

Data Management Working Party

Membership

Dr Gerry Dolan
Dr David Keeling

Nancy Brodie
Christina Burgess
Liz Carrol
Prof Peter Collins
Lynne Dewhurst
Claire Foreman
Emma Franklin
Prof Charles Hay
Dr Rob Hollingsworth
Dr Ri Liesner
Ben Palmer
Jon Currington
Vacant post

Representing

Co-Chair
Co-Chair

UK Haemophilia Data Managers Forum
The Haemophilia Society
The Haemophilia Society
Representing Wales
National Haemophilia Database
NHS England
Haemophilia Nurses Association
UKHCDO Ltd & National Haemophilia Database
Medical Data Solutions and Services
Invited Guest
Medical Statistician
NHS England
Patient Representative

UKHCDO Working Party Chairs

Dr Liz Chalmers	Paediatric Working Party
Dr John Hanley	Musculoskeletal Working Party
Dr Dan Hart	Inhibitor Working Party
Prof Mike Laffan	Von Willebrand Working Party
Dr Andrew Mumford	Rare Disorders Working Party

The UKHCDO Data Management Working Party has a key role in the organisation. The major part of the work of the NHD is the collection and analysis of data from the Haemophilia Centres in the United Kingdom and this is overseen by the working party. The aggregated national data are particularly important for national procurement and managing the subsequent contract. As well as phenotypic data, genotype data is being accrued at an impressive rate and will be particularly valuable in patient management and research. The NHD is undertaking a thorough review of the patient information leaflets so that patients remain fully informed about the NHD and the (anonymous) use of their data. We have to be careful when we debate what additional information would improve patient care and the Data Management Working Party remains committed to ensuring that outcome measures are relevant and manageable.

We recognise the demands for increased quality and volume of data and recognise the need for regular meetings for data managers to support and help them with the range of issues involved in collecting accurate data.

More detailed, patient generated, data is becoming available in greater quantity through Haemtrack which is now accessible on Android as well as iPhone. The Data Management

Working Party has set up a dedicated group (The Haemtrack Management Group) to explore these data.

The research and development activities of UKHCDO working parties requires close collaboration with NHD and the Data Management Working Party. An excellent example of this is the paper "Factor VIII brand and the incidence of factor VIII inhibitors in previously untreated UK children with severe haemophilia A, 2000-2011" published in Blood this year.

We would like to take the opportunity again to thank Professor Hay for managing the National Haemophilia Database on behalf of the UKHCDO and to Rob Hollingsworth and MDSAS for their continued support and maintenance of our national information systems. Lynne Dewhurst, Ben Palmer, Helen Brown, Rachel Lockwood, Sarah Rooney, Tom Sharpe, Jess Smith and Amy Tidmarsh and Hua Xiang of the National Haemophilia Database have been invaluable in their very high quality work on our behalf.

Finally, last but not least, we wish to acknowledge all the important work done at the Centre level and acknowledge work by individual patients and the Haemophilia Centre staff and we thank them for their tireless work in providing data for this very important resource.

Dr Gerry Dolan & Dr David Keeling
Chairs & Secretary, UKHCDO Data Management Working Party