

# The National Haemoglobinopathy Registry (NHR)



## Data Protection Privacy Notice

### Introduction

This document explains why information is collected about you by the National Haemoglobinopathy Registry (NHR) and how your information may be used. This is called a Fair Processing Notice or Privacy Notice. It describes how the NHR collects, uses and processes your personal data and associated information and how, in doing so, it complies with its legal obligations to patients. Your privacy is important and the NHR is committed to safeguarding your data privacy rights.

Information for patients on the work of the NHR can be found at [www.nhr.org.uk/patient-info/](http://www.nhr.org.uk/patient-info/) .

This notice will address the following areas:

- Key definitions
- What is the NHR?
- Why the NHR collects your information
- What personal information does the NHR collect?
- Where does the NHR collect your information from?
- How does the NHR use your information?
- Who your information is shared with
- The NHR's lawful basis for collecting your information
- How the NHR maintains the confidentiality of your information
- The NHR and partner organisations
- How long your information will be stored
- Your individual rights
- Objections and complaints
- Changes to this notice

### Key definitions

**Data controller** – the organisation, person or persons who determine the purposes and means of processing personal data. For the purpose of this notice and how it affects your data the data controllers are NHS England and the organisations providing data to the

registry. NHS England and the Organisations will operate as joint controllers having separate and distinct roles in relation to the data processed for the purpose of the registry.

**Data processor** – in relation to your personal data, means any person (other than an employee of the data controller) who processes the data on behalf of the data controller. The data processor for the NHR is MD SAS Ltd City View House, 5 Union Street, Ardwick, Manchester, M12 4JD.

**Data protection officer** – an existing employee or externally appointed person in place to assist in monitoring internal compliance, informing and advising on data protection obligations, providing advice regarding Data Protection Impact Assessments (DPIAs) and acting as a contact point for data subjects and the supervisory authority.

## What is the National Haemoglobinopathy Registry?

The NHR is a secure clinical registry of patients in the UK with haemoglobinopathies and rarer inherited anaemias. The registry collects information on patients treatments and complications as well as which centres the patient receives or has received clinical care at. Specific information already on standard hospital records is entered on NHR from all the sites at which the patient receives clinical care. This allows the NHR to collate information from these centres as well as other sources such as the National Blood Service (NHSBT) to ensure there is a central record accessible for all clinical teams in one registry. The data on the NHR can be accessed by specialist centre teams to ensure that when a patient is attending their centre they have clinically important information and know which centre is the primary haemoglobinopathy centre.

The NHR is commissioned by NHS England (NHSE) and operated by Medical Data Solutions and Services (MDSAS) under a data processing contract. NHS England also provides governance oversight for the NHR. Clinical recommendations for research is provided by the UK Forum for Haemoglobin Disorders (UKFHD) which is a not for profit organisation of health care professionals caring for patients with haemoglobinopathy and rare inherited anaemias. The UKFHD is registered with the Charity Commission. Full details of their work can be found at <https://haemoglobin.org.uk>.

## Why the NHR collects your information

The NHR collects patient information to improve the healthcare and outcomes of people with haemoglobinopathies and rarer inherited anaemias. This is achieved through using the data received to:

- To support the direct clinical care for patients with haemoglobinopathies and rarer inherited anaemias. This is the primary purpose of the NHR.
- Audit care provided – this is where the standards of healthcare given to people with these disorders treated in haemoglobinopathy units/hospitals are compared against each other and against national guidelines.
- Identify trends in the nature and frequency of complications and their outcomes within the population and subgroups of the population.
- Provide commissioners and policy makers with aggregated and de-identified information to improve the delivery of services for patients with haemoglobinopathies and rarer inherited anaemias.
- Assess the impact of quality improvement initiatives.
- Facilitate research - this is where the data are used to improve understanding of diseases, treatments and interventions.

## What personal information does the NHR collect?

The NHR collects information about your treatment, monitoring tests and complications related to your disorder and or its treatments as well as personal identifiers such as; your name, date of birth and NHS number. These identifiers are held securely within the registry and are needed to allow your information to be linked to other NHS registries and databases. This is to understand your care pathway and ensure that all relevant information about your care is available to health care professionals involved in your care.

## Where does the NHR collect your information from?

Your data is entered onto the NHR by the healthcare team at the centre providing you with care. This data is then linked to other relevant national health-related data such as the NHS Blood & Transplant records on transfusion.

