



Northern Ireland Haemophilia Comprehensive Care Centre
& Thrombosis Unit
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HSC Belfast Health and
Social Care Trust
caring supporting improving together

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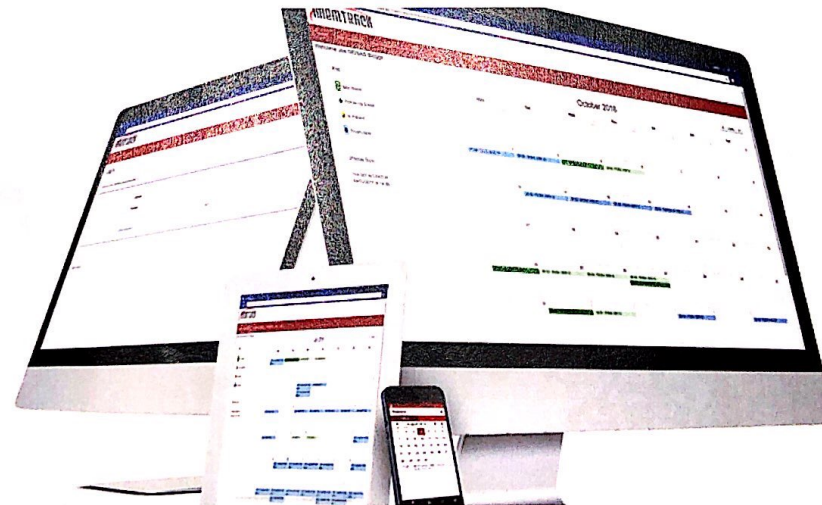
An Introduction To Haemtrack

If you are on home treatment, you will have agreed to keep and return accurate home treatment records so that your haemophilia treatment can be assessed.

Home treatment records are very useful for the Haemophilia Team because they help us to assess your treatment and bleeding pattern. This helps us work out whether you are on the best treatment and to advise you how to improve your treatment.

Instead of recording this information on paper and bringing it or sending it to the centre, we would prefer you to complete your records electronically after each treatment by way of the **Haemtrack** website or mobile phone app.

This easy to use system helps you to report all your bleed and treatment information as quickly as possible in order for the NI Haemophilia Comprehensive Care Centre to provide you with the best possible care.



Haemtrack

What Is **Haemtrack**?

- A secure treatment recording system connecting you to the NI Haemophilia Comprehensive Care Centre through the **Haemtrack** website or mobile phone app.
- It enables you to record all treatments as they occur.
- It allows the NI Haemophilia Comprehensive Care Centre to see your up to date treatment information to help improve your care.

Why Do We Need Your Information?

Your treatment information allows the NI Haemophilia Comprehensive Care Centre to regularly review your records to ensure you are receiving the best possible treatment for you. It also ensures that:

- Target joints can be identified and your response to treatment can be monitored. Recurrent or ongoing problems can be identified and discussed with staff at clinic attendances.
- Importantly it gives your clinician access to your treatment records (including bleeds) at each clinic visit to ensure they can provide informed care decisions.
- Information is immediately available for your doctor if you require the completion of forms for benefits or legal purposes.

Is **Haemtrack** Used For Research?

Yes, **Haemtrack** provides access to information that has never before been possible, allowing the **Haemtrack** team to carry out new research into "real world" treatment practices. This information will be anonymously analysed to assess the range of treatment practice. Some of this research will be funded by and conducted anonymously in collaboration with industry to support the introduction of improved treatments and product safety requirements. **Haemtrack** do not conduct clinical trials and your choice of treatment and any potential participation in such clinical trials is entirely between you and your centre doctor.

What Are My Rights?

The use and storage of personal information is regulated by the Data Protection Act 1998 and the General Data Protection Regulation 2018. According to the Act, you must be told about any of your personal data that is held on computer and why is collected. You have the right to ask for some or all of your information to be removed from the **Haemtrack** database by asking the NHD or the NI Haemophilia Comprehensive Care Centre.



Data Protection Act 2018



The Technology

If you want to access via your computer or laptop, then visit www.haemtrack.nhs.uk and complete the simple registration steps. Once you complete the registration steps, this will register your interest with the NI Haemophilia Comprehensive Care Centre and once accepted, you can immediately start to enter your data. The information that you enter on **Haemtrack** will be immediately accessible by the centre.

You can also download the **Haemtrack** app on to your iPhone or Android smart phone using the Apple App Store or Google Play, or by scanning the QR barcode:



What If I Don't Have Access To Technology?

Patients who do not have access to a computer, laptop or mobile phone can still submit a paper return detailing their infusions and the details will be entered onto **Haemtrack** by the NI Haemophilia Comprehensive Care Centre's Data Manager.

Home Delivery

The **Haemtrack** system is compulsory to all patients who have their clotting factor delivered directly to their home. You will have to agree to complete accurate details about your treatment. Further information regarding home delivery is available from the NI Haemophilia Comprehensive Care Centre.

How Do I Use **Haemtrack**?

Whilst **Haemtrack** is relatively straightforward to use, if you would like training on how to use it, please contact any member of the NI Haemophilia Comprehensive Care Centre.

An information pack including user manual will be supplied to all users, and a short training video is also available to view. To view this video, please visit <https://youtu.be/ifceM54u74I> or scan the QR code:



Additional training can be given either face to face, which could be at your next clinic appointment or arranged for a separate date, or by video call, via Zoom or MS Teams.

The staff at the NI Haemophilia Comprehensive Care Centre are more than happy to answer any queries you may have regarding **Haemtrack**. Please do not hesitate to contact us.

Alternatively you can contact the **Haemtrack** team direct:

email: support@mdsas.com

tel: 0161 277 7917

or: National Haemophilia Database Administrator

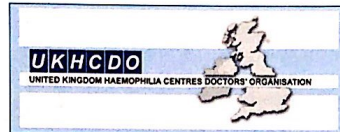
City View House

Union Street

Ardwick

Manchester

M12 4JD



An Introduction to **Haemtrack** Video

The contents of this information leaflet is also available to view as a video on YouTube. To view this video, please visit <https://youtu.be/uFMUq6GfJTU> or scan the QR code:



Contact Us

For more information on Haemtrack, or to register your interest in a training session, please contact:

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