

Data Management Working Party

Membership

Chair:	Professor Peter Collins
Commissioner representative:	Will Horsley
Co-Director of the National Haemophilia Database:	Professor Charles Hay
Co-Director of the National Haemophilia Database:	Prof Pratima Chowdary
Data Managers' Forum representative:	Lynne Dewhurst
Haemophilia Nurses Association representative:	Emma Franklin
Haemophilia Physiotherapists Group representative:	David Stephensen
Haemophilia Society representative:	Role open at present
MDSAS representative:	Dr Rob Hollingsworth
Patient representatives:	Barry Flynn Paul Sartain
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 Susie Shapiro
Genetics Working Party	Dr Keith Gomez
Inhibitor Working Party	Drs Dan Hart and Charles Percy
Musculoskeletal Working Party	Prof Pratima Chowdary
Paediatric Working Party	Dr Elizabeth Chalmers
Peer Review Working Party	Dr John Hanley
Von Willebrand Working Party	Prof Mike Laffan
Unclassified Bleeding Disorder Working Party	Dr William Thomas
UKHCDO Executive Committee:	
Chair	Dr Ri Liesner
Secretary	Dr Kate Talks
Treasurer	Rachel Rayment
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 24th April 2020 (virtual) and 17th Sept 2019 (virtual). The terms of reference for the Working Party are available on the UKHCDO website and have been reviewed.

The DMWP oversees 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 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. Recently the way that platelet disorders are recorded has been updated. NHD has started to collect limited information on gene therapy.

Examples of current 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. In June 2020 UKHCDO received a rule 9 request from the Infected Blood Inquiry that asked for a number of statistical analyses to be reported. NHD staff have worked with UKHCDO to prepare the reports. This work is ongoing at present.

Haemtrack

Commissioners for England and the devolved countries of the UK continue to 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 and Emicizumab to be collated.

A group is being established to review the current version of Haemtrack and recommend whether any updates in functionality are required.

Pharmacokinetic analyses through NHD

A system has been developed whereby individual pharmacokinetic data can be entered through NHD into the WAPPs-Hemo system. This supports tailoring and personalisation of prophylaxis for individual patients. The system functions for all licensed brand of factor VIII and factor IX.

UKHCDO would like to thank many individuals involved in the work of the NHD. Professor Hay and Professor Pratima Chowdary are the clinical co-directors of NHD working on behalf of UKHCDO.

The following people work for the National Haemophilia Database and have been invaluable in their commitment to collecting and analysing the data on our behalf. Their role in supporting the aims of the Infected Blood Inquiry has been especially important.

Katie Allen	Andrew McNally
Liz Ardern	Ben Palmer
Lynne Dewhurst	Sarah Rooney
Mike Grove	Tom Sharpe
Rachel Lockwood	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
October 2020