

### **What are my rights under the data protection act (1998);**

In the past, information on standard patient treatments was collected for administrative, audit and research purposes without informing the patient. In recent years, however, the use and storage of such information has been increasingly regulated by successive Data Protection Acts, to prevent misuse of data and possible breakdown in confidentiality. The current Data Protection Act (1998) governs the retention of electronic records of any personal information, which can be traced in any way to an individual either by their name or number or other identifier. According to the act, you must be informed of the sort of personal data that is held on computer and the purpose for which it is held. You have the right to ask that some or all of your data be removed from the database by applying to the database (see below for contact details). This is an opt out rather than an opt in system. You also have the right to request a copy of your entry in the database for a statutory fee of £10, laid down by the act. Applications, with proof of identity should be sent to Lynne Dewhurst, NHD Administrator (see below). Further details of this process are also available on our website [WWW.UKHEDO.org](http://WWW.UKHEDO.org)

### **What should I do if I have concerns about the database?**

You should meet with your local haemophilia centre director or specialist nurse to discuss the database further or take up the matter by writing directly to the database itself C/O Ms Lynne Dewhurst, NHD Administrator, National Haemophilia Database, University Dept of Clinical Haematology, Manchester Royal Infirmary, Oxford Road, Manchester M13 9WL.  
[lynne.dewhurst@cmmc.nhs.uk](mailto:lynne.dewhurst@cmmc.nhs.uk)

### **Why we hope that you will agree to your data being included in the database.**

The National Haemophilia Database is vital for continued delivery of high quality haemophilia care and improvements in the service. Competition for funding within the health service has never been fiercer, whereas the cost of haemophilia care has increased more than a hundred fold in the past 20 years, more than doubling in the last three years alone. We need this information to continue to negotiate with commissioners for improvements in treatment and to help commissioners to plan for haemophilia services year on year. It also helps us to improve treatment by gaining a better understanding of bleeding disorders through clinical research into bleeding disorders, their management and complications.

Dr CRM Hay Chair UKHEDO

Dr G Dolan Chair Data Management Working Party - January 2007.

### **A word from the Haemophilia Society: -**

The Haemophilia Society is strongly supportive of the work of the UKHEDO in developing and sustaining the National Haemophilia Database. Storing your medical data in this centralised manner will not only benefit individual patients but also the whole bleeding disorders community, as it will enable a whole host of data analysis and research to be done.

Roddy Morrison, Chairman of the Haemophilia Society  
January 2007



# **The National Haemophilia Database**

## **Your Questions Answered**

**A leaflet for patients and their relatives**  
From the UK Haemophilia Centre Doctors' Organisation (UKHEDO)

## What is the national Haemophilia Database and what is it used for?

The National Haemophilia Database (NHD) is a register of patients with bleeding disorders living in the UK, which was originally established in Oxford in 1968. This database collects data from haemophilia centres that are required by the Department of Health and Commissioners. The NHD provides invaluable information with which to negotiate for improvements in the haemophilia service that will in turn lead to improvements in patient care. The data is also essential for healthcare planning, useful for national audit and research (but not clinical trials). The data used for these purposes is presented as anonymous group-reports and cannot therefore be traced back to individual patients.

## What sort of information is collected?

We collect information on patient diagnosis, date of birth, GP code, NHS number, the types and amounts of treatment used to treat bleeding, and the risk-factors for some complications of treatment, such as inhibitors and transfusion reactions and thrombosis, basic data on HIV infection but not currently hepatitis. We have recently started to collect data on potential exposure to variant Creutzfeld Jacob disease (vCJD) so that this potential risk can be properly evaluated. We also collect information on causes of death in patients with bleeding disorders. We are required to collect this data by the Departments of Health of England, Scotland, Wales and Northern Ireland and by local health Commissioners (representatives of local health authorities who "commission" and pay for specific services for patients). A complete list of all the data we collect can be viewed on the UKHCDO website: [WWW.UKHCDO.org](http://WWW.UKHCDO.org)

## What information will be kept in the future?

In the future, with changes in the nature and organisation of Haemophilia Services and advances in treatment, we will need to keep more detailed information on basic treatment of bleeding, treatment outcome and the natural history of haemophilia. We also wish to collect more information on the treatment of two major complications of haemophilia of recent years, inhibitors and hepatitis C. This will help advance the understanding and treatment of these conditions and in turn improve the standard of care. This information is vital when negotiating for adequate resources for your treatment and care.

