

Data Management Working Party

Membership

Dr David Keeling (until 2016 AGM)
Dr Ri Liesner

Representing

Nancy Brodie	UK Haemophilia Data Managers Forum
Christina Burgess	The Haemophilia Society
Liz Carrol	CEO, The Haemophilia Society
Prof Peter Collins	Representing Wales / Chair Therapeutics Task Force
Lynne Dewhurst	National Haemophilia Database
Bartholomew Flynn	Patient Representative
Claire Foreman	NHS England
Emma Franklin	Haemophilia Nurses Association
Prof Charles Hay	UKHCDO Ltd & National Haemophilia Database
Dr Rob Hollingsworth	Medical Data Solutions and Services
Ben Palmer	Medical Statistician
Jane Pearson-Moore	NHS England
Dr Hua Xiang	National Haemophilia Database

UKHCDO Working Party Chairs

Dr Elizabeth Chalmers	Paediatric Working Party
Dr Gerry Dolan	Musculoskeletal Working Party
Dr Dan Hart	Inhibitor Working Party
Prof John Pasi	Genetics Working Party
Prof Mike Laffan	Von Willebrand Working Party

Meetings

The working party met on 29th January and 1st July 2016.

Activities

The UKHCDO Data Management Working Party (DMWP) remains the key group for overseeing all aspects of collecting and analysing data from patients with inherited bleeding disorders in the UK. The DMWP works closely with NHD to ensure that accurate and relevant data are collected from patients and centres. The work of the NHD is regulated by the Data Protection Act and is governed by the data Protection Officer for Central Manchester Foundation Trust. The range and quality of data collected have yielded important information about the patterns and intensity of treatment and have helped the Haemophilia Centres and commissioners understand and manage services.

The research potential of data generated by the National Haemophilia Database is clear. This remains an important function of NHD and this aspect of activity is overseen by the DMWP and by UKHCDO. There has been collaboration with the pharmaceutical industry. These projects have been limited to anonymised data mainly to help with regulatory requirements.

NHD data-analysis has been pivotal in convincing NHS England to allow introduction of new EHL products.

NHD continues to collect genetic mutation results from centres.

Adverse Events emails reminders are now going out.

Platelet aggregation results and platelet nucleotides can now be recorded on NHD.

Registration for VWD has been completely re-organised.

For severity classification of haemophilia, it has been agreed to use the ISTH classification.

Severe haemophilia	< 1
Moderate haemophilia	1 - 5
Mild haemophilia	>5 - <40

So patients registered as 1% would be classified as moderately severe

Haemtrack

A new CQUIN was negotiated between commissioners and clinicians. Identifying money that haemophilia centres don't already have:

For recruitment up to 50%	£12.000/year
For compliance >50% <70%	- £800/pt/year
Compliance >70%	- £6000/pt above 70%

For those already doing well, the middle payment will not apply. Baseline was taken at Q3 (Sept - Dec 2015).

The commissioners for England and the devolved countries of the UK fully support the use of Haemtrack as a means of capturing individual patient events and treatment. The goal is to have all patients on home treatment using this system. NHS England are making Haemtrack use a pre-condition for using EHL products.

IT update

HCIS: Version 2.1 of HCIS is currently in development with a number of updates to improve integration with NHD. Also included will be an interface to MyPKFiT (when activated in MyPKFiT). The Joint score form is again being updated in response to feedback

Haemtrack Redevelopment: The Haemtrack system now has over 850,000 treatment records on the system and 2751 patients registered. A new responsive website is in development which will enable use on all smartphone platforms, simplifying maintenance and also enabling clinician use on mobile devices. There is also the option of language translation.

Haemtrack Video Consultation - Haemtrack now has the ability for clinicians to hold patient video consultations within the Haemtrack system. The system also has the ability to be used as an educational tool with the possibility of recording consultations should this be required. Video consultations will now be trialled in a number of centres.

UKHCDO Website: A new UKHCDO website has been developed which uses new technologies to allow the NHD to directly maintain the content of the site without IT input. The new website will also display appropriately formatted on mobile devices.

UKHCDO owes gratitude to many individuals involved in the management of data from the UK. We wish to thank Professor Hay for managing the National Haemophilia Database on behalf of the UKHCDO. Thanks also to Rob Hollingsworth and MDSAS for their continued support and maintenance of our national information systems. Lynne Dewhurst, Ben Palmer, Katie Allen, Helen Brown, Rachel Lockwood, Sarah Rooney, Tom Sharpe, Jessica Broughton Smith and Hua Xiang of the National Haemophilia Database have been invaluable in their very high quality work on our behalf. We also wish to acknowledge all the important work done at the Centre level and for the support of all the patients for supporting this important work.

Dr David Keeling
Chair UKHCDO Data Management Working Party
Prof Charles RM Hay, Director NHD