarer inherited anaemias. It has a longstanding relationship with patient organisations such as the United Kingdom Thalassaemia Society and the Sickle cell society who are members of the committee.

The UKFHD strongly supports the work of the NHR as a central registry where information is held from multiple sources (such as hospital records and NHSBT) to help improve patient safety

nationally. A central registry holding clinically important information on the NHR will not only benefit individual patients but also the whole haemoglobinopathy community.

### **Why is my information stored in the NHR?**

The storage of your medical information in this database is not optional as its primary use is to support your medical care. The NHR is integral to delivering care for inherited anaemias across the country in the same way that hospitals will store your data securely in order to be able to provide your care. It is also important to know how many people receive treatment at each STC and HCC so that the right level of services are provided across the country.

If you have any further questions, you can meet with your local treatment doctor or specialist nurse, or alternatively contact the NHR itself using the contact details below. If you wish to be removed from or not entered onto the NHR then annual review information will be retained or entered with an anonymised identification number known only to your treating centre.

This is to ensure that accurate figures are available to NHS England. Annual review information is available on the website ([Link](#))

If you choose not to be included in the NHR, clinically important health records will not be available on the NHR if you become unwell and require treatment in another hospital. Your health information will only be accessible by contacting your main treatment centre.

### **What are my rights under the Data Protection Act 2018/GDPR?**

The current Data Protection Act 2018 concerns the storage and processing of records of any personal information and is subject to GDPR, which can be traced in any way to an individual either by their name or number or other identifier. According to the act, you must be informed of the sort of personal information that is held and the purpose for which it is held. You have the right to ask that some or all of your identifiable information be removed from the database. To arrange this please contact the NHR data manager at your local SHT or HCC.

You also have the right to request a copy of your entry in the database. Applications, with proof of identity, should be sent to the NHR data manager at your local SHT or HCC.