

## UK Haemophilia Data Managers' Forum Group

The UK Haemophilia Data Managers Forum Group celebrates 10 years in existence this year with our initial launch meeting having been held in May 2005. Ten years on there are 51 Haemophilia Comprehensive Care Centres/Haemophilia Centres represented on this Group and many of the improvements in the data management of haemophilia have been borne from our bi annual meetings

At our latest meeting in April 2015, there was much discussion around the ongoing changes and improvements to all the systems (HCIS, NHD and Haemtrack). These systems are constantly being improved and none more than Haemtrack. At this meeting the Group were shown the new improvements currently under construction and future plans for this system. These include:

- Barcoding
- Auto-syncing
- Multiple User Accounts
- Telemedicine – video consultations
- Haemtrack App (improved security)
- Validation processes
- Stock wastage

The Group are also regularly updated with examples of how useful the Haemtrack data can actually be and are requested to assist in encouraging patients to use this system.

Another key focus for the Group this year has been the education of haemophilia data managers. It was highlighted through the Data Management Working Party that there was a lack of knowledge and understanding of the data being entered to the various systems. To address this, an education programme is currently under draft and almost ready for submission to a member of the Data Management Working Party for approval. This will then be incorporated into systems training days and hopefully compulsory for both new and existing data managers.

There is now a mentoring system in place for new haemophilia data managers whereby they pay an initial visit to the NHD office followed by a visit to another haemophilia ccc/centre to spend a day with an experienced haemophilia data manager. Thus affording them the opportunity to discuss any issues they may have within their post with regards to understanding what is required of them and facilitate a one to one tutorial for any of the systems they may be struggling with. The data manager can then call on this mentor for advice if encountering further problems or understanding with any of the systems once they have returned to their own centre.

The timeframe for commencing both these educational programmes is Spring 2016.

Sponsorship to facilitate meetings is currently problematic with many of the pharmaceutical companies unwilling or unable to assist with UK Data Managers Forum Group meetings. It is therefore proving a challenge to organise a two day meeting and we are currently dependant on guidance and assistance given by the UKHCDO Data Management Working Party and Advisory Committee.

Finally, on behalf of the group, I would like to thank SOBI for their sponsorship of our September 2014 meeting and Novo Nordisk for their partial sponsorship of the April 2015 meeting. Thank you to Professor Hay for his support and presentations at our meetings. Also, I would extend thanks to Drs Dolan, Keeling, Liesner and all members of the Data Management Working Party for ongoing support, advice, mentoring and encouragement.

Nancy Brodie  
Chairman, UK Haemophilia Data Managers' Forum  
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