

Data Management Working Party

Membership

Chair: Professor Peter Collins

Commissioner representative: Will Horsley
Director(s) of the National Haemophilia Database: Professor Charles Hay
Data Managers' Forum representative: Lynne Dewhurst
Haemophilia Nurses Association representative: Emma Franklin
Haemophilia Physiotherapists Group representative: David Stephensen
Haemophilia Society representative: Liz Carroll
MDSAS representative: Dr Rob Hollingsworth

Patient representative: Barry Flynn

Representatives of Northern Ireland, Scotland and Wales:

Northern Ireland: Dr Gary Benson
Scotland: Dr Elizabeth Chalmers
Wales: Professor Peter Collins

UKHCDO Working Party Chairs:

Co-morbidities Working Party: Dr Rhona Maclean
Genetics Working Party: Dr Keith Gomez
Inhibitor Working Party: Dr Dan Hart
Musculoskeletal Working Party: Dr Pratima Chowdary
Paediatric Working Party: Dr Elizabeth Chalmers
Peer Review Working Party: Dr John Hanley
Von Willebrand Working Party: Prof Mike Laffan

UKHCDO Executive Committee:

Chair: Dr Ri Liesner
Secretary: Dr Kate Talks
(Other execs listed above)

Members of the NHD as nominated by the Director(s) of the National Haemophilia Database:

Working Party Secretary: Lynne Dewhurst
Ben Palmer
Dr Hua Xiang

Meetings

The UKHCDO Data Management Working Party (DMWP) met on 21st March 2019 (Manchester) and 20th Sept 2019 (London). The terms of reference for the Working Party are available on the UKHCDO website and have been reviewed.

The DMWP oversees all aspects of data collection and analysis of patients with inherited bleeding disorders undertaken by the National Haemophilia Database (NHD). The DMWP

and NHD are jointly responsible for the accuracy and completeness of the data collected. The DMWP has delegated most of the responsibility for assessing and overseeing requests for analysis of NHD data to the Data Analysis Group (DAG) which is a subcommittee of the DMWP.

The DMWP regularly reviews the information that is collected on patients and revises this as necessary. Any member of UKHCDO can suggest changes to the data that are collected and these will be considered by the DMWP. At present the way that platelet disorders are recorded is being updated and the NHD will start to collect limited information on gene therapy.

All members of UKHCDO are encouraged to suggest data analyses to the DMWP and DAG, this can be done by individual members or through UKHCDO Working Parties.

Examples of ongoing UKHCDO projects supported by NHD are:

- The Acquired Haemophilia A registry
- Real world experience of Emicizumab for people with and without inhibitors
- Immune Tolerance Induction registry
- Enhanced half-life factor VIII and IX registry
- Mortality in severe haemophilia

The DMWP and NHD are ensuring that the Infected Blood Inquiry has full access to the information held by the NHD along with any help in the interpretation of that data that is required by the Inquiry.

Consent to use data for research

The NHD has become a research registry after a successful application to ethics. This means that people on the database will be approached and asked whether they agree for their routinely collected information to be used for observational and epidemiological research. The consent process has been successfully trialled at a number of centres and will be rolled out to all centres soon. Signed consent forms can be uploaded through a Quick Response (QR) code and this system is working well.

Haemtrack

The Haemtrack system continues to expand with more patients registered and more treatments recorded. Commissioners for England and the devolved countries of the UK encourage the use of Haemtrack as a means of capturing individual patient events and treatment. This has allowed important information about the impact of enhanced half-life factor VIII and IX to be collated. The introduction of Emicizumab will be closely observed.

IT update

Centres can now record on HCIS whether a patient is taking prophylaxis and what the prescribed regimen is.

NHD aims to link with the WAPPS-Hemo (www.WAPPS-HEMO.org) population pharmacokinetics programme run by McMaster University. This link will allow centres to input 2-3 factor VIII or factor IX levels and receive an interactive read out that allows levels to be predicted at any time after an infusion. In addition, the effect of potential prophylactic regimens can be explored with patients to better optimise treatment. The system has the advantage that all concentrates, including enhanced half-life factor VIII and IX, can be used.

UKHCDO would like to thank many individuals involved in the work of the NHD. Professor Hay is the clinical Director of NHD and oversees its function on a day to day basis on behalf of UKHCDO.

The following people work for the National Haemophilia Database and have been invaluable in their very high-quality work collecting and analysing the data on our behalf.

Katie Allen
Liz Ardern
Helen Brown
Lynne Dewhurst
Rachel Lockwood
Ben Palmer
Sarah Rooney
Tom Sharpe
Hua Xiang

We also thank Rob Hollingsworth and MDSAS for their continued support and maintenance of our national information systems.

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.

Prof Peter Collins,
Chair UKHCDO Data Management Working Party

Prof Charles RM Hay,
Director NHD

September 2019