

Children's Haematology Unit Belfast

An Introduction To **Haemtrack**

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

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

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

This easy to use system helps you to report all bleed and treatment information as quickly as possible in order for the Children's Haematology Unit to provide the best possible care.



Haemtrack

What Is **Haemtrack**?

- A secure treatment recording system connecting the patient to the Children's Haematology Unit through the **Haemtrack** website or mobile phone app.
- It enables you to record all treatments as they occur.
- It allows the Children's Haematology Unit to see your child's up to date treatment information to help improve their care.

Why Do We Need Your Child's Information?

Treatment information allows the Children's Haematology Unit to regularly review your child's records to ensure that they are receiving the best possible treatment. It also ensures that:

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

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 the choice of treatment and any potential participation in such clinical trials is entirely between the patient and the 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 child's personal data that is held on computer and why is collected. You have the right to ask for some or all of their information to be removed from the **Haemtrack** database by asking the NHD or the Children's Haematology Unit.



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 the registration steps are completed, this will register interest with the Children's Haematology Unit and once accepted, you can immediately start to enter your data. The information that you enter on **Haemtrack** will be immediately accessible by the unit.

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?

If you do not have access to a computer, laptop or mobile phone, you can still submit a paper return detailing your child's infusions and the details will be entered onto **Haemtrack** by the Children's Haematology Unit'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 child's treatment. Further information regarding home delivery is available from the Children's Haematology Unit.

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 Children's Haematology Unit.

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/mWXaNWkLLXI> or scan the QR code:



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

The staff at the Children's Haematology Unit 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/IYkuWf_MmRk or scan the QR code:



Contact Us

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

Ray McKeown, Data Manager

NI Haemophilia Comprehensive Care Centre & Thrombosis Unit

Belfast City Hospital, Lisburn Road, Belfast, BT9 7AB

Tel: 028 9504 0444

Email: ray.mckeown@belfasttrust.hscni.net