

Privacy Notice

UKHCDO Ltd is committed to protecting and respecting the privacy of your personal data. This privacy notice explains how your data is collected, used, transferred, and disclosed by us. It applies to data collected when you participate in our observational research, events; use our website, products or services; interact with us through social media, email, post, text or phone; apply for employment with us; or are employed by us.

This privacy notice explains:

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Who is UKHCDO Ltd?

UKHCDO Ltd, a subsidiary of the registered charity the United Kingdom Haemophilia Centre Doctors' Organisation, a national group of doctors who look after people with bleeding disorders. The UK National Haemophilia Database (NHD) collects the data and is a register of people in the UK with all types of bleeding disorders.

All these organisations are committed to protecting and respecting all your personal information which we may collect and which you share with us, through submissions from your Treatment Centres and the Haemtrack home treatment system, or as you are a job applicant, employee or ex-employee, contractor or temporary employee, or a service provider.

All personal information provided by or collected from you is handled in accordance with privacy and data protection laws in the countries where we operate and, on the terms, set out in this Notice. This Privacy Policy explains in detail the types of personal data we may collect about you when you interact with us. It also explains how we store and handle that data and keep it safe.

The sections detailed in this policy should answer any questions you have but if not, a question and answers document for people with bleeding disorders that have provided data during their treatment is available here (<https://www.ukhcdo.org/wp-content/uploads/2026/03/Privacy-Notice-Patients-Questions-and-Answersv8.0.pdf>). Alternatively, please do get in touch with us at support@ukhcdo.org.

What is personal data?

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Personal data is any information which identifies and is about a living person. It might be possible to identify the individual through a single, specific identifier, such as a name; or by combining several different identifiers, such as job role and team. Some information is considered particularly sensitive because of the serious impact that it might have on the individual concerned if the data was lost or stolen. This 'special category' data includes racial or ethnic origin; political opinions; religious or philosophical beliefs; trade union membership; health; sex life or sexual orientation; and genetic and biometric data (such as your fingerprint). We may collect special categories of personal data about pupils, examination candidates, job applicants, event attendees, and employees, where we have a lawful basis to do so.

How we keep your data secure?

We have put appropriate organisational safeguards and security measures in place to protect your data from being accidentally lost, used, or accessed in an unauthorised way, altered or disclosed. We keep your data confidential within a secure infrastructure protected by multiple firewalls and we are committed to keeping the security of these systems as up-to-date and as secure as possible. We already encrypt special category data within some of our products. We also limit access to your personal data to those employees, associates, contractors and other third parties who have a business need to know it. They will only be permitted to process your data on our instructions and will always be subject to a duty of confidentiality.

We require any third party who is contracted to process your personal data on our behalf to have security measures in place to protect your data and to treat such data in accordance with the law. We have put in place procedures to deal with any suspected personal data breach and will notify you and the UK Information Commissioner of a breach where we are legally required to do so.

The data we collect about you

The following groups of personal data may be collected and processed by UKHCDO Ltd if you are a person being treated for a bleeding disorder:

- **Identity Data** such as your first name, last name, title, date of birth, gender, NHS number (England and Wales), CHI number (Scotland) and Health and Social Care Number (Northern Ireland) and special category health related information. A full list of the information collected may be viewed on our website, [Download the NHD Dataset 2020](#) –  650kb
- **Contact Data** such as your e-mail address, home address, and telephone number.
- **Survey Data** such as your comments and opinions provided in response to a survey.

In addition, we may collect the following additional groups of data with respect to job applicants, employees or ex-employees, contractors, and temporary employees:

- **Identity Data** such as proof of your identity (e.g. passport, valid driving licence or birth certificate).
- **Contact Data** such as information about your marital status, next of kin, dependents, personal and emergency contacts details to be used in the event of an emergency.
- **Recruitment Data** such as details of your education, qualifications, occupation, work history, experience, referees, training and skills development; nationality, entitlement to in the UK, criminal record (if your role requires this) and equal opportunities monitoring information;
- **Employment Data** such as the terms and conditions of your employment, salary or fee payments, benefits, work patterns, NI number, attendance, holidays, sickness, disciplinary or grievance issues, medical or health conditions, disabilities (for which UKHCDO Ltd needs to make reasonable adjustments); and information about your

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vehicle, driving licence, MOT and insurance documents if you drive on company business;

- **Performance Data** such as performance reviews and ratings, performance development plans and related correspondence; and timesheet information.
- **Activity Data** such as the websites our employees visit while using an UKHCDO Ltd computer or UKHCDO Ltd network, and the activity logs held within UKHCDO Ltd systems and databases.
- **Communications Data** such as the emails you send or receive via the UKHCDO Ltd email system.

