Data Management Working Party

Membership

Dr Gerry Dolan	Chairman
Lynne Dewhurst	Secretary and NHD
Dr Charles Hay	UKHCDO Chairman
Dr Rob Hollingsworth	Software Engineer, MDSAS
Nicola Howe	Pan Thames Haemophilia Consortium
Mr Christopher James	The Haemophilia Society
Prof Christopher Ludlam	Invited member
Sue Mather	Commissioner
Mr Ben Palmer	Research Analyst Statistician

Working Party Chairmen

Dr Julia Anderson	Dental Task Force
Dr Paula Bolton-Maggs	Transition Task Force
Nancy Brodie	UK Haemophilia Data Managers Forum
Ms Helen Child	Patient Representative
Dr Peter Collins	Inhibitor Working Party
Emma Franklin	Haemophilia Nurses Association
Dr Mike Makris	Morbidity & Mortality Working Party
Prof John Pasi	Genetics Working Party

Remit

The working group oversees the management and activities of the National Haemophilia Database and has special responsibility for the development of the database and the information systems comprising the national health informatics strategy for haemophilia.

The group met three times during the year, in Manchester.

This year has been very busy for NHD and for the Data Managers and staff of the UK Haemophilia Centres and on behalf of the UKHCDO Data Management Working Party, I wish to convey my thanks to the hard work and commitment of all those involved.

THE NATIONAL HAEMOPHILIA DATABASE

Data Collection

This year has seen a great improvement in the timely return of the required quarterly data from centres. We greatly appreciate the effort from centres to achieve this. Looking towards next year's data collection this trend continues with almost all the data returned already for the first quarter. The timely return of quarterly data has enabled us to use this data to accurately monitor the National Procurement Framework Agreement enabling swift actions be made to ensure compliance within the Framework.

Additional data collection exercises continue and a great deal of effort has been made to reduce the burden of required data entry for centres. This effort has resulted in changes to the hepatitis C look-back data collection exercise and also the proposal for the genetic laboratories to enter mutation data required for the genetics module of the NHD. Looking forwards, for the collection of required outcome data we hope to make in-depth use of the data entered by patients into the HAEMTRACK patient home therapy system, this will require very little input from centres thus minimising workload. The first report from the HAEMTRACK system is included in Appendix 3.

We will continue to work hard where possible to minimise the amount of additional data required by NHD, though it should be noted that in some instances we are mandated to collect data by the Department of Health and Commissioners. NHD continues to work with the UK HDMF to improve the experience and communication of data collection exercises.

NHD encourages suggestions for additional reports and figures for the annual report. Likewise requests for data from the NHD by individuals or organisations can also be made; a formal mechanism for this exists and can be accessed from the UKHCDO website (http://www.ukhcdo.org)

The 2011 NHD data set is shown in Appendix 4.

Patient Registration Card

The national patient registration card is now 'live'. A number of centres volunteered to pilot the card and we are very grateful for their time and input. Centres will receive the blank card stationary from the NHD and the stationary allows direct printing by inkjet or laser printer onto the laminated card. New software on the NHD website facilitates the printing of the card and flexibility has been built-into the design to allow changes to the information on the card should this be required over time.

UKHCDO Health Informatics Strategy

In the previous year the health informatics strategy received two key awards, winning the 'Excellence in Major Healthcare IT Development' – E-Health Insider award and a medal (top three in the country) for 'UK Public Sector Project of the Year' at the UK IT Industry Awards.

Development of the strategy continues apace to meet the changing needs of service developments, ever changing IT technologies (such as video conferencing) and UKHCDO working party projects.

Key areas of development for the NHD website during the past year include the new 'Bleeding Disorders Card', 'Inhibitor Surveillance project' and the 'Hepatitis C look-back project'. The Bleeding Disorders Card software is now 'live' on the NHD website.

Working party projects have been a key source of development activity. A new genetic mutation portal is under final development and will enable genetic laboratories to enter and review mutations on the NHD. Significant work is also underway for the new clinical outcomes group to ensure a standardised national approach across all IT strategy systems, and the adoption of new functionality such as the recording of joint health, quality of life and home treatment records.