## How does the NHR use your information?

### Your clinical information

- Local hospital IT systems collect and store identifiable information, treatment information and laboratory results for routine use by clinical teams delivering healthcare to people with haemoglobinopathies and rare inherited anaemias. Specific information from hospital IT systems is entered on the NHR so clinically important information is available on a central registry to support teams should a patient access care outside of their own local Specialist Haemoglobinopathy Team (SHT)
- A list of important health information has been agreed to be necessary to monitor the health status and quality of healthcare provided by the NHS to people with haemoglobinopathy and rare inherited anaemias. These items and information on access to treatments and health resource utilisation is entered on the NHR.
- What resources are needed by a centre to provide care for patients and how those resources are used are important for NHS planning to ensure treatment is available equitably for all patients and resources are planned for and provided appropriately where it is needed. A simple example of this is access to community services or a specialised haemoglobinopathy nursing team.
- The relevant information is entered on the NHR by your healthcare team.
- This is stored securely by the NHR with access strictly controlled to only those people with a legitimate purpose and permission to access the data.
- If the NHR needs to ask the hospitals to clarify the information that they have entered the NHR sends a secure email back to them with a query attached.

## Who your information is shared with?

Your data is entered on the NHR by your primary specialist haemoglobinopathy team. Your data is shared with different groups in a number of ways:

### Direct clinical care:

Your team enter clinically relevant details about your health into the NHR so this information is available to a clinical team who may see you in another hospital. A simple example of this is if there is a complication following blood transfusion that your centre knows about but you become unwell while in another part of the UK, the temporary team looking after you can look at the previous history and ensure treatment is appropriate based on your history. The direct clinical care part of the NHR is to help avoid patients developing complications due to the health information not being centralised.

The access to the NHR is only for those with a legitimate reason to access your data and is managed in a similar way as a hospital based electronic patient record. Only Haemoglobinopathy teams will have access to the NHR and it is important when you do need care elsewhere that the haemoglobinopathy team are informed so they can access your data from the NHR.

Another example of this type of data is where your record may be linked with the National Blood service record to ensure that all your blood transfusion records ( blood groups, antibodies, complications related to transfusion) are recorded in one central area from a variety of different sources. The purpose of this is to improve patient safety and ensure that critical information is available for clinical teams involved in your care.

### **Data not used for direct clinical care**

This data is data that does not improve your care or safety directly but helps improve aspects related to providing your care. This data is provided as de-identified, anonymised and aggregated data and does not include patient identifiers. The best example for this is the specialised services quality indicators.

These are a set of data that haemoglobinopathy teams are expected to provide to NHSE commissioning team about the quality of the care that patients receive. A set of indicators has been developed and are reviewed annually to ensure these are appropriate for improvement of patient care. Data is provided to commissioning teams as aggregated figures based on designated treating centres. All this data is non identifiable and submitted as a percentage or as a number of patients.

For example a quality indicator is the percentage of children who are eligible to have had a transcranial doppler ultrasound for stroke prevention. This is reported as a percentage for each specialist haemoglobinopathy centre to ensure that all centres provide this for eligible patients.

The NHR shares your information with third parties to fulfil some of its duties and functions. Your data are only shared under strictly controlled circumstances.

Grouped, **anonymised** data are shared with other parties in the form of summaries and reports produced by the NHR. In addition, applications can be made by external parties to the NHR for anonymised data where a detailed justification for having the data is given and safeguards are in place for how the data will be stored, used and deleted once their work is completed. You cannot be identified as this data contains no personal identifiable information. An example of this is data required by NICE and or NHSE to support the assessment and possible commissioning of a new treatment for a haemoglobinopathy or rarer inherited anaemia.

The NHR links data with other databases to improve understanding of haemoglobinopathies and rare inherited anaemias in the context of wider health conditions and services. Such data linkages are permitted under the various legal bases for audit and research work and where appropriate governed by a signed data sharing agreement between the data controllers of each respective database. Examples include:

- NHS Blood and Transplant to get additional information about red cell antibodies and genetics of blood groups that affect transfusion safety as well as blood usage to plan for services.
- Public Health England to ensure that the Newborn Screening Outcomes data is linked with newly diagnosed infants born in England.

The NHR will also share information as required by law, for example, to comply with a court order.

## **The lawful bases for collecting your information**

All of the legal bases listed in this section are subject to safeguards required by the General Data Protection Regulation (GDPR) and with due consideration to your rights as an individual.