We also collect, use and share aggregated data such as statistical or demographic data for a number of different purposes. Aggregated data may be derived from your personal data but is not considered personal data in law as this data does not directly or indirectly reveal your identity. For example, we may aggregate for the purpose of developing annual reports about the treatment of bleeding disorders for National Health Commissioners. However, if we combine or connect Aggregated Data with your personal data we pseudonymise your data so that it cannot directly or indirectly identify you, and we treat the combined data as personal data which will be used in accordance with this privacy notice.

How we collect your data

We may collect personal data from you when you: register at a Haemophilia centre; participate in surveys or related events; interact with us through social media, email, post, text or phone, or use one of our cookies. In addition, we will also collect personal data from job applicants, employees, ex-employees, trustees, contractors, and temporary employees during their recruitment screening and throughout the tenure of their employment with us.

The legal basis for processing your personal data

The law requires us to inform you of the legal basis for collecting and processing your personal data, where we are the Data Controller, or Joint Data Controller. These include:

- **Performance of contract:** In most cases, this occurs when we have a contract with you to either provide a product or service to you, or to receive something from you. Examples include employment contracts; agreements for the provision of our products or services; and procurement contracts. We are also acting under the performance of contract if we collect or process your data for the purposes of entering a contract, if you have expressed an interest in working with us.
- **Legitimate interests:** We may have a legitimate interest in processing certain personal data, which does not relate to the performance of a contract agreed with you. If we rely on our legitimate interests to justify processing your data, we will have conducted an assessment to evaluate the fairness of this; and will only undertake the processing if it is reasonable to do so and will not cause undue risk to you. An example of this is where our data processing is based on improving patient care and serve the wider public interest: 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.
- **Legal obligation:** We may be legally obliged to process certain data about you, for example to report the results of our longitudinal observational research with National Health Commissioners or protect employee safety while travelling on UKHCDO Ltd. business. In some cases, we are obliged to share personal data with third parties, such as NHS England, NHS Digital or HMRC.

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- **Public Interest:** We are obliged to maintain a permanent record of your special category health related data ([Download the NHD Dataset 2020](#) –  650kb) under our service level agreements with NHS Regional Commissioners of services to people with bleeding disorders. This is both a legal obligation and necessary for the performance of a task carried out in the public interest. 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.
- **Consent:** 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](#)
- In Scotland, we have the same ethical approval for five years from the Public Benefit and Privacy Panel for Health and Social Care where we are processing special categories of data, for example data concerning health, racial or ethnic origin, genetic information, and gender, we also need to meet an additional condition in the GDPR, the condition is: Article 9(2)(h) – processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3 of article 9(2)(h).
- For patients registered in Northern Ireland consent is required for specific research

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activities and consenting to the exchange of personal identifying data between UKHCDO and the Strategic Planning and Performance Group (SPPG) of the Department of Health (DoH) to acquire longitudinal mortality data

Supported applications allow the controller(s) of the relevant data sources, if they wish, to provide specified information to the applicant for the purposes of the relevant activity without being in breach of the common law duty of confidence. Support provides a lawful basis to allow the information to be processed by the relevant parties for the specified purposes without incurring a breach of the common law duty of confidence only. applicants must ensure the activity remains fully compliant with all other relevant legislation.

How we use your data

Your personal data is used by us to support a range of different purposes and activities. These are listed in the table below together with the types of data used and the legal base(s) we rely on when processing them, including where appropriate, our legitimate interests. Please be aware that we may process your personal data using more than one lawful basis, depending on the specific activity involved. Please contact us if you need details about the specific lawful basis, we are relying on to process your personal data where more than one basis is set out below.

Purpose/ Activity	Type of Data	Lawful Basis
To use data of people who are treated by health service providers for the purpose of observational research in adherence to a service level agreement.	Identity	- Performance of a contract with a health service provider - Necessary to comply with a legal obligation - Public interest necessary for the performance of a task carried out in the public interest.
To exchange personal data identifiers with National Health Service providers for the purpose of accessing mortality data	Identity	- Necessary for our legitimate interests (UKHCDO supported mortality studies) - Necessary to comply with a legal obligation (for example Infectious Blood Inquiry Require us to provide mortality data for their research purposes) - Public interest necessary for the performance of a task carried out in the public interest

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		(for example, annual reports to NHS England)
To undertake research projects with third party pharmaceutical providers to better understand bleeding disorders and their treatments	Identity	- Performance of a contract with a third-party pharmaceutical provider - Necessary to comply with a legal obligation - Public interest necessary for the performance of a task carried out in the public interest.
To protect the security of commercial and personal and special category data in our care by securing and monitoring activity within our network, internet and email.	- Identity - Technical - Usage - Activity - Communications	Necessary for our legitimate interests (protecting the data entrusted to us by customers and commercially sensitive data about our business)

