

Revised : September 2023

# HAEM

## TERMS OF SERVICE

### CONFIDENTIALITY AND SECURITY ON THE INTERNET

UKHCDO has taken measures to ensure the security and confidentiality of any information that you provide to this site, the Internet is not an absolutely secure medium, and is not under UKHCDO's control. Use of the Internet is solely at your own risk and is subject to the applicable laws and regulations. Haemtrack communication between your PC, Mac or smartphone and your Haemophilia Centre uses the internet and is encrypted using industry standard technologies as used in Internet banking. UKHCDO has taken measures to ensure the security and confidentiality of any information that you provide to Haemtrack.

### VARIATIONS TO THESE TERMS AND CONDITIONS

If we make changes to these terms and conditions you will be informed through the Haemtrack system.

### PRIVACY STATEMENT

We are strongly committed to maintaining your privacy.

UKHCDO provides this service to your Haemophilia Centre. In order to use this site, you must be invited by your Haemophilia Centre and/or physician and provide personal information. This Privacy Statement tells you how we use, share, and protect the privacy of that information. Haemtrack is designed to be a bridge to facilitate communication between the Patient and his/her Healthcare Professional. It allows the Patient to record their personal treatment and bleed information and to share that information with their Healthcare Professionals in a timely manner. Haemtrack will allow you to record data about your condition and treatment on the Internet. The data you provide when you register or record your treatment information is considered to be personal to you.

### What information does Haemtrack collect from you?

Haemtrack collects information from you in two ways.

Active information collection is when we gather information that you decide to send to us, for instance when you complete a registration form or record your treatment data or send us an e-mail. Active information may include data such as your name, date of birth, phone number, address and email address. Passive information collection is when we collect data from you that you have not actively given us, such as the type of web browser and operating system you use. Passive data does not include personal health information and will not be linked to the personal information you have provided on the Haemtrack site. Haemtrack is intended to be used by Healthcare Professionals, Patients and their caregivers. UKHCDO invites a Haemophilia Centre to participate in the use of Haemtrack. The Haemophilia Centre registers the Healthcare Professionals and invites patients to participate. During registration, you will be required to choose a username and password. Every time you visit Haemtrack, you must provide your username and password in order to get into the areas of Haemtrack where personal information can be accessed. Please note that if you choose not to register, you will not be able to use the entire site.

### Patient and Caregivers

Your Haemophilia Centre may register you for Haemtrack by providing your name, address, phone number, date of birth and email address. Once you are a registered user of Haemtrack you may enter data about your condition and treatment in the Haemtrack site for your Healthcare Professionals to view.

You will be able to export your data to an excel spreadsheet. Once the data has been exported it becomes the responsibility of the person exporting the data to ensure the privacy and security of the exported data.

### **Healthcare Professionals**

You may register with us through the Haemophilia Centre by providing your country of residence, email address, name, address, phone numbers and pager numbers. This information will be used on the Haemophilia Centre home page staff directory so that staff and patients will know how to contact you. Once you are a registered user of Haemtrack, you may enter data and view patient information.

You will be able to view your Patient'-s' data on reports and in some cases export to an Excel spreadsheet. Once the data has been exported, it becomes the responsibility of the Haemophilia Treatment Centre and you to ensure the privacy and security of the exported data.

### **How Haemtrack uses the information that it collects**

Only you, your caregivers, and staff selected by your doctor at your Haemophilia Centre and the National Haemophilia Database (NHD) may use the data we collect from you. We may use or release personal information from this site as required, to reply to your requests or to comply with the law, as required by legal action, and to protect against liability, the security and integrity of the site and the safety of its users.

Data provided by, or collected from you, will be held on a protected server on the secure NHS network (Health and Social Care Network – HSCN), accessible by your hospital and the NHD.

We may view and use de-identified data, and other details regarding site usage, treatment patterns and other information about our site. To de-identify the data means to remove all personal and Haemophilia Centre identifiers.

We will not sell, lease, transfer, share, or otherwise allow access to your identifiable personal data with any outside parties, except as we have explained in this Privacy Statement or as we tell you at the time you provide the information. All analyses of data for research and audit purposes will use anonymized data.

### **Your choices regarding the collection and use of your information**

We do not want to collect personal data from you that you do not want us to collect. We tell you at all active data collection points whether what we request is required to use the site, or, if it is optional. It is important for your Healthcare Professionals to have accurate information in a timely manner; therefore, we provide you with access to your personal data so that you can update it or correct errors in order to help keep the data current and complete. We may not allow you access to certain information if doing so would harm, or put at risk, another person's privacy, or if we are entitled or obliged by law to withhold the information in the circumstances.

When you give us information at this site, you consent to the use and release of your data as we have explained in this Privacy Statement. 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. For more information on UKHCDO's Privacy Statment and your rightd please click on the followinig link:  
<https://www.ukhcdo.org/wp-content/uploads/2023/06/UKHCDO-Privacy-Notice-2023-v0.5.pdf>

If you ever decide you do not wish to participate in Haemtrack, if you are unable to access your personal data or would like to review your data, you may contact us by email at: [nhd.support@nhs.net](mailto:nhd.support@nhs.net) or by mail at: UKHCDO, Suite 1, 2nd Floor of Anchorage One, Anchorage Quay, Salford Quays M50 3YJ

### **What security measures Haemtrack has**

UKHCDO wants your personal data to remain safe. However, there are no systems that are 100% secure or error-free. Therefore, we cannot guarantee the security or accuracy of the information we gather.

