

# Haemtrack Group

## Membership

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The Group met twice, in February and June 2016.

## High level data from the Haemtrack Database:

Number of treatment entries: 912,000 (Prophylaxis: 752,253, Bleed treatments: 104,000)

Number of users: 2800+

Number of sites: 51

## Activities

The main activities of the group during the year were to carry out a survey of patients, data managers and clinicians; oversee and guide Haemtrack system development; Participate in the formation of a new Haemtrack CQUIN.

*Results of the Haemtrack Surveys:* There were 419 responses from patients/carers, 45 responses from Data Managers or Lead Nurses and 40 responses from clinicians.

The results of the survey provided extremely valuable insight into the use of Haemtrack and also provided guidance towards future development work for Haemtrack.

*Haemtrack CQUIN:* The group was involved in the development of the Haemtrack CQUIN. Some centres have taken this up and others, including centres that were keen to participate have not, usually because their commissioners did not choose this CQUIN. In many cases they did not consider this financially worthwhile. Smaller centres were reluctant to pay the operational expenses of £1000 to NHD or felt that it was not worth their while because of the small numbers of patients under their care.

NHD have calculated the baseline Denominator for each centre, having cross-checked with participating centres, and requested from centres what their target recruitment and compliance was.

The NHD is now calculating the ongoing compliance of patients. The number of infusions per week was looked at as a measure of compliance. This is proving difficult due to the prescribing practice of centres. E.g. The NHD collects information on what the patient is issued. If the patient is issued 4 months of treatment then this is incomparable to quarterly Haemtrack (HT) usage data. It was decided to look at comparing the 6 months data up to the end of December 2015 initially.

NHSE need to know how many patients per centre are using / compliant with HT and how many new patients sign up and use HT compliantly.

Other areas of work carried out by the group during the year included:

*Encouraging clinical use of Haemtrack:* Supplying all clinicians / Nurses / Data Managers with a test Haemtrack Patient account enabling Clinicians/Nurses to encourage patients to use the system, showing the patient how important the data is.

*Use for research or as a research platform:* Modifications to Haemtrack now enable it to be used as a study diary, thus avoiding duplication of effort for patients participating in such studies. The system would export the relevant data for the specific studies. If required, the Haemtrack dataset can also be extended according to required study data collection fields. It is being used for the ECHO study and may be used for other studies. The US ECHO group plan to pilot the new version of Haemtrack.

*Validation:* There is now an option to block validate prophylaxis and looking closer at bleed treatments.

*Recent Updates to Haemtrack:*

- Information about how often an incorrect password can be entered and what to do if you cannot remember the password.
- Allowing centres to unlock patient user accounts.
- Video consultations are currently being piloted.
- Barcode scanning. Baxalta and Pfizer products are included. Other companies are being approached
- The app has been updated to show the number of treatments awaiting sync
- Enable the management of more than one account through the app (where parents/carers are managing accounts for more than one child).

*Future developments:*

MDSAS is developing a new version of Haemtrack. The first version was developed in 2008 but has been modified since. The new version will use the latest browser technology and mobile devices technology. Combined with video consultation, this means that whole clinics could be managed by mobile phone or computer if required. The US will pilot this. A video consultation module will be developed as a separate application for use outside of Haemtrack for telephone clinics for mild bleeders who would not otherwise use Haemtrack.

Dr Rob Hollingsworth &  
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