

Data Management Working Party

Membership

Chair:	Dr Kate Talks
Commissioner representative:	Will Horsley
Co-Director of the National Haemophilia Database:	Professor Charles Hay
Co-Director of the National Haemophilia Database:	Professor Pratima Chowdary
Data Managers' Forum representative:	Lynne Dewhurst
Haemophilia Nurses Association representative:	Emma Franklin
Haemophilia Physiotherapists Group representative:	Dr David Stephensen
Haemophilia Society representative:	Kate Burt
MDSAS representative:	Dr Rob Hollingsworth

Patient representatives:	William McKeown Paul Sartain
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Representatives of Northern Ireland, Scotland and Wales:

Northern Ireland	Dr Gary Benson
Scotland	Dr Ryan Rodgers
Wales	Professor Peter Collins

UKHCDO Working Party Chairs:

Co-morbidities Working Party	Dr Susie Shapiro
Genetics Working Party	Dr Keith Gomez
Inhibitor Working Party	Dr Charles Percy
Musculoskeletal Working Party	Professor Pratima Chowdary
Paediatric Working Party	Dr Mary Mathias
Von Willebrand Working Party	Prof Mike Laffan (for Dr C Millar)
Laboratory Working party	Dr Vince Jenkins & Will Lester
Unclassified Bleeding Disorder Working Party	Drs William Thomas & Mike Desborough

UKHCDO Executive Committee:

Chair	Dr Ri Liesner
Secretary	Dr Susie Shapiro
Treasurer	Dr 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
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Meetings

The UKHCDO Data Management Working Party (DMWP) met on 17th Sept 2020 (virtual), 26th March 2021 (virtual) and 23rd September 2021 (virtual). The terms of reference for the Working Party were reviewed and are available on the UKHCDO website; in the course of the year there

have been a number of changes in roles and new members welcomed; the list provided reflects the current membership.

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 which will be considered by the DMWP. The NHD information governance arrangements were assured by NHS Digital in September 2020 and compliance against the standards within the NHS Data Security Protection Toolkit have been met for 2020/21. Over the last year the application process for the NHD to collect, hold and process mortality data from death certificates has continued with NHS Digital (England and Wales) and the relevant authorities in Scotland and Northern Ireland. New patient information leaflets have been developed to reflect the changes.

Recently an Adverse Events Panel has been established to support the consistent and timely assessment of all Adverse Events (AE) reported electronically to the NHD. The panel meets monthly and is co-chaired by the NHD directors with additional UKHCDO members providing representation from EUHASS and the paediatric and inhibitor working parties. Summary reports are provided to the DMWP and included in the annual NHD report.

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
- The previously untreated patient (PUP) registry

The DMWP and NHD have made all data held by the NHD available to the Infected Blood Inquiry. In April 2020 the NHD/UKHCDO received a Rule 9 request asking for detailed statistical analyses of the data held. Work on the report in response to the request has continued through 2021 with submission anticipated within the next few weeks.

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 Haemtrack user group was established in early 2021 to review the current version of Haemtrack and recommend whether any updates in functionality are required. This work is still ongoing.

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.

The UKHCDO would like to thank the many individuals involved in the work of the NHD including Professor Charles Hay and Professor Pratima Chowdary, the 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

Liz Ardern

Lynne Dewhurst

Mike Grove

Rachel Lockwood

Andrew McNally

Ben Palmer

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

Dr Kate Talks,
Chair UKHCDO Data Management Working Party
October 2021