

The logo for UKHCDO, consisting of the letters 'UKHCDO' in white on a dark blue background.

UNITED KINGDOM HAEMOPHILIA CENTRES DOCTORS' ORGANISATION



National Haemophilia Database:

Your Questions Answered FOR PATIENTS REGISTERED IN SCOTLAND

A leaflet for people with bleeding disorders and their relatives

From the UK Haemophilia Centre Doctors' Organisation
(UKHCDO)

What is the National Haemophilia Database?

The UK National Haemophilia Database (NHD) was established in 1968 and holds information on people registered with a bleeding disorder within the United Kingdom (UK). It contains details of more than 40,000 people, both alive and deceased. The NHD is managed by the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO), who work with practitioners who are based within the Haemophilia Centres in the UK and have an interest in the care of people with inherited bleeding disorders. UKHCDO is the data controller and processor and determines the purpose and means of processing the personal data collected

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 is used for two important purposes: non - research activity which involves regular reporting to facilitate disease monitoring, healthcare planning, current and future needs and funding, safety, drug safety, and efficacy. Secondly, research into bleeding disorders to understand the behaviour of bleeding disorders, the development of these conditions, the outcome of current treatment options and complications of the conditions and their treatments.

What sort of information is collected?

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 not working properly because of an inhibitor, allergic reactions to treatment and other rare complications. Monitoring the safety of drugs used for bleeding disorders is a very 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 consented to this at the time of the test. We also collect information on life expectancy and the cause of death. Improvements in treatment have resulted in a dramatic improvement in the life expectancy of people with severe bleeding disorders and this information helps us explain this and to support newly diagnosed patients and their families. A full list of the information collected may be viewed on our website: <http://www.ukhcdo.org/patient-information/>.

We also collect information such as your/your child's name, date of birth, NHS number, diagnosis, severity, date, and cause of death. 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.

We share your name, Date of Birth and NHS Number with NHS Central Register (NHSCR) to obtain mortality data. NHSCR use this detail (known as identifiers) to identify individuals who have died and to provide the NHD with relevant death certification information including the date and cause of death.

What is Haemtrack?

Haemtrack is a web-based system that allows you to enter all treatment that you/your child is given 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 ensure you/your child is on the most effective treatment 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 the staff of National Haemophilia Database. All reports from the database use anonymized, aggregated data with small numbers suppressed. This means that you cannot be identified as an individual.

The NHD provides regular statistical reports to the NHS Scotland, NHS England, NHS Wales, other devolved national equivalent organisations, NHS Commissioners, Public Health England, and Pharmaceutical companies about bleeding disorders to help with healthcare planning and monitoring and evaluation of the effectiveness of treatment and to ensure that treatment is adequately funded. Every year an overall report is produced. 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 and MHRA, 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 and planning purposes?

The Scottish Public Benefit and Privacy Panel for Health and Social Care (PBPP) gave approval in September 2021 for Haemophilia Centres in Scotland to share data with the NHD to enable it to collect, store and process confidential data for research and non-research purposes, without written consent from the individuals concerned. This agreement from PBPP recognises the practical difficulties in obtaining written informed consent, for example, from people lost to follow up or deceased.

You have the right to 'opt-out' of research at any point without it affecting you/your child's treatment and without having to give a reason. To opt-out of your/your child's data being used for research activity of the database, contact the NHD to request a Patient Opt-out form, using the NHD contact details on the back page.

The NHD observes and studies the effect of routine treatment that has been agreed between you and your Haemophilia Centre as part of normal management. The database does not conduct clinical trials of unlicensed “experimental” treatments. Any participation in such 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 and post introduction drug safety monitoring (pharmacovigilance) of new drugs, required by the drug regulators. You/your child will be excluded from these studies if you decide to opt out for research.

What about confidentiality?

Your confidentiality is very important. The NHD is held on a secure system, which can only be accessed by authorised personnel, and is fully compliant with data protection legislation. All communications between the database and your Haemophilia centre are through secure encrypted links within the NHS. All data that is shared with any third party is anonymised and in the form of aggregated reports to avoid an individual being identified. Your data will be kept no longer than is necessary.

The database is maintained according to all NHS and legal standards. The database is inspected every two years by a representative of the “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.

What are my rights?

The storage and use of personal information is regulated by Common Law, the Data Protection Act 2018 and General Data Protection Regulation 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. For comprehensive detail on patient information please use the following website link to our Privacy Policy: <http://www.ukhcdo.org/patient-information/>.

... 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

The COVID pandemic has shone a spotlight on the critical importance of data to support healthcare planning, obtaining treatment and allocation of resources. The National Haemophilia Database, established over forty years ago, is of huge importance to our community. It helps ensure your voices and choices are part of ensuring treatments remain safe and clinicians and commissioners can monitor how different treatments impact lives. The Haemophilia Society works with UKHCDO and the national database to ensure we can continue to campaign for patient access to the best treatments for all.

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