One way we protect your personal data is through the use of usernames and passwords, and 2-factor authentication as used in electronic banking. This safety measure only works if you keep your username and password secret. If you ever think your username or password are no longer secret or are being used by the wrong people, contact your Hemophilia Treatment Centre right away. Haemtrack allows you to reset your password if you provide a valid username. Once Haemtrack has received the correct information, you will receive a link to reset your password to the e-mail address you provided. It is very important to keep the e-mail address in your profile up to date because that is the address that will be used to send you the instructions. To protect your privacy, address, phone number, date of birth or any other personal information will not be included in the email.

Haemtrack has implemented security measures to protect the privacy and security of the data within the site. Haemtrack cannot however guarantee the privacy and security of the data once it has been exported.

We take other steps to secure your data. For example, any treatment data you give us is securely encrypted during transmission and storage. Encryption is the translation of data into a secret code. To read an encrypted file, you must have the key that allows you to read it, so that even if someone were able to obtain the data, they would not be able to make sense of it.

### **How Haemtrack protects the privacy of children and persons with legal guardians**

Children and persons with guardians who are invited by their doctor to use Haemtrack are required to provide the same data as adult participants. This Privacy Statement applies equally to children and adults with guardians.

We require written parental or guardian consent before we allow children or persons with guardians to use Haemtrack. If the way we collect personal data changes, we will post the changes here. If there are changes to the policy, we will ask for the parent or guardian's consent before using or disclosing information about the child or adult. We reserve the right to collect, use, and release a person's name and online contact information without parental or guardian consent, to the extent that it is necessary in order to protect the security of our site, to protect us from liability, and as required by law. We always welcome questions from parents and guardians, and encourage them to contact us at the address below. Parents and guardians have the right to review and request the deletion of personal data collected at this site. To review personal data, or to have data deleted, please notify the Haemophilia Treatment Centre Haemtrack Administrator who will notify Haemtrack at [nhd.support@nhs.net](mailto:nhd.support@nhs.net). You also have the right to revoke your consent to our collection of your child's information, or that of the adult to whom you are a guardian, and/or your information. To revoke consent, please contact your Haemophilia Treatment Centre who will notify Haemtrack.

### **What happens if we change this Policy Statement?**

We may change this Privacy Statement at any time. If we do change the Privacy Statement, the new Privacy Statement will be posted here, along with the date it was changed. You will be asked to agree with the changes by way of a notice that will appear the first time you log onto Haemtrack after the date of the change. All data we collect or receive after we post the new Privacy Statement will be subject to the terms explained in the new Privacy Statement. We want you to know that we will not use your personal information, or release your personal information that you provided, before a new Privacy Statement is posted without first getting your consent by way of the notice referred to above. If you do not give us your consent, we will handle your information in the way you agreed to with the previous Privacy Statement. If you do not agree to the new Privacy Statement, you will not be able to use the site. The Privacy Statement will be available each time you sign on to Haemtrack, and we encourage you to review the Privacy Statement if you have questions or concerns about entering your personal data.

### **Clinical Research:**

The National Haemophilia Database may analyse anonymised Haemtrack data to investigate treatment trends over time and in patients of different age and severity, different treatment patterns and the clinical outcome of different approaches to treatment. In so doing, they may link this with data held on the National Haemophilia Database.

Such observational research will help us to understand and evaluate variations in clinical practice and help us to optimize clinical management of bleeding disorders in the future. Only anonymised data is reported. Only "observational" research is conducted. Observational research is non-interventional research where one observes the outcome of normal treatment. In such research the patient is not asked to change treatments or treatment regimen or given experimental treatment. This contrasts with interventional studies or clinical trials where their managing doctor would take explicit written consent for them to participate and use an investigational agent or new approach to treatment. The choice of your treatment remains a matter entirely between you and your haemophilia Centre.

This Haemtrack research is mainly funded by NHS Health Commissioners but may also be funded by grants provided to the National Haemophilia Database by Industry and some studies may be conducted collaboratively with industry. However, no third party will be provided with any identified personal data. Third parties will be provided only with anonymised reports and in some cases even the brand of factor concentrate will not be identified, where it is not directly relevant to the analysis.

### **How you can withdraw from Haemtrack**

If you ever decide that you do not wish to participate in the use of Haemtrack, you may stop at any time by notifying your Haemophilia Treatment Centre Haemtrack Administrator.

### **How you can contact Haemtrack with questions or comments**

If you have questions, comments, concerns or complaints about this Privacy Statement, or the information practices of this site, send us an email at [nhd.support@nhs.net](mailto:nhd.support@nhs.net) or by mail at: UKHCDO, Suite 1, 2nd Floor of Anchorage One, Anchorage Quay, Salford Quays M50 3YJ.

Please note that if you choose to contact Haemtrack directly, you will be providing personally identifiable information to UKHCDO. If you do not wish to provide this information to UKHCDO, please direct all questions to your Haemophilia Centre Haemtrack Administrator, who will contact Haemtrack to obtain the information or assistance you need. We will take steps to answer your questions or concerns and will try to fix problems you bring to our attention. We welcome your comments and feedback regarding Haemtrack and our products, services and programs. E-mail may not be secure. As a result, you should carefully consider what information you wish to send to us via e-mail. We suggest that you do not send clinical or medical information via email.

### **APPLICABLE LAWS**

This site contains information about treatments and therapies, which may or may not be available in other countries. Each country has specific laws, regulations and medical practices governing the communication of medical or other information on the Internet. Nothing in this site should be viewed as a solicitation or promotion of any particular treatment or therapy, which is not authorised, by the laws and regulations of the country where the reader resides, or as a promotion or advertisement of any products or services.

The treatment log facility provided on this site is intended to supplement, but not to replace, communication with your doctor or other medical professional in respect of your Haemophilia Centre. Remember! Haemtrack is not an emergency notification tool! Contact your designated emergency number immediately should a serious or life-threatening event occur. This site is not intended to replace a medical record.

Legal Information

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