New IT applications nearing release include the web-enabled version of HCIS. This is scheduled to begin piloting in November and uses the very latest technologies such as Microsoft Silverlight to enhance the user interface and reporting functionality. The HAEMTRACK iPhone application, following approval by 'Apple', is due for release in the spring and will offer patient's the ability to record their treatment on the move, integrating directly with the central HAEMTRACK database, together with functionality to identify the nearest treatment centre to the patient's location.

The HAEMTRACK system continues to be very successful with nearly eight hundred patients registered (mostly severe) across thirty two sites, and over eighty thousand treatment entries recorded. New functionality for the HAEMTRACK system is currently being investigated including the ability to hold patient consultations via video-link, dosing compliance features etc. If you are not already using the HAEMTRACK system we would strongly recommend its use, to register for the system simply contact the NHD on nhd.support@nhs.net.

National Procurement

NHD continues to work successfully in partnership with the Department of Health and the Commercial Medicines Unit (CMU) to monitor the national framework agreement. Monitoring of this procurement agreement, which continues to secure substantial savings, is a significant exercise for NHD and UKHCDO. As part of this exercise NHD provides regular updates to Commissioners and Centres on the progress of the Agreement.

Clinical Outcomes group

This group under the chairmanship of John Pasi has developed proposals for collecting clinical outcome measures on patients. It is proposed that such data will be collected through a number of mechanisms including Haemtrack and HCIS. A short report is included following this report and will be presented by John Pasi at the AGM.

Hepatitis C projects

Skipton Fund Payments

NHD continues to provide support for individuals and haemophilia centre staff to assist with claims for ex gratia payments following the changes in the criteria announced by the Skipton Fund.

HCV look-back Exercise

This project commissioned by the Department of Health following the Archer report has been under way for some time now and is a major data collection exercise. A number of changes have been made to the project to ease the burden of reporting for centres. A status report is included in Appendix 2.

Penrose Inquiry

This inquiry has been set up in Scotland to examine the circumstances surrounding the transmission of HCV by coagulation factor concentrates. In relation to this exercise the NHD has been working hard this year to enter historic paper-based centre submissions from the 1970s into the national database, this work has now been completed.

Other Projects

Inhibitor Surveillance

Several changes have been made to the dataset for inhibitor surveillance. The key aspects were to collect key data on treatment up to 50 exposure days on all patients and to collect data quarterly. Data collection has been slow and a review of this is under way.

Switching Inhibitor Surveillance

The project is gathering data now and an initial project report has been produced. In the long-term it is hoped the data from the project will provide information as to the equivalence of clotting factor products.

Interaction between the National Haemophilia Database and the National Institute for Health Research (NIHR) portfolio study (Comprehensive Clinical Research Network)

NIHR Comprehensive Clinical Research Network (CCRN) is one of eight NIHR Networks. The CCRN is made up of 25 Comprehensive Local Research Networks (CLRNs). There have been discussions between DMWP and NIHR to develop a role for NHD in advising on clinical studies related to haemophilia in the UK. It has been suggested that NHD could identify eligible patients and at which centre they are registered and also disseminate information about new studies registered in the UK. There are on-going discussions about implementing these proposals.

Haemophilia Centre Audit

Significant updates are currently being made to the Haemophilia Centre Audit Pro-forma. Facility is to be provided for patient representation at the audit and changes are being made to the patient satisfaction survey. It is hoped that all the changes will be in place for the next audit round.

The possibility of including non-comprehensive Haemophilia Centres in future audits is currently being evaluated.

UKHCDO Website

The UKHCDO website continues to be maintained at http://www.ukhcdo.org. The website has the facility to advertise Haemophilia related vacancies. If you have any vacancies you wish to advertise (free of charge) please contact support@ukhcdo.org.

NHD Support

To contact the NHD a central support point is available for routine enquiries, telephone 0161 277 7991 or email support@UKHCDO.org.

I would like to pay tribute to Charlie Hay, Lynne Dewhurst, Rob Hollingsworth and colleagues and to all Haemophilia Centre Data Managers for their enormous efforts to maintain, develop and extend the UKHCDO database which remains the most comprehensive haemophilia database available.

Dr Gerry Dolan
Chairman, Data Management Working Party
October 2011