

Data Management Working Party

Membership

Chair:	Professor Peter Collins
Commissioner representative:	Will Horsley
Director(s) of the National Haemophilia Database:	Professor Charles Hay
Data Manager Forum representative:	Nancy Brodie
Haemophilia Nurses Association representative:	Emma Franklin
Haemophilia Physiotherapists Group representative:	David Stephenson
Haemophilia Society representative:	Liz Carroll
Haemtrack User Group Chair:	Dr Gerry Dolan
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:

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

UKHCDO Executive Committee:

Chair	Dr Ri Liesner
Secretary	Professor Mike Laffan (Other execs listed above)

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

Working Party Secretary	Lynne Dewhurst
	Bruce Cowen
	Ben Palmer
	Dr Hua Xiang

Meetings

The UKHCDO Data Management Working Party (DMWP) met on 9th December 2016 (London) and 12th May 2017 (Manchester).

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 regularly reviews the information that is collected on patients. Any member of UKHCDO can

suggest changes to the data that are collected and this will be reviewed by the DMWP. The terms of reference for the Working Party have been revised and formalised recently.

The DMWP and NHD are jointly responsible for the accuracy and completeness of the data collected. The work of the NHD is regulated by the Data Protection Act. A review of the NHD by the Central Manchester Foundation Trust Caldicott Guardian took place on the 24th August 2017.

The NHD has been receiving an increasing number of requests for data analyses from the NHS, members of UKHCDO and pharmaceutical companies. In order to deal with these requests in a timely fashion and to provide more detailed oversight of data analyses and reports a Data Analysis Group (DAG) has been established. The DAG is a subgroup of the DMWP and meets monthly, a separate report is provided.

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 registry
- Immune Tolerance Induction registry
- Enhanced half-life factor VIII and IX registry
- Mortality in severe haemophilia

Haemtrack

The Haemtrack system continues to expand with more patients registered and more treatments recorded. A paper describing the introduction of Haemtrack has been accepted by Haemophilia (Hay et al. The Haemtrack Home-Therapy Reporting System: design, implementation, strengths and weaknesses: a Report from UKHCDO.)

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. The goal is to have all patients on home treatment using this system. NHS England made Haemtrack use a pre-condition for using enhanced half-life products. Haemtrack is the subject on an ongoing CQUIN in England with the aim of increasing its use.

Haemtrack Video Consultation - Haemtrack has the ability for clinicians to hold patient video consultations within the Haemtrack system. This can be accessed through “clive.mdsas.com”

IT update

Version 2.1 of HCIS has been rolled out to all users.

The Haemophilia Joint Health Score form has been updated in response to feedback.

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

It is planned that the database will be re-written over the next few years to ensure ongoing functionality. This will be a major undertaking jointly performed by NHD and MDSAS.

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
Helen Brown
Bruce Cowen
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 2017