Haemtrack Group

Membership

Dr Gerry Dolan	Chair
Mrs Nancy Brodie	
Dr Elizabeth Chalmers	
Dr Pratima Chowdary	
Ms Lynne Dewhurst	
Prof Charles Hay	
Dr Rob Hollingsworth	
Dr Lishel Horn	
Clare Ibbs	
Dr Ri Liesner	
Mr Enis Muminovic	
Mr Ben Palmer	
Prof John Pasi	
Mrs Debra Pollard	
Mr Antony Woolcomb	
Dr Hua Xiang	

Meetings

The Group met once in 2015 on 9th April 2015, having previously met on 1st August 2014. The next meeting is scheduled for 25th February 2016.

The group discussed the following issues:

Vision and Current Status:

It is intended that most patients with severe haemophilia and those with other severities or disorders on home therapy will use Haemtrack. Currently, about 2500 patients use Haemtrack. A strategy is being put in place to encourage further recruitment and to improve compliance amongst those using the system. A patient information leaflet has already been printed and distributed. It is important to emphasise the clinical utility of the system in providing data which can be used to optimise the patient's treatment and it is important that clinicians go over the records with the patients in the centre and in outpatients, as much as anything to demonstrate that the data is clinically useful and that this is not just an empty bureaucratic exercise.

A further strategy will be to develop a Haemtrack CQUIN to run from 2016-18. The details of this are currently being negotiated to include new funding for nursing staff to support the system, acknowledging that this can be a significant amount of work. It is envisaged that the CQUIN will be associated with a graded system of rewards to provide a direct incentive for centres to maintain Haemtrack usage and to improve both recruitment and compliance. This will be linked with the number of patients recruited and the proportion providing good quality data. It is hoped that, in the medium term,

Haemtrack will provide data to optimise patient treatment and illuminate variation in clinical practice linked with outcome.

Current Status of the Data and Compliance

A good deal of work are being done to analyse Haemtrack compliance and treatment patterns and outcomes in patients who are compliant with their record keeping. These are providing a valuable insight into centre to centre variation in treatment practice and treatment outcomes. This will be presented in detail in a forthcoming Haemtrack report. Good compliance (>75% of treatment reported) is found in about 50% of registrants. We would clearly wish to gradually improve on this proportion.

No consensus has been reached on the optimal approach to data validation at a centre level. Clearly, some centres use the data routinely for clinical management and, at the other extreme, others do not look at it at all, judged from the obvious errors slipping through and detected at the NHD level. Most obvious errors (e.g. wrong product, all entries including bleeds entered as prophylaxis, missing data etc.) would be obvious on cursory screening in clinic.

MDSAS are exploring automated validation and NHD attempt reconciliation between the Haemtrack record and the centre return.

Questionnaires have been developed By the Haemtrack Group (Pratima Chowdary, Lishel Horn, Anthony Woolcombe and Debra Pollard) for patients and clinicians, which will be issued shortly and which will give us further insight into the strengths and limitations of the system and ways in which it is used and permit the system to be used for ongoing clinical management as well as non-interventional research.

Clinical/Pharmacosurveillance studies

Haemtrack will be used as a tool for observational non-interventional studies investigating patient outcomes and quality of life, e.g. the ECHO registry. The use of this system rather than another one will minimise duplication of effort.

Technical development

A new and more complex "strong" password has been introduced. Whilst this may be regarded by many users as a nuisance and has led to some patients being "locked out" of their account, it is much more secure. Bar code reading has been introduced for Pfizer and Baxter products and MDSAS is working on the bar codes of other manufacturers. A new version of Haemtrack will soon be introduced and will include auto-synch and the ability to manage multiple accounts from one device (e.g. for parents with children).

Video consultation using Haemtrack is also being piloted and a project to introduce decision support for clinicians is being evaluated.

Professor Charles RM Hay
December 2015