

## PRIVACY POLICY

### Who is collecting the data?

UKHCDO Ltd, a subsidiary of the registered charity the United Kingdom Haemophilia Centre Doctors' Organisation, and the National Haemophilia Database (NHD) collect the data. 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.

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.

We want everyone who supports us, or who comes to us for support, to feel confident and comfortable with how any personal information you share with us will be looked after or used.

We hope the sections detailed in this policy will answer any questions you have but if not, please do get in touch with us at [support@ukhcdo.org](mailto: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. It was started in 1969 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) - a national group of doctors who look after people with bleeding disorders. Your local Haemophilia Centre collects information about you and your bleeding disorder and sends it, within the NHS, to the NHD to store and analyse. Some people also enter information about their treatment on to a home treatment system call Haemtrack. Information submitted to Haemtrack is combined with information submitted by the treatment centres and all this information is stored and analysed by the NHD. 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 such as your name, NHS number, date of birth and what bleeding disorder you have, its severity and how it is treated. 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.

Every 3 months, 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.

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#### UKHCDO Ltd Board

**Prof Charles R M Hay, Prof Christopher Ludlam, Prof Peter Collins, Dr Ri Liesner, Dr Pratima Chowdary, Dr Andrew Will, Dr Katie Talks**

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**Company No.** 05768634 (England and Wales)  
**Name & Registered Office:** UKHCDO Limited, City View House, Union St, Ardwick, Manchester, M14 4JD  
**VAT Reg No.:** 930 8422 35

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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 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)(e) – processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

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)(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.

## 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 the National Haemophilia Database. All reports delivered from the database use anonymised data. This means that you 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 a summary of this report on our website [www.ukhcdo.org](http://www.ukhcdo.org). This information can help to improve treatment and services across the country. 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 quantify the consequences of transfusion transmitted infection in public inquiries.

## How will the information be used?

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.

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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 therefore 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.

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.

### What rights does the data subject have?

Your rights

Listed below are the rights that are relevant to the information that we process. For a list of all your rights under GDPR see: <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/>

**Right to be informed** - You have the right to be informed about the collection and use of your data.

**Right to access** - You have the right to access a copy of the data we hold on you.

**Right to Rectification** - You have the right to request that information is corrected if it's inaccurate.

**Right to Erasure** (Right to be Forgotten) - You have the right to request that your information is removed.

**Right to lodge a complaint** with a supervisory authority - If you think we have infringed your privacy rights, you can lodge a complaint with the relevant supervisory authority.

You may request access to the information we hold about you at any time and may request us to rectify, update or restrict processing of such information. We may ask you to verify your identity and for more information about your request. We will seek to act on your request in the timescale required by applicable data protection laws.

We will use reasonable endeavours to ensure that your personal data is maintained and up to date and this is done through regular communication with your Haemophilia Centre.

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You may, in certain circumstances (for example, if we have processed your data unlawfully) have the right to request that we erase your personal data. We will respond to your request within the timescale required by applicable data protection laws and will only disagree with you if certain limited conditions apply.

If we agree to your request, we will delete your data but 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. 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.

### **How can the data subject raise a complaint?**

If you wish to exercise any of these rights or raise a complaint on how we have handled your personal data, you can contact us on [support@ukhcdo.org](mailto:support@ukhcdo.org) or write to the UKHCDO DPO:

City View House  
Union Street  
Ardwick  
Manchester  
M12 4JD

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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