

UK Haemophilia Data Managers Forum Group

Membership

The group currently has a membership of 89

Mission

The United Kingdom Haemophilia Data Managers Forum Group is a national group which strives to share information, whilst encouraging and supporting personnel involved in the collation and analysis of Haemophilia Data throughout the UK.

The UK Haemophilia Data Managers Forum Group has continued to support this mission statement throughout this year. Late 2013 saw a change in Office Bearers of this Group as voted by its members, Nancy Brodie returned as Chair and Lynne Dewhurst as Secretary.

Meetings

A meeting held in November 2013 identified a need to review and update our Terms of Reference within which the above mission statement is held and to which as a Group we continually strive to work. These updates were made and accepted in agreement with members of the Group and include:

- The term for elected Office Bearers simulates that adopted recently by UKHCDO. This has also been endorsed by UKHCDO via the UKHCDO Data Management Working Party.
- All finances shall be managed through UKHCDO Ltd in order to maintain transparency of the Group.
- All members should show mutual respect without bias to other members at all times.

Three meetings of this Group have been held over the past year. Consistent topics include but are not limited to:

- Updates on all current systems (NHD, Haemtrack and HCIS)
- Updates from relevant working parties
- Data Protection
- Home Delivery
- Haemnet

Attendance at these meetings has been very good with an average of 20+ members in attendance at each. This is especially encouraging in a year which has been yet again, very busy for data managers, not least with the recent tendering process for rFVIII concentrates and the requirements of information prior to and after the award of contract on 1st April.

Many interesting and pertinent presentations have been given at these meetings. Professor C Hay took time to give presentations at 2 meetings, discussing the NHD and updating the Group on some important work undertaken from this system. He also gave an update on the highlights from the UKHCDO Bleeding Disorder Statistics for 2012/13. Professor Hay was

very cognisant that little of this work could be produced without the input and hard work of the Haemophilia Data Managers.

Another informative presentation of note was given to the Group by Alison Greenwood from the Commercial Medicines Unit (CMU) updating on the national tender for clotting factor concentrates. This gave everyone a better understanding of why it was important to supply accurate figures in a timely manner.

In the year ahead this Group will continue to be all inclusive and support new and old members at all times. An education need has been identified and it is planned to initiate and take forward a grassroots training programme which will be for existing and new data managers; educating on all systems (NHD, Haemtrack and HCIS), as well as initiating a much needed mentoring programme for new Data Managers. This should create a better understanding of the role of the Data Manager on the relevance and necessity for accurate technical capability of the systems and data entry but equally important, create a better understanding of Haemophilia which, combining these areas, should assist in facilitating even better data collation and information transfer.

As always, the Group would like to extend thanks to sponsors whose funding has enabled the meetings to take place and Sarah Rooney for her very efficient organisation of these meetings on our behalf. Also, thanks to Dr Dolan and UKHCDO who continue to support this group (particularly Prof C Hay for the time he has spent presenting at our meetings), the Data Management Working Party for continued endorsement and guidance and finally Dr R Liesner for ensuring the Group complies with proper financial procedures.

Nancy Brodie – Chair
Lynne Dewhurst – Secretary
UK Haemophilia Data Managers Forum
September 2014