

Data Management Working Party

Membership Representing

Dr Gerry Dolan	Co-Chair
Dr David Keeling	Co-Chair
Lynne Dewhurst	National Haemophilia Database
Emma Franklin	Haemophilia Nurses Association
Dr Charles Hay	UKHCDO Ltd & National Haemophilia Database
Dr Rob Hollingsworth	Medical Data Solutions and Services
Ben Palmer	Medical Statistician
Nancy Brodie	UK Haemophilia Data Managers Forum
Jon Currington	NHS England
Rachel Youngman	The Haemophilia Society
Vacant post	Patient Representative

UKHCDO Working Party Chairs

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

The UKHCDO Data Management Working Party has been particularly active this year. As in previous years, a major part of the work has been managing the collection and analysis of data from the Haemophilia Centres in the United Kingdom. The data quality has improved year on year and we wish to acknowledge the considerable effort from the Haemophilia Centre Data Managers and other staff as well as the staff at the National Haemophilia Database.

These aggregated data are very important for national commissioning. In an era when the whole of Health Service is coming under increased scrutiny, our UKHCDO data means that we are much better placed than other specialities to plan resources for health care and to develop initiatives that may improve the quality and cost effectiveness of care. This is illustrated in key data from the UKHCDO bleeding disorder statistics that will be presented at this meeting. One very important finding is that the consumption of factor concentrate has not increased in the past twelve months despite an increased number of patients being treated. This is a significant departure from all previous years where there has been a steady increase in the amount of factor consumed. Such data provide good evidence for commissioners and other interested stakeholders that we are continually assessing the care we provide and have been making efforts to contain or even reduce costs. These data will be used by bodies such as the CRG to develop policies in line with the strategy of NHS England and it likely that there will be much closer collaboration between NHD and the CRG in the next few years

For some time, we have realised that more detailed, patient generated data would add to the quality and relevance of NHD data. In this, the early promise of Haemtrack is now being realised and there is a considerable body of data that is available for analysis. The Data Management Working Party is setting up a dedicated group to take this work forward. The uptake of Haemtrack across the UK continues and this has been greatly facilitated by the availability of both iPhone and android apps.

The research and development activities of UKHCDO working parties requires close collaboration with NHD and the Data Management Working Party is the key governance body for this work and liaises closely with other Working Parties in key projects. Such examples are the UK Switching Study and the PUP Inhibitor Study currently undertaken by the Inhibitor Working Party which will be presented at the AGM.

Post marketing surveillance is increasingly recognised as an important way of generating evidence on safety and efficacy of therapeutic products used in bleeding disorders. Such studies can be cumbersome and extremely expensive to run on an international basis and for several years now the UK NHD has been closely liaising with pharmaceutical bodies and regulators to generate important data.

The Data Management Working Party remains very committed to developing relevant and manageable outcome measures for haemophilia care. In this respect they have been reviewing issues such as the collection and recording of data such as joint function and joint scoring and provide, as part of a routine collection of data, the resources necessary to complete the requirements for a national quality dashboard for haemophilia and to provide information for CQUIN measurement.

We recognise the demands for increased quality and volume of data and we offer a variety of resources to help data managers and other haemophilia centre staff who are collecting such information. For the next year and beyond we plan regular detailed programme of meetings with data managers to help with the range of issues involved in collecting accurate data.

The current configuration of the National Haemophilia Database has been a very significant step forward in generating quality data. This is recognised both nationally and internationally by a wide variety of healthcare professionals and commissioners. However, the continual improvements have now reached the stage where a major overhaul or re-write of the database is now required. It is agreed that we need to take this forward and over the next year there will be some detailed consultation with Haemophilia Centres and other stakeholders as to how this should be done.

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 of the National Haemophilia Database have been invaluable in their very high quality work on our behalf. We would like give thanks to John Currington and the commissioners of healthcare of the countries in the United Kingdom for their recognition

of the National Haemophilia Database as an important resource and for their continued support for this.

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
Co-Chairs, UKHCDO Data Management Working Party