

## What are our rights?

The use and storage of personal information is regulated by the Data Protection Act (DPA 1998). According to the Act, you must be told about any of your child's data that is held on computer and why it is collected. You have the right to ask for some or all of the information to be removed from the database by asking the National Haemophilia Database (see below for contact details) or your Haemophilia Centre. This is an opt-out rather than an opt-in system. You also have the right to request a copy of the entry in the database for a statutory fee of £10 (DPA 1998). An application form can be downloaded from the UKHCDO website or requested from The NHD Administrator.

## ....and if we are worried about all this?

Ask your local Haemophilia Centre doctor or specialist nurse to discuss the database further, or write to the database itself c/o The NHD Administrator (contact details below).

## Why we hope that you will agree to your child's data being included in the database

The National Haemophilia Database is vital for continued delivery of high quality care for haemophilia and other bleeding disorders and to help drive improvements in the service. Competition for funding within the health service has never been fiercer, whilst the cost of haemophilia care is very high and has increased in recent years. We need this information to negotiate for improvements in treatment, and to help commissioners plan for haemophilia services year on year.

It also helps us to gain a better understanding of bleeding disorders through clinical research into their management and complications.

Prof CRM Hay  
Director - National Haemophilia Database

Dr G Dolan  
UKHCDO Chair  
November 2014

## A word from the Haemophilia Society: -

"The Haemophilia Society recognises the importance of the National Haemophilia Database believing it helps provide the sound evidence required by commissioners when deciding whether to fund treatment or services. The Database also enables clinicians to gain a deeper understanding of the specific healthcare needs of all people living with a bleeding disorder, and is a valuable resource for our whole community"

Liz Carroll, Chief Executive  
The Haemophilia Society  
December 2014

## Contact details:

The National Haemophilia Database Administrator  
City View House  
Union Street  
Ardwick  
Manchester, M12 4JD

Email: [support@ukhcdo.org](mailto:support@ukhcdo.org)

Website: [www.ukhcdo.org](http://www.ukhcdo.org)

Telephone: 0161 277 7917

Paediatric version

**UKHCDO**

UNITED KINGDOM HAEMOPHILIA CENTRES DOCTORS' ORGANISATION



**Your Questions Answered**

**A leaflet for Parents  
and their Children**

**From the UK Haemophilia Centre Doctors'  
Organisation (UKHCDO)**

## What is the National Haemophilia Database?

The National Haemophilia Database (NHD) is a register of UK patients (adults and children) with all kinds of bleeding disorders, which was established in 1969. The database is managed by the UK Haemophilia Centre Doctors' Organisation (UKHCDO) - the doctors who treat bleeding disorders in the UK. This database collects information from Haemophilia Centres, which is required by the NHS and which helps us to plan haemophilia services, inform purchasing decisions and to learn more about the treatment and complications of these conditions. This also helps to ensure that all patients continue to receive high quality care with safe and effective treatments.

## What sort of information is collected?

We collect the following information on your child: identity, diagnosis, treatment and complications of the treatment given. We are required to collect this information by the NHS. A complete list of all the information collected can be seen on our website [www.ukhcdo.org](http://www.ukhcdo.org).

## Confidentiality

Patient confidentiality is very important. This is especially important to us since our database includes patient names and NHS numbers.

The data are stored on a secure computer within the NHS. Information is sent from Haemophilia Centres via the NHS network, using industry-standard encryption to protect the data.

The database is regularly inspected by the "Caldicott Guardian" to ensure that we are following recommended protocols for secure information handling. The inspection report can be viewed at [www.ukhcdo.org](http://www.ukhcdo.org). Identifiable data (e.g. information with your child's name or NHS number) is only shared with the Haemophilia Centre that is treating your child.

**Reports and research from the database always use anonymised data that cannot be traced back to individual patients.**

## What do we do with this information?

Every three months, we report treatment data to the NHS Commissioners (who pay for the treatment).

An annual report is also produced. A summary of this may be seen on our website [www.ukhcdo.org](http://www.ukhcdo.org). This reports treatment trends, side effects and complications of bleeding disorders. This report is made available to UKHCDO members, Haemophilia Centre Staff, the Haemophilia Society, the NHS, and the Pharmaceutical Industry.

Specialised reports and treatment guidelines written by UKHCDO are published regularly in medical journals. These publications are intended to improve our understanding of bleeding disorders and to improve patient care. They may be downloaded from [www.ukhcdo.org](http://www.ukhcdo.org).

## Can information about my child be used for research?

Yes. UKHCDO uses the information collected to learn more about the course of bleeding disorders, their treatment and complications. The database is internationally respected for this research. This has helped us to improve treatment over the years and to negotiate with the NHS for improvements in treatment. We hope that this will lead to further improvements in treatment in the future.

The type of information collected by NHD has become very valuable to the medicines regulators and to individual pharmaceutical organisations conducting assessments necessary to obtain licenses for new products. UKHCDO collaborates in these ventures using only anonymised data from the database.

## Is my child being used for clinical trials without my knowledge?

No. The database does not conduct clinical trials. Your choice of treatment and any participation in a clinical trial is entirely between you and your Haemophilia Centre doctor.

## How is the database funded?

To protect the future of the database, it is funded from several sources, mainly the NHS but also the pharmaceutical industry. Industry-sponsored projects include non-commercial natural history research and also collection of anonymised real-world treatment data for industry and medicines regulators.