The medical information that the NHR collects is also afforded extra protection under the GDPR, alongside other special categories of data such as health records and ethnicity. A full list of special category data types can be found [here](#). To process these types of data, the NHR relies on the following legal bases:

1. For the purposes of preventative or occupational medicine and providing health and treatment management systems and services (Article 9(2)(h) of the GDPR)
2. To ensure high standards of quality and safety of health care (Article 9(2)(i) of the GDPR)
3. For the purposes of archiving in the public interest, and using data for scientific research purposes, and statistical analysis (Article 9(2)(j) of the GDPR)

The NHR collects information that is part of the essential activity of the NHS and the data are used in important medical audits and research:

- Audit is a way of finding out whether clinical teams are doing what they should be doing by asking if they are following guidelines and applying best practice
- Research is designed to provide new knowledge which can be generalised to benefit other patients

## **How the NHR maintains the confidentiality of your information**

Staff who enter data or access patient data on the NHR are subject to contractual confidentiality conditions as they are NHS employees and are required to complete Information governance training annually to ensure they are fully aware of the importance of protecting patient information. The NHR is situated on secure NHS servers and therefore subject to robust internet security processes in line with other NHS databases.

The NHR processes information under a number of lawful bases:

The processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller under Article 6(1)(e) of the GDPR.

NHR is committed to protecting your privacy and will only use information collected lawfully in accordance with the:

- Data Protection Act (2018)
- General Data Protection Regulation (GDPR – EU) (2016/679)
- Human Rights Act (1998)
- NHS Act (2006)
- Health and Social Care Acts (2001) & (2012)
- Access to Health Records Act (1990)

- Common Law in England and Wales, Scots law in Scotland, and Northern Ireland law in Northern Ireland
- NHS Codes of Confidentiality, Information Security and Records Management.

The NHR will keep your information secure in accordance with its legal responsibilities; including taking reasonable steps to safeguard against your information being accessed unlawfully or maliciously by a third party, accidentally lost, destroyed or damaged.

The NHR will not disclose your information to third parties without your consent unless there are exceptional circumstances such as situations when the health and safety of others is at risk, or where the law permits or requires information to be passed on.

## **NHR and partner organisations**

The NHR was established through an initiative of the UKFHD and NHS England in 2009. The UKFHD is the multiprofessional organisation representing the UK haemoglobinopathy community, dedicated to improving services and outcomes for patients and families through education, research and training for the prevention and effective treatment of haemoglobinopathies and rarer inherited anaemias. You can find out more about The UKFHD at <https://haemoglobin.org.uk/about-us/>

## **How long will your information be stored?**

Data will be held on the NHR in line with the [NHS Records Management Code of Practice](#).

## **Your individual rights**

This section describes how you can access, amend, erase and move your personal data, withdraw your consent and object to or complain about the data that the NHR holds about you.

### **Right to access your data (data subject access request)**

You have the right to see or have a copy of your personal information held by the NHR. If you want to receive this information, you should make a written request to the NHR (see the section below on 'How to contact the NHR'). The NHR will normally provide your information within one month of receiving all the information needed from you to respond to your request.

### **Right to rectification (right to amend your data)**

You have the right to have your information amended. Please contact the hospital treating you if you want information at the NHR corrected. The hospital treating you regularly enters your information to the NHR and information should be corrected on the unit/hospital records.

### **Right to opt out of the NHR being sent my data**

As the primary purpose of the NHR is to support your direct care and improve patient safety by ensuring the relevant clinical information relating to your care is available on a single point of entry you cannot opt out of your information being added to the NHR. The NHR record is the primary record supporting your care. It links critical transfusion safety information across hospital and National Blood service records as well as previous complications relating to your health.

Article 18 of the GDPR provides data subjects with the right to request the restriction of data processing however these are under limited circumstances and you should speak to your care provider if you have any concerns about how your information is used in the NHR. Your data will not be linked with transfusion records from the national blood service identifiable patient information is required to do this. However, your data will remain in the NHR in an anonymised form with an identifier number known only to your clinical team so they can ensure the quality indicator they report to NHSE is complete and reflective of their clinical service.

## **Objections and complaints**

Should you have any concerns about how your information is managed, please contact the data protection officer for the National Haemoglobinopathy Registry (see the section below on 'How to contact the NHR'). If you are still unhappy following a review by the data protection officer, you have a right to lodge a complaint with the Information Commissioners Office (ICO) using the details below:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

Telephone: 0303 123 1113  
Fax: 01625 524510

## **Queries in relation to your data on the NHR**

If you have any concerns or questions regarding this privacy notice, how your data are used, or wish to exercise your rights, please contact your care team.