For job applicants, employees, ex-employees, contractors, trustees, and temporary employees only:

Purpose/ Activity	Type of Data	Lawful Basis
To recruit the right people for our business, and manage their working relationship with us, including job role and responsibilities, salary or fee payments, progression, training, performance management and disciplinary or grievance procedures.	- Identity - Contact - Recruitment - Financial - Transaction - Activity - Employment - Performance - Technical - Usage - Survey - Communications	- Performance of a contract with you - Necessary to comply with a legal obligation - Necessary for our legitimate interests (e.g. to monitor equal opportunities, to gather employee feedback; to contact your next of kin in case of emergency)
To arrange travel for you on UKHCDO Ltd business and making appropriate safety arrangements for this, including monitoring your travel.	- Identity - Contact - Communications	- Performance of a contract with you - Necessary to comply with a legal obligation - Necessary for our legitimate interests (e.g. to contact your next of kin in case of emergency).

How we share your data

We may disclose and share your personal data with the parties set out below, for the purposes outlined in the tables above:

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- government agencies, their partners and other third parties to comply with our legal obligation, public interest responsibilities or legitimate interests (such as NHS England, NHS Scotland, NHS Wales, NHS Digital, NHS National Services Scotland, Strategic Planning and Performance Group (SPPG) of the Department of Health (DoH) Northern Ireland, European Haemophilia Safety Surveillance, European Medicines Agency, Pharmaceutical Companies or HRMC to fulfil our accounting responsibilities).
- UKHCDO has been asked to share confidential patient data with the Infected Blood Compensation Authority (IBCA). Data sharing from the UKHCDO enables IBCA to have access to the data held by the National Haemophilia Database on treatment for bleeding disorders, which may be directly or indirectly relevant to the eligibility criteria for claiming compensation as recommended by the Infected Blood Inquiry. This data will hopefully supplement data from other sources to support applications for compensation. UKHCDO will continue to share this important data with IBCA to support its processing of claims from infected and affected individuals until this process is complete. The legal basis for sharing and processing personal data between both organisations is being undertaken further to statutory obligations and remit as set out by the Victims and Prisoners Act 2024 and relevant GDPR articles for each organisation.

Business partners, suppliers (including their sub-contractors) or other third parties that we use to support the operation of our business. For example, to: carry out criminal or credit checks; support the logistics involved in the secure storage and transportation of archive material; provide IT systems and software, internet access, website or hosting solutions; organise events; provide training and development services; deliver employee benefits, run our payroll, perform occupational health checks and referrals, and provide employee assistance;

- our professional advisers include auditors, lawyers, bankers, and insurers who provide professional advice, accounting, banking, legal, insurance, and pension services, or to meet our audit responsibilities.

We require all third parties to respect the security of your personal data and to treat it in accordance with the law. We do not allow our third-party service providers to use your personal data for their own purposes and only permit them to process your personal data for specified purposes and in accordance with our instructions.

- For example, where you have consented for us to do so and after this point where the Health Research Authority advised we have section 251 support where we can process confidential patient information without consent, we will share your data with a third party in respect of non- research or research purposes, we may pass your data on to the relevant third party administering the non-research or research activity.

Retention policy

All our data processing activity has been reviewed to ensure all categories of data are retained for periods as designated by our legal requirements and following best practice as outlined by the Information Commissioners' Office. For example, our longitudinal observational research with National Health Commissioners involves looking for any changes in the number of people affected with bleeding disorders, the effect of treatment trends over time and complications and the side-effects of their treatment. Therefore, we are required to retain certain categories of data indefinitely. Other personal data will be held for no longer than is necessary to protect our legitimate interest as a data controller. In some circumstances we may anonymise personal data so that it can no longer be linked to you, in which case we may use such information without further notice to you.

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International transfers

Where data is transferred outside of the EEA to our service providers, we take steps to ensure that appropriate measures and controls are in place to protect that data in accordance with relevant data protection laws and regulations. In each case, such transfers are made in accordance with the requirements of Regulations (EU) 2016/679 (the General Data Protection Regulations or “GDPR”) and may be based on the use of the European Commission’s Standard Model Clauses for transfers of personal data outside the EEA.

Your rights

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, the Data (Use and Access) Act 2025 and the National Data Opt Out legislation which 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.

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- **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 of your rights under GDPR 2016, Data Protection Act 2018 and the National Data Opt Out, please see the following:

[A guide to the data protection principles | ICO](#)

[A guide to individual rights | ICO](#)

[National Data Opt-Out - NHS England Digital](#)

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.

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

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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 to 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 UKHCDO DPO:

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

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.

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