

Patient Broadcast: The National Haemophilia Database (NHD) has been granted Section 251 Support for the purpose of using patient data for research and non-research purposes.

The UK National Haemophilia Database (NHD) was established in 1968 and holds information on people registered with a bleeding disorder within the United Kingdom (UK). It contains details of more than 40,000 people, both alive and deceased. The NHD is managed by the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO), an association of doctors who work within the Haemophilia Centres in the UK and have an interest in the care of people with inherited bleeding disorders. UKHCDO is the data controller and processor and determines the purpose and means of processing the personal data collected.

The NHD serves two important purposes: non-research activity which involves regular reporting to the NHS to support disease monitoring and healthcare planning, for example, assessment of current and future needs, and the safety, and effectiveness of treatment. Secondly, research into bleeding disorders and their complications to understand the natural history of these conditions and the outcomes of treatment. The data is collected from haemophilia centres and from the Haemtrack home therapy recording system which can be used to improve future care. Some information such as name, date of birth, NHS number, diagnosis, disease severity, date, and cause of death are collected and the reason these are collected is given below:

- NHD registration number - used to link an individual to the death certificate
- NHS number- used to identify the person with a bleeding disorder and perform linkage to the certificate
- Forename - to help confirm the identity of the individual (complementary to or in absence of NHS number)
- Surname - to confirm identity of individual (complementary to or in absence of NHS number)
- Date of birth - to calculate age at the time of diagnosis and age at the time of death

The information listed above is shared with NHS Digital to obtain information on causes of death. NHS Digital use this information to provide the NHD with death certification information, including the date and cause of death. NHS Digital can provide NHD with mortality data on behalf of the Office for National Statistics (ONS) and is sourced from civil registration data. This information may be shared in the form of anonymised aggregated reports for both research and non-research purposes with other organisations, such as the Department of Health, NHS England and Wales, Scotland and Northern Ireland, Health Protection Agency, Pharmaceutical companies, and the Drug Regulators e.g., the Medicines and Healthcare products Regulatory Agency and the European Medicines Agency.

UKHCDO have obtained support under section 251 of the NHS Act from the Department of Health and the Health Research Authority to collect, store and process patient data without consent. When a person recorded in the database with a bleeding disorder dies the NHD can be notified of the details such as the date and the cause of death, without obtaining informed consent. For further information on Section 251, please follow the HRA link here: [Section 251 Support Frequently Asked Questions](#)

The NHD is held on a secure system and can only be accessed by authorised personnel and is fully compliant with data protection legislation and NHS standards. All data that is shared with any third party is anonymised to avoid identification of any individual. Your data will be kept no longer than is necessary.

You have the right to 'opt-out' at any point without having to give a reason. To opt-out of your data being used for research activity of the database, contact the NHD to request a Patient Opt-out form, using the contact details below. Follow this link to the National Data Opt-Out service to opt-out of your confidential data being used for research and planning in England: <https://www.nhs.uk/your-nhs-data-matters/>.

For comprehensive detail on patient information please use the following website link to our Privacy Policy: <http://www.ukhcdo.org/patient-information/>.

National Haemophilia Database contact details

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Email address: support@ukhcdo.org Phone number: 0161 277 7991

Title: UK National Haemophilia Database - Research Registry – Broadcast – Section 251 and Mortality Data		
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