



Patient Information about the National Haemoglobinopathy Registry

What is the National Haemoglobinopathy Registry (NHR) and why do we need your information?

The National Haemoglobinopathy Registry (NHR) is a confidential database of patients with red cell disorders (mainly sickle cell disease and thalassaemia major) living in the UK. The aim of the registry is to improve treatment and services for people with red cell disorders.

Information obtained from the NHR helps to secure funds to develop improvements in treatment and patient care in your treatment centre. The information is also essential for healthcare planning, identifying patient numbers and research into improved treatment.

Patients cannot be identified from reports published by the NHR as they are presented anonymously.

How is patient confidentiality guaranteed?

Patient confidentiality is extremely important. Patient information is stored in a secure NHS information centre in accordance with security standards laid down by the Data Protection Act (DPA) of 1998. The NHR is reviewed annually to confirm that it continues to comply with legislation such as the DPA and NHS information governance requirements (IGSOC).

Information is collected electronically using passwords, encryption and other security methods. All information is held within the NHS network which incorporates a number of features to ensure security of the information. This is more secure than a paper system or the post and the NHR cannot be used to identify a patient's address.

What sort of information is collected?

The NHR collects annual information on an individual's name, diagnosis, date of birth, GP code, NHS number, the use of blood transfusion, type of treatments given, results of your blood and other monitoring tests, growth and development data, and serious health events such as stroke. The NHR also collects information on causes of death. A list of all information collected can be viewed on the NHR website.

Information for the NHR is collected from Treatment Centres and other bodies such as NHS Blood and Transplant and NHS Digital.

Who manages the database?

The database is managed by the Steering Group of the NHR. This group may include a person with Sickle Cell or Thalassaemia along with representatives from NHS England, UK Thalassaemia Society, Sickle Cell Society, Clinicians, Health Commissioners, and IT experts. This group reviews and approves requests for data from the NHR but does not have access to individual patient data.

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What information will be kept in the future?

In the future, with changes in the nature and organisation of treatment services and advances in treatment, we will need to keep more detailed information annually on treatment provided to individuals and the outcomes of such treatment. The ongoing collection of this information is vital for securing adequate resources for your treatment and care.

What types of reports and information is produced from the database and who has access to them?

A yearly NHR report is produced. The report summarises national treatment and complications. The report is also available freely on the NHR Website. Smaller reports are produced on specific topics when requested.

Information obtained from the database will also be used for research purposes; for example, for studying the overall progression of sickle cell disease and thalassaemia among individuals living in the UK, uptake and outcome of specific treatments and interventions, etc.

Information and reports produced by the NHR are made available to various organisations including treatment centres, the UK Thalassaemia Society, the Sickle cell Society, Department of Health, NHS England and Industry.

All the reports published from the NHR are anonymous and therefore patients will not be identifiable in them.

Statement from the UK Haemoglobinopathy Forum

The UK Forum is responsible for overseeing developments in treatment care and strongly supports the work of the NHR in collecting data which is then used to improve the clinical treatment service. Storing this information on the NHR will not only benefit individual patients but also the whole haemoglobinopathy community.

What should I do if I do not wish my information to be stored, or have concerns about the database?

You should meet with your local treatment doctor or specialist nurse, or alternatively contact the NHR itself using the contact details below. **If you do not give consent your information will not be stored.**

What are my rights under the information protection act (1998)?

The current Data Protection Act (1998) concerns the storage of records of any personal information, 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 information be removed from the database by applying to the database (see below for contact details). You also have the right to request a copy of your entry in the database for a statutory fee of £15. Applications, with proof of identity should be sent to the NHR Administrator.

Contact the NHR

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