Request for Analysis from the National Haemophilia Database

Your application will be reviewed by the UKHCDO Data Analysis Group (DAG) who meet monthly. The DAG is a subgroup of the Data Management Working Party (DMWP) and will be take responsibility for the validity of analyses undertaken. The DAG will consider proposed analyses and advise on methodology, feasibility and likely timelines of the proposal.

All analyses will be performed by DAG members and NHD staff and no external agent will have access to National Haemophilia Database (NHD) / Haemtrack data.

Analyses will be interpreted and publications developed by the DAG either alone or in collaboration with the applicant as agreed in advance. The final decision to publish analyses of NHD / Haemtrack data will remain with UKHCDO.

Data collection and availability

National Haemophilia Database *(Haemophilia Centre-reported products issued to people with bleeding disorders)*
The NHD collects data on diagnosis, management and complications of people with congenital or acquired bleeding disorders in the UK (https://www.ukhcdo.org/wp-content/uploads/2020/09/NHD_HT-Data-Set-2020.pdf). NHD data is collected on a quarterly basis and is available for analysis 4 months following the end of the quarter.

Haemtrack Data *(self-reporting treatment)*
Haemtrack is a home therapy reporting system completed by, or on behalf of, people with bleeding disorders (https://haemtrack.mdsas.com/). The majority of Haemtrack users have severe haemophilia A or B. Haemtrack data is available for analysis one month after entry. Haemtrack does not document untreated bleeds.

Important: Haemtrack compliance is tested by comparing product usage as reported through Haemtrack with product issues reported by centres to the NHD. Therefore, any analysis requiring the use of Haemtrack data from compliant Haemtrack users will necessitate waiting for the equivalent NHD data to be available.

* Required

Applicant Details

1. Name of applicant *

2. Job title

3. Organisation name *

4. Address

5. Post code

6. Telephone

7. Email *

Project Details

8. Project Title *

9. Aims and objectives of proposed analysis *

10. Please state proposed hypothesis, if applicable.

11. Please state intended beneficiaries of the proposed analysis *

12. Please provide subject inclusion criteria and categorisations e.g. age, gender, bleeding disorder diagnosis (e.g. haemophilia A, haemophilia B, Von Willbrand disease, other (please specify)), severity/ factor level, inhibitor status etc. *

13. Please specify required study period (NHD data is available at quarterly level or higher, e.g. calendar year(s), financial year(s), and Haemtrack data is available at weekly level or higher. All analyses require a lag of three months for data submission and cleaning, e.g. data to 31st March 2023 is available for analysis from July 2023.

    *

14. Please provide an outline of the requested data and/or analyses (e.g. market share, treatment patterns (issues, dosage, infusions per week), bleeding rates and other outcomes). Please also describe requested groups for sub-analysis (e.g. in terms of diagnosis, severity, age group, product subtype etc) *

Report Delivery Information

15. Do you require clinical interpretation? *

- ◯ Yes
- ◯ No

16. Further bespoke requirements for the report

17. Additional Comments

18. Desired Delivery Date *

19. Please explain why the report is desired by the above date, including any implications if this timeline is not met *