Data Management Working Party

Membership

Dr Gerry Dolan	Chairman
Dr David Keeling	Co-Chairman
Lynne Dewhurst	Secretary & National Haemophilia Database
Emma Franklin	Haemophilia Nurses Association
Dr Charles Hay	National Haemophilia Database
Dr Rob Hollingsworth	Software Engineer, MDSAS
Nicola Howe	Pan Thames Haemophilia Consortium
Chris James	Haemophilia Society representative
Sue Mather	North West Specialised Commissioning Team
Ben Palmer	Research Analyst Statistician
Heather Williams	UK Haemophilia Data Managers Forum
Vacant position	Patient Representative

UKHCDO Working Party Chairmen

Dr Peter Collins	Inhibitor Working Party
Dr John Hanley	Musculoskeletal Working Party
Dr Mike Makris	Morbidity & Mortality Working Party
Prof John Pasi	Genetics Working Party
Prof Mike Laffan	Von Willebrands Disease Working Party
Dr Andrew Mumford	Rare Bleeding Disorders Working Party
Dr Elizabeth Chalmers	Paediatric 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 in Manchester since the last AGM.

Once again this has been a very busy year 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 for all the hard work and commitment of all those involved.

The new commissioning arrangements will bring many changes for NHD. Having consistently lobbied with commissioners to minimise duplication of effort by harmonising their and our data requirements, it seems very likely that from 2013, NHD will be collecting CQUIN data for the National Commissioning Board. These changes also bring changes in funding. A large proportion of our funding comes from SCGs that are about to be replaced by a National Commissioning Board. We will have to apply to this new body to provide funding for the database. This clearly brings much uncertainty.

The National Haemophilia Database

Data Collection

We greatly appreciate the effort from centres to achieve the timely return of nationally requested data. The timely return of quarterly data has this year enabled us to produce the annual report earlier and to use the data to accurately monitor and inform the National Procurement Framework Agreement which is on-going. It has also been noted that there has been an improved response time to NHD when data queries are raised and this is also very much appreciated, especially given the existing Haemophilia Centre workload.

The Outcomes Group finalised the desired objectives for data required to quantify patient outcomes. It is clear that some of this data collection, especially joint scoring and quality of life assessments, will have resource implications for centres and this will need to be closely monitored. Hopefully, since both are to be CQUINs in 2013/14, such resources will be made available, where required.

The HAEMTRACK patient home therapy system is continuing to thrive with almost 150,000 individual patient treatments now recorded. It is envisaged that this will prove a valuable data source for outcome data. *This is described more fully in the HAEMTRACK report: Item 4 of this report*

As always we will continue to work hard where possible to minimise the amount of additional data required by NHD and to avoid duplication of effort, 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 try to work with the UK Haemophilia Data Managers Forum (UK HDMF) to improve the experience and communication of data collection exercises and encourages the UK HDMF to meet two to three times per year.

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). On this occasion, the previous report and the content of this current report were reviewed through a series of conference calls with DMWP members and stakeholders. We are very grateful to the participants in those calls for their helpful comments and suggestions. The 2012 NHD dataset is available on the UKHCDO website (http://www.ukhcdo.org)

The Patient Registration Card

The national patient registration card has now been rolled-out to all centres and on the whole has been a great success. In the past year there have been a number of changes to the card content in response to feedback from Haemophilia Centres. The registration card must be printed from the NHD website and is populated from the NHD. This has resulted, as envisaged, in a significant increase in patient registrations and requested patient data updates (e.g. levels) to the NHD. Some Centres have reported issues with the ink on the card becoming faded and thus a plastic cover has been sourced to seal the cards.

The Patient Information Leaflet

The patient information leaflet was reviewed this year in consultation with all stakeholders, including the Haemophilia Society. The patient information leaflet is regularly reviewed in response to database changes.

Projects

Hepatitis C 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. In partnership with DH, the data to be collected was reviewed and reduced to facilitate the progress of this exercise, which had been progressing very slowly. The exercise is still on-going and the work of Haemophilia Centres to collate and supply the data requested is very much appreciated. It is anticipated that this data collection will continue for a further year. A status report is included as item 3 of this report

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 switching project has more or less completed gathering data now and an initial project report has been produced. A report for publication is in preparation. Data collection to investigate risk-factors for inhibitor development is on-going.

UKHCDO Health Informatics Strategy

The ability to collect ever increasing amounts of data now relies more than ever on the UKHCDO informatics strategy. Development of the strategy continues apace to meet the changing needs of service developments, ever changing IT technologies and UKHCDO working party projects.

HAEMTRACK:

The HAEMTRACK system continues to be very successful with nearly thirteen hundred patients registered (mostly severe) across thirty nine sites, and almost one hundred and fifty thousand individual treatment entries recorded.

The HAEMTRACK iPhone application was launched in summer and has received universally positive feedback from patients. Following its launch over 180 patients (17% of all HAEMTRACK users) adopted the application almost immediately. It is hoped to launch applications for other mobile platforms in the coming year. Pilots have been developed for Home Delivery / Patient Stock Management and Video Consultation in the HAEMTRACK system and it is hoped they will go-live in the coming year.

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.

Web HCIS:

The web-enabled version of HCIS is scheduled to begin piloting in November/December, with a pilot centre already identified to evaluate newly implemented Haemophilia Centre network management functionality. The system uses the very latest technologies such as Microsoft Silverlight to enhance the user interface and reporting functionality.

Adverse Events Reporting:

The data collected by the UKHCDO Adverse Events System has been unified with the EUHASS Reporting System. Centres reporting adverse events to the NHD and wishing to submit to EUHASS do not now need to re-enter the data onto the EUHASS system. This reduces data entry burden for Haemophilia Centres. All adverse events have been unified, except inhibitors which are undergoing final review before implementation.

Genetic Mutation Portal

The genetic mutation portal has been slightly delayed whilst it undergoes final testing by laboratory personnel. It is hoped that this will be completed and rolled-out very shortly, with laboratories entering mutation data through the NHD portal.

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. This will also form the basis for the next contract, to be negotiated in 2013/14.

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.

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

The work between NIHR and NHD continues and is viewed by both organisations as a very successful and beneficial exercise. A survey of Haemophilia Centres has been conducted to identify Haemophilia Centres that carry out clinical trials, in order to inform and direct clinical trials recruitment more effectively.

Haemophilia Centre Audit

Significant updates to the Haemophilia Centre Audit Pro-forma are currently being finalised. Work has also been undertaken with the Haemophilia Society to enhance participation of patient auditors and to develop an online patient survey has been developed.

A pilot-audit using the new processes has been carried out and this was very successful.

UKHCDO Website

The UKHCDO website continues to be maintained at http://www.ukhcdo.org. UKHCDO welcomes suggestions for additional contents on the website.

NHD Support

To contact the NHD a central support point is available for routine enquiries, telephone 0161 277 7991 or email support@UKHCDO.org. Confidential patient enquiries can be sent from a NHS.net email account to NHD.Support@nhs.net.

Data Protection

The NHD in-line with Data Protection requirements is a consented database that is regularly inspected by the Caldecott guardian to ensure that it meets all requirements in relation to the Act.

The National Information Commissioners Office (ICO) has also reviewed the NHD and advised on required consent measures which have been adopted by the NHD. These have included the production and regular review of a patient information leaflet.

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
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