

The logo for UKHCDO, consisting of the letters 'UKHCDO' in a bold, white, sans-serif font, each letter contained within a dark blue square.

UNITED KINGDOM HAEMOPHILIA CENTRES DOCTORS' ORGANISATION



National Haemophilia Database: Your Questions Answered

**A leaflet for people with bleeding
disorders and their relatives**

From the UK Haemophilia Centre Doctors'
Organisation (UKHCDO)

This leaflet is to inform you about information that is held by the UK National Haemophilia Database about you or your child's bleeding disorder and what is done with that information. If you have further questions please ask your nurse or doctor at the Haemophilia Centre or the database on support@ukhcdo.org.

What is the National Haemophilia Database?

The UK National Haemophilia Database (NHD) is a register of people in the UK with all types of bleeding disorders started in 1969. Its purpose is to improve the care of people with bleeding disorders. The database is held within the NHS and managed by the UK Haemophilia Centre Doctors' Organisation (UKHCDO) – the UK wide group of doctors who look after people with bleeding disorders. Your local Haemophilia Centre collects information and sends it, within the NHS secure system, to the NHD to store and analyse. The management of the database is overseen by a committee that includes a Haemophilia Society UK representative and a patient.

Why is the information collected?

The information is collected to help your Haemophilia Centre treat you or your child's bleeding disorder and to allow the NHS to plan clinical services for people with bleeding disorders. The information helps us ensure that people with bleeding disorders continue to receive safe, high quality care and to improve that care. The information is also used to make sure that the treatment and care of people with bleeding disorders is funded and that new treatments are made available as soon as possible. The NHS requires us to collect this information for them.

By combining information from many people across the UK over a long period of time we are able to get a much better understanding of these conditions, their treatment and complications. This helps us to identify issues that we may need to address. The information held by the NHD is kept forever so we can track changes in the number of people affected with bleeding disorders and the effect of different treatments over time.

What sort of information is collected?

We collect information such as your/your child's name, NHS number, date of birth and what bleeding disorder you/your child has. The NHS number is important so that we can map data to Health Authorities and avoid double counting of people. We need to know your name so we can issue you with a Bleeding Disorder Card that you should always carry with you to help in emergency situations.

Every three months, your Haemophilia Centre sends information about what and how much treatment you/your child has been given and whether any complications or problems have occurred. Complications may include treatment becoming ineffective (not working properly) because of an inhibitor, allergic reactions to treatment or other rare complications. Monitoring the safety of treatment used for bleeding disorders is an important feature of the database.

We may also collect information about your/your child's joints and muscles because these can be affected by severe bleeding disorders. In some cases, genetic tests are also done and the results of these are added to the NHD if you signed a consent form agreeing to this at the time of the test. We also collect information on life expectancy and cause of death. Improvements in treatment have caused a dramatic improvement in life expectancy of severe bleeding disorders and this information helps us explain this and support newly diagnosed patients.

A full list of the information collected may be viewed on our website, www.ukhcdo.org.

What is Haemtrack?

Haemtrack is a web-based system that allows you to enter all treatment that you/your child give at home and report information about any bleeds that happen. You can enter this information through a computer or your phone. Your Haemophilia Centre can see the information that you have entered on Haemtrack and use this information to see how well your/your child's treatment is working and to suggest changes to treatment if necessary.

What is done with my information?

Your personal information is not revealed to anyone outside of your treatment centre and staff of National Haemophilia Database. All analyses and reports from the database use anonymised data. This means that you/your child cannot be identified as an individual.

The NHD provides regular reports to the NHS about bleeding disorders to help with healthcare planning and monitoring safety and effectiveness of treatment and to ensure that treatment is adequately funded. Every year an overall report is produced, and you can see this report on our website www.ukhcdo.org. This information helps to improve treatment and services across the UK. We also report on drug safety to the European Medicines Agency, a body responsible for the safety of all medicines and send anonymised information to a group called the European Haemophilia Safety Surveillance (EUHASS) which collects information about possible side effects of treatment for bleeding disorders from across Europe. Anonymised information from the NHD has been of value to help understand and quantify the consequences of transfusion transmitted infection in public inquiries that are looking at the infections caused by blood products given in the past.

All requests for reports that are produced by the NHD are overseen by a committee which includes patient representatives.

Can my information be used for research?

It is up to you whether you want your/your child's information used for research. Your/your child's information will not be used for research if you withhold consent. You will be given a separate information sheet about this and will be asked to sign a consent form.

The NHD observes and studies the effect of routine treatment that has been agreed between you and your Haemophilia Centre. The database does not conduct clinical trials. Any participation in a clinical trial is entirely between you and your Haemophilia Centre team.

How is the database funded?

The National Haemophilia Database receives funding from several sources. It is mainly funded by the NHS but also receives money from the pharmaceutical industry. Pharmaceutical industry-sponsored projects include observational studies describing bleeding disorders, their treatment and complications. You/your child will be excluded from these studies if you decide to withhold consent for research on your consent form.

What about confidentiality?

Your confidentiality is very important, especially as the database includes your/your child's name and NHS number. **All research and reports from the database use anonymised data so that nothing can be traced back to you as an individual. Where information relevant to your clinical care becomes apparent through our analyses, this will be fed back to your haemophilia centre to be discussed with you.** The database is maintained according to all NHS and legal standards. The database is inspected every two years by a "Caldicott Guardian", an independent person who ensures that we are following all the standards required for secure and fair data handling. The most recent inspection report may be viewed at www.ukhcdo.org.

The data are stored on a secure computer within the NHS and information is sent from Haemophilia Centres within the NHS network using industry-standard encryption which is GDPR (the new data protection law) compliant.

What are my rights?

The storage and use of personal information is regulated by Common Law, the Data Protection Act (2018) and a new General Data Protection Regulation introduced in 2018. According to the regulations, you must be told about any of your/your child's personal data that is held on computer, why it is collected and what it is used for.

You can request a copy of your/your child's entry in the database. An application form can be downloaded from the UKHCDO website or requested from The NHD Administrator.

... and if I am worried about all this?

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

Why we hope that you will agree to your information being included in the database

The National Haemophilia Database is vital for continued delivery of high quality care for people with bleeding disorders. The information is needed to push for improvements in treatment and services and to help bring in new treatments when they become available. The database helps the NHS to plan services year on year and ensure that adequate funding is allocated to treat people with bleeding disorders.

A word from the Haemophilia Society

"We know how important the data collected on the National Haemophilia Database is. It helps ensure treatments remain safe and enables the health care professionals and commissioners who pay for treatments to understand and track the difference high quality treatment makes on someone's life. Without this UK wide information collected over many years, it would be much harder to campaign for improvements in treatment and ensure new treatments are available as soon as possible. This database enables the UK to use the information to improve care in ways many other countries across the world wish they could. It is very important we maintain this valuable resource."

Liz Carroll, Chief Executive
The Haemophilia Society
December 2018

Contact details:

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