

Data Analysis Group

Membership

Co-Chair (Chair of Data Management Working Party)	Professor Peter Collins
Co-Chair (Director of NHD)	Professor Charles Hay
User representatives:	Ros Cooper Paul Sartain
UKHCDO members:	Dr Elizabeth Chalmers Dr Pratima Chowdary Dr Dan Hart Dr Ri Liesner
Haemophilia Nurses and physiotherapy representatives:	Simon Fletcher David Stephenson
National Haemophilia Database:	Bruce Cowen Lynne Dewhurst Ben Palmer Dr Martin Scott (observer) Dr Hua Xiang

Meetings

The Data Analysis Group (DAG) is a subgroup of the Data Management Working Party. Its role is to assess and prioritise applications to analyse data held by NHD, including Haemtrack and joint score data. Applications are assessed based on data governance considerations, scientific merit and available resources. The group has met monthly since April 2017.

Requests for analyses are submitted on a standardised form. This form has been revised and updated and is available from NHD.

The DAG reviews and discusses all applications. It provides feedback to the applicant and works with them to refine the proposal, if necessary. The contributions from the user representatives have been particularly useful in assessing the applications.

Requests for data analyses have been submitted by individual members of UKHCDO, UKHCDO working parties, NHS England and pharmaceutical companies.

Projects that have been reviewed include

Project outline	Applicant
Enhanced half-life concentrate registry	UKHCDO project
Uptake of Elocta in England	Separate requests were submitted by NHS England and SOBI
Mortality in severe haemophilia	Individual member of UKHCDO
Obizur post-marketing surveillance	Shire
Unmet needs in haemophilia (Thunder study)	Roche
ReFacto AF PUP surveillance	Pfizer
Impact of revised classification of von Willebrand disease	VWD Working Party
Demographics and treatment of Von Willebrand disease in the UK	Shire
Health economics analysis of osteoporosis in haemophilia	HCD Economics (University of Chester)
Comparison of multidisciplinary team staffing between CCCs	Individual member of UKHCDO
Evaluation of Haemophilia Networks and Pathways of Care Delivery	Individual member of UKHCDO
UKPK study	Individual member of UKHCDO on behalf of study team

The DAG has recommended revision of some analyses before agreeing for them to proceed. This has ensured that accurate analyses are done and appropriate conclusions drawn. In some cases further discussions have taken place between members of NHD or UKHCDO working parties and the applicant to clarify and refine projects and to take them forward. When analyses are completed they are reviewed by DAG before being released and in some cases have been revised at this stage.

All members of UKHCDO are encouraged to suggest analyses and are invited to collaborate with the DAG on these projects.

Prof Peter Collins,
Chair UKHCDO Data Management Working Party

Prof Charles RM Hay,
Director NHD

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