Haemtrack Group

Membership

Dr Gerry Dolan	Chairman
Ben Palmer	Secretary
Nancy Brodie	
Dr Elizabeth Chalmers	
Dr Pratima Chowdary	
Lynne Dewhurst	
Prof Charles Hay	
Dr Rob Hollingsworth	
Dr Lishel Horn	
Clare Ibbs	
Dr Ri Liesner	
Prof John Pasi	
Debra Pollard	
Antony Woolcomb	
Dr Hua Xiang	
Patient Representative (position currently vacant)	

Mission

To optimise the quality of the Haemtrack data and to direct the development and rollout of the system and the analysis of the data

Meetings

The full group met for the first time on 1st August 2014 though there had been earlier more limited meetings and conference calls to set the group up and start the ball rolling. The group is made up principally of centre directors with an interest in this area, Haemophilia Nurse Specialists, Physiotherapists and statisticians (Ben Palmer and Hua Xiang). This is a sub-group of the Data Management Working Party.

In the first meeting and previous conference calls, the group was principally concerned with reviewing the Haemtrack system as it currently exists, to review the questions asked by the software and to identify any ambiguity which may give rise to inconsistency in the way that patient enter data. This has been extensively discussed and two questionnaires have been devised and were reviewed, one for the patients and one for the centres. These will be sent out shortly.

Previously, it had been impossible for centres to review and amend incorrect data sent in by patients (usually batch or brand data). Recently, the software had been amended to permit centres to do this and it was necessary for centres to validate the data before it was uploaded. This seemed to be working well in pilot sites. There will be a two-phased approach, with non-HCIS centres getting it first, and HCIS centres getting it with the new version of HCIS.

Questionnaire

Debra Pollard, Lishel Horne, Ri Liesner and Antony Woolcomb drafted two questionnaires (one for patients and one for centre staff), which have been reviewed by the whole group. It was thought that the staff questionnaire would be purely electronic, whereas the patient questionnaire would have both electronic and paper versions. Not all questions would be relevant to both electronic and paper versions of the patient questionnaire. The electronic version could be attached to the Haemtrack website, although attaching it to the smartphone apps would be more complicated. Electronically, there are several things that can be done to capture patients. The aim of the questionnaires is to identify how the patients and centres use Haemtrack as a guide to its future management and modification.

Information Leaflets

Nancy Brodie, Charles Hay and Rob Hollingsworth have written a patient information leaflet, which will help patients understand the purpose of Haemtrack and how to use it. This is currently being reviewed by patients to ensure that is written at the right level and is understandable.

A similar leaflet is being written for centres but this will be finalised once we have analysed the results of the Centre Questionnaire. Almost all Comprehensive Care Centres (93%) are now using Haemtrack and almost 98% of eligible patients in those centres are registered. Uptake by patients registered to use Haemtrack by Haemophilia Centres is far lower, about half. Clearly many of these centres are not convinced of the value of the system or may not be staffed adequately to introduce it.

Consent

All patients give consent when they register with Haemtrack for the first time. This is done on-line. The consent and information leaflet in current use is heavily based on the Advoy leaflet, which went before. This is a rather legalistic document which is no longer considered fit for purpose and so it is being rewritten, to replace the current document within three months.

Data analysis

Hua Xiang PhD has been appointed as a data miner. She has been identifying a subset of Haemtrack data of good quality for further more detailed analysis. Some of this analysis is presented in the Haemtrack Report. The group is actively reviewing the possibilities for future analysis of this dataset.

Software Updates –Progress Implementation review

A barcoding app project is underway. Apple iOS has a built-in barcode reader for the iPhone, with free support. The android equivalent will follow.

Data validation has been implemented for all non-HCIS centres, and will follow for HCIS centres when they get the new version of HCIS (currently being piloted at RFH).

Data management skills education was discussed. A rolling step-by-step training and accreditation programme is required due to staff turnover.

The next meeting is planned for November.

Prof CRM Hay
October 2014
Manchester