UKHCDO
UNITED KINGDOM HAEMOPHILIA CENTRE DOCTORS' ORGANISATION

Privacy Policy - Patient Questions and Answers

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 63,000 records, of whom 43,000 are alive. The NHD is managed by the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO), who work with practitioners who are based within the Haemophilia Centre's 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. The management of the database is overseen by a committee that includes patient and Haemophilia Society representatives.

What data is being collected?

We collect information classed as 'special category data' 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. The identifiers below are shared with NHS Digital to obtain mortality data. NHS Digital use the identifiers to provide the NHD with this data. This information includes date and cause of death. NHS Digital can provide NHD this data on behalf of the Office for National Statistics (ONS) and is sourced from civil registration data:

- NHD registration number - identifier to enable linkage between a patient
- NHS number- to identify patient and perform linkage
- Forename - to confirm identity of patient
- Surname - to confirm identity of patient
- Date of Birth - to calculate age at diagnosis and age at death

Your Haemophilia Centre sends information about what and how much treatment you have been given and whether any complications of treatment or your bleeding disorder have occurred. Complications may include treatment becoming ineffective because of an inhibitor, infections such as viral diseases and their consequences or allergic reactions to treatment or other rare complications. Monitoring the safety of treatment used for bleeding disorders is an important feature of the database.

In some people with more severe bleeding disorders, we also collect information about the health of joints and muscles because these can be affected by 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 in recent decades and this information helps us counsel newly diagnosed patients.

A full list of the information collected may be viewed on our website, http://www.ukhcdo.org/patient-information/.

What is Haemtrack?

Haemtrack is a web-based system that allows you to enter all treatment that 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 see how well treatment is working and to suggest changes to treatment if necessary.

What is the legal basis for processing the data?

Our handling of information about you is based upon statutory powers which underpin the legal bases that apply for the purposes of the GDPR. The legal bases for most of our data processing is:

Article 6(1)(f) – processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child.

Where we process special categories of data, for example data concerning health, racial or ethnic origin, genetic information, and gender, we need to meet an additional condition in the GDPR. Where we are processing special categories of personal data for purposes related to the commissioning and provision of health services the condition is:

Article 9(2)(j) – processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

Will the data be shared with any third parties?

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, aggregated data with small numbers suppressed. This means that you cannot be identified as an individual. Where you have given your explicit consent to share your data with a third party, for example for monitoring treatment for research purposes, your identity will not be revealed as the data will be pseudonymised.

The NHD provides regular statistical reports to the Department of Health, NHS England, other devolved nation equivalents, NHS Commissioners, Health Protection Agency, and pharmaceutical companies 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.

Will the information be used for research and planning purposes?

In November 2025, we were successful in applying to the Health Research Authority Research Ethics Committee (REC) to renew our ethical approval to undertake research. The UK Bleeding Disorders Research Registry (previously known as UK National Haemophilia Research Registry) has had its ethical approval to undertake research renewed for a further 5 years until 21 November 2029 (IRAS Project ID 339857). UKHCDO is the data controller and custodian for the data in both the National Haemophilia Database and for the UK Bleeding Disorders Research Registry (UK-BDRR). They agreed that for England and Wales, we could have a dual legal basis for collecting, holding, processing, analysing individuals' data for research purposes.

- We have implemented a new explicit consent process for all Haemophilia Centres across all UK regions (England, Wales, Scotland and Northern Ireland) to undertake with all individuals with bleeding disorders who are in receipt of treatment at their centre. This has now been implemented and will continue for at least the next five years.

- In December 2025, we were successful in applying to the Health Research Authority Confidentiality Advisory Group for Section 251 support in England and Wales, which will be renewed annually. This in effect permits the NHD to collect, hold, process, analyse confidential data for both research and non-research purposes and to transfer confidential data between parties without there being a breach of our common law duty of confidentiality. We applied for this for the following reasons:

- If an individual with a bleeding disorder is lost to follow up, or

- If any individual with a bleeding disorder recorded in the database dies, we can be notified of their deaths and the details such as the date and cause, without obtaining informed consent. It is an NHS Digital requirement that we have this support when applying for mortality data. For further information on Section 251, please follow the HRA link here: Section 251 Support Frequently Asked Questions

The information is collected to help your Haemophilia Centre treat your bleeding disorder and to allow the NHS to plan clinical services for people with bleeding disorders. The information helps us to 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 patients with bleeding disorders is adequately funded and that new treatments can be introduced as soon as possible. The NHS requires us to collect this information.

The data we hold is also used to undertake research projects so that we can better understand bleeding disorders and their treatment. This research may be presented at conferences and published in academic journals, a list of these presentations and papers is available on our website. Reports are also produced for pharmaceutical companies that manufacture treatments for bleeding disorders. These reports combine information from many people and no data is released about you as an individual. You cannot be identified in these reports.

How long will the data be stored for?

Bleeding disorders are uncommon conditions and by combining information from many people across the UK over a long period of time we can get a much better understanding of these disorders, their treatment, complications, and the side-effects of their treatment. The information held by the NHD is kept as long as is necessary, but in some cases may be kept indefinitely so we can look for any changes in the number of people affected with bleeding disorders and the effect of treatment trends over time.