## What types of reports are produced from the database and who has access to these?

A national audit report is currently produced annually though we may report some treatment data more frequently in future. All data in the report is anonymous group-data and cannot be traced back to individual patients. The report summarises national trends on bleeding disorders, their treatment and complications. This report is made available to UKHCDO members, the Haemophilia Society, Department of Health, Commissioners, Health Authorities and Industry. The main tables and charts from this report may be viewed on the UKHCDO Website [WWW.UKHCDO.org](http://WWW.UKHCDO.org). Additional specialised reports and patient treatment guidelines from UKHCDO are written by UKHCDO Working Parties and published regularly in medical journals. Information in all these reports is anonymous and there is no information traceable to individual patients. These publications are intended both to improve our understanding of bleeding disorders and to improve patient care. These publications are listed on the UKHCDO website: - [WWW.UKHCDO.org](http://WWW.UKHCDO.org).

## Can information about me be used for research?

The research and clinical audit conducted by UKHCDO using the National Haemophilia

Database requires only anonymous data and does not involve any change in the patient's treatment e.g.: reviewing the risk factors for inhibitor development or the age and cause of death in haemophilia. Research of this sort does not require the patient to be identified in any way and does not require specific consent. Informed consent is required if you are to participate in a clinical trial or medical research study where your treatment may be changed and where identifiable personal data may be used. Medical research of this sort is governed by ethical rules and regulated by hospital and national ethical committees and national regulatory bodies. On the rare occasions when UKHCDO conduct such a clinical trial, informed consent would be obtained from participants in the usual way.

## Who manages the database?

The database is managed by the Data Management Working Party of UKHCDO. This group includes a haemophilia patient representative and a Haemophilia Society representative along with representatives from the Haemophilia Nurses Association, Commissioners from two Health Authorities, an IT consultant and the chairmen of the UKHCDO working parties. The group is chaired by the Vice Chair of UKHCDO.

## How is patient confidentiality guaranteed?

Absolute patient confidentiality is extremely important. This is a "named database" in which we store data on named individuals identified also by their NHS number. The data is stored in a secure office in Manchester Royal Infirmary in accordance with security standards laid down by the Data Protection Act (DPA) of 1998. The National Haemophilia Database is inspected regularly to confirm that its procedures comply with DPA and Caldicott Legislation.

Data is collected electronically from haemophilia centres using an encrypted link within the NHS network, protected from the world wide web and incorporating a number of other security features to ensure security of the data in transit. This is actually far more secure than a paper system or the post. The combination of passwords, encryption and other security features provide a much higher level of security than normal e-mail, internet shopping or even internet banking.

Information with the patient's name or NHS number (named data) is only shared with the patient's own haemophilia centre. Haemophilia centres can only access data on their own patients. Even for family tracing they are only told which haemophilia centre to approach for further information. No outside agency is permitted identified or "named" data on any individual patient. Reports from the database always use anonymous data that cannot be traced back to individual patients.

## Why not just collect anonymous data?

The Data Protection Act (1998) defines "named data" as any data identified in any way that can be traced back to the patient. This includes not only the patient's name but also their NHS number. We have a duty to maintain as accurate a database as possible and maintaining a named database enables us to cross check data and to avoid double counting of patients attending more than one centre. It is very common for patients with bleeding disorders to attend at least two centres and some individuals have been registered over the years with up to seven centres around the country. Without a named database, these patients would be counted multiple times and have multiple unconnected records instead of one record going back sometimes as far as 1969. Having a named database also permits us to provide patients with extracts of their own data.