Data Management Working Party

Membership

	Representing
Dr Gerry Dolan	Co-Chair
Dr David Keeling	Co-Chair
Mrs Nancy Brodie	UK Haemophilia Data Managers' Forum
Christina Burgess	The Haemophilia Society
Liz Carroll	The Haemophilia Society
Prof Peter Collins	Representing Wales
Lynne Dewhurst	National Haemophilia Database
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
Dr Ri Liesner	Invited Guest
Mr Ben Palmer	National Haemophilia Database, Medical Statistician
Dr Hua Xiang	National Haemophilia Database, Data Miner

UKHCDO Working Party Chairs

Dr Elizabeth Chalmers	Paediatric Working Party
Dr Dan Hart	Inhibitor Working Party
Prof Michael Laffan	Von Willebrand Working Party
Dr Andrew Mumford	Rare Disorders Working Party

The UKHCDO Data Management Working Party remains the key group for overseeing all aspects of collecting and analysing data from patients with inherited bleeding disorders in the UK.

Meetings

The DMWP met on 9th January and 10th July 2015.

Activities

Data Collection and Quality

The DMWP works closely with NHD to ensure that accurate and relevant data are collected from patients and centres. This has been an on-going process and feedback from data managers, commissioners, nurses, clinicians and NHD staff has been valuable in fine tuning the data collection tools.

We review and update the information that patients are given regarding the type of data that are collected and how it may be used. 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.

Development

There have been very major improvements in the range and quality of data collected over the past several years. These have yielded important data about the patterns and intensity of treatment and have helped the Haemophilia Centres and commissioners understand and manage services.

However it has been increasingly apparent that the lack of detailed, individual patient data has hindered the development of clear and relevant patient outcomes for Haemophilia. These are essential tools for assessing the quality and cost effectiveness of care. To address this, a self- reporting program for patients (Haemtrack) was developed several years ago. This has grown in range and detail and has the potential to greatly add to our understanding of haemophilia and its treatment. Smartphone Apps have been developed to aid input of data from patients. 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.

A Haemtrack Management Group has been established to oversee further development and analysis.

Consent

Following a consultation with commissioners the Data protection Registrar and members of the group, the consent leaflet was simplified, rewritten and a paediatric version produced approved, printed and distributed. A Haemtrack leaflet and on-line consent form were also written and distributed in hard copy and on line.

The information commissioner endorsed our "layered" approach to consent whereby further details were easily available on-line to those giving consent who wished to have greater detail.

Genotype Database

More than 1500 genotypes are now recorded in the genotypic section of NHD. It has also been agreed that centre directors should have access to the logged on genotypes for their own patients, though they will require a specific lo-on code. Furthermore, the data required for a successful search has been minimised to make searching easier and more likely to be effective, including a minimum of a name and date of birth, or NHS or NHD number, where available and the "centre where registered " field is now optional. Data from deceased patients may also be seen.

Adverse Event Reporting

The group wished to strengthen pharmacovigilance within the database. The system of reminders to report adverse events was reviewed. It was agreed to send out monthly reminders for adverse events. This has been piloted but has had a poor response. New questionnaires for intracranial haemorrhage have been developed. In addition, we also ask for reports of any new episodes of: - Inhibitors; Infection; Death; allergic or other acute events; malignancy; thrombosis, poor efficacy event; any other unusual adverse effect.

During the course of the year it has become necessary to renegotiate our contract with the Health and Social Care Information Centre (HSCIC) for mortality data. This is a complex and protracted process during which time they stopped sending us mortality data. Centres should inform NHD of the death of any patient with a bleeding disorder. Our data suggests that as few as 40% of such deaths are reported to NHD.

Research

The research potential of data generated by the National Haemophilia Database was recognised early after its inception. Since then, many UK studies on the epidemiology of haemophilia and its complications have made major contributions to the world literature on haemophilia. This remains an important function of NHD and this aspect of activity is overseen by the DMWP and by UKHCDO. Successful projects have been undertaken by the working parties, particularly the Inhibitor WP and the Paediatric WP. NHD also report and collaborate with National Institute for Health Research Clinical Research Network (NIHR CRN).

There has been collaboration with the pharmaceutical industry. These projects have been limited to anonymised data on real-life use or product-specific use to help with regulatory requirements. Protocols for these collaborations with industry have been reviewed by the group and agreed in principle.

As ever, 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, 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.

Finally, last but not least, we 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 Gerry Dolan & Dr David Keeling
Chairs & Secretary, UKHCDO Data Management Working Party
Prof Charles RM Hay, Director NHD