Some categories of personal data we hold will need to be retained for longer than others. To determine the appropriate retention period for personal data, we consider the amount, nature and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure of personal data, the purpose for which the data is processed, the applicable legal requirements and our contractual obligations. Other personal data will be held for no longer than is necessary to protect our legitimate interest as a data controller.

All data that is shared with any third party to avoid an individual being identified, is anonymised, aggregated data with small numbers suppressed.

What about confidentiality?

Your confidentiality is very important, especially as the database includes your/your child’s name and NHS number. The NHD is held on a secure system, can only be accessed by authorised personnel, and is fully compliant with data protection legislation and NHS standards. All data that is shared with any third party to avoid an individual being identified, is anonymised, aggregated data with small numbers suppressed. 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 “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 your rights as a data subject?

You have several rights under the data privacy legislation relevant to the United Kingdom, for example, the General Data Protection Regulations 2016, The Data Protection Act 2018 and more latterly, the National Data Opt Out legislation is a service that allows patients to opt out of their confidential patient information being used for research and planning.

This includes, under certain circumstances, the right to:

- request access to your personal data.
- request correction of your personal data.
- request erasure of your personal data.
- request the restriction of processing of your personal data.
- request the transfer of your personal data.

- object to processing of your personal data.
- object to automated decision making.
- complain to us and the Information Commissioner.

Details of each of these rights are set out below:

- **Access your data**: You can access to the data we hold on you at any time, by making a Data Subject Access Request. The more specific you can be about what you want to know, the better. We will need to confirm your identity before we release data to you.

- **Rectify your data**: You can ask us to correct any data we hold about you that is inaccurate.

- **Request erasure**: You have the right to 'be forgotten', in certain circumstances. This right does not apply if it would prevent the performance of a contract with you or if there is another legal requirement for us to retain your data. If erasure is not possible, you may be able to ask us to restrict processing.

- **Request the restriction of processing of your data**: You may ask us to suspend the processing of your data under certain circumstances, for example pending a review of the accuracy of the data or after you have objected to our use of the data through the National Data Opt Out, and we need to establish whether we may lawfully continue processing it. Follow this link to the National Data Opt-Out service to op-out of your confidential data being used for research and planning in England: https://www.nhs.uk/your-nhs-data-matters/

- **Request the transfer of your data**: In some cases, you can ask us to transfer the data you originally provided to us to yourself or to another company. This only applies to data you provided directly, or that we observed about you through automated means.

- **Object to the processing of your data**: You can object to our processing of your data for research purposes and request to opt out, or on the basis of our stated legitimate interests (defined in the table above). In some cases, we may have compelling lawful grounds to process your data which override your rights and freedoms.

- **Object to automated decision-making**: You can also object to the processing of your personal data where profiling is being used to make assumptions about your behaviours or preferences; for example, to target marketing communications. You have the right not to be subject to automated decision-making and can require that any such decisions are reviewed by a human.

- **You can lodge a complaint**: If you believe your data is being handled in a way that breaches data protection legislation, you can lodge a complaint with us directly. You also have the right to complain to the UK Information Commissioner. Please be aware that we take the handling of your personal data very seriously. As such, we would always appreciate the opportunity to address any concerns you may have directly with you.

For further information on all your rights under GDPR 2016, Data Protection Act 2018 and the National Data Opt Out, please see the following:

https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulationgdpr/individual-rights/

https://ico.org.uk/for-organisations/data-protection-act-2018/

https://digital.nhs.uk/services/national-data-opt-out/mythbusting-social-media-posts

If we agree to your request for your data to be deleted, we will generally assume that you would prefer us to keep a note of your name on our register of individuals who would prefer not to be contacted. That way, we will minimise the chances of you being contacted in the future where your data are collected in unconnected circumstances. If you would prefer us not to do this, you are free to say so.

Where we process your data based on consent you have provided to us, you have the right to withdraw your consent at any time and have such data deleted. You also have the right to opt through the National Data Opt Out. Where we are legally permitted to do so, we may refuse your request and will give you reasons for doing so. If practicable, we may at your request transfer your personal data to a third-party controller where such personal data is processed.

You will not normally have to pay a fee; however, we may charge a reasonable fee if your request is clearly unfounded, repetitive, or excessive. Alternatively, we may refuse to comply with your request in these circumstances. We will always try to respond to any legitimate request within one month. Occasionally it may take us longer than a month if your request is particularly complex or you have made a number of requests. In this case, we will notify you and keep you updated.

We may need to request specific information from you to help us confirm your identity and ensure your right to access your personal data (or to exercise any of your other rights). This is a security measure to ensure that personal data is not disclosed to any person who has no right to receive it. We may also contact you to ask you for further information in relation to your request to speed up our response.

How can you contact us?

If you have any questions or concerns about the way in which we collect, hold or process your data, or simply wish to exercise your rights (as identified in the previous section) please contact us directly us on support@ukhcdo.org or write to the NHD DPO:

The National Haemophilia Database
Suite 1 on part 2nd Floor of Anchorage One
Anchorage Quay
Salford Quays
M50 3YJ

Email: support@ukhcdo.org
Website: www.ukhcdo.org
Telephone: +44 (0) 161 850 8102

If you are not satisfied with our response or any of our data processing activities, you can complain to the Information Commissioners Office at:

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

Our privacy policy has been compiled to comply with the law of every country or legal jurisdiction in which we aim to do business. If you think it fails to satisfy the law of your jurisdiction, we should like to hear from you.