**Request for Analysis**

**from the**

**National Haemophilia Database**

**Please complete sections 1 to 14 and return to**

**Lynne Dewhurst**

**National Haemophilia Database**

**City View House**

**Union Street**

**Ardwick**

**Manchester**

**M12 4JD**

**or email** [support@ukhcdo.org](mailto:support@ukhcdo.org)

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| --- | --- |
| Reference |  |
| Date received |  |
| Status |  |

# Date of application 06/03/2018

# Applicant Details

|  |  |
| --- | --- |
| Name |  |
| Job title |  |
| Organisation name |  |
| Address |  |
| Post code |  |
| Telephone |  |
| Email |  |

# Project Title

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# Purpose and justification for the analysis

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# What is your hypothesis?

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# Who will benefit from this analysis?

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# Areas required for analysis (examples are shown on the last page)

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# Inclusion criteria (please select criteria below, if additional criteria are required use the text box to specify)

HAEMOPHILIA A

HAEMOPHILIA B

VWD

INHIBITORS

OTHERS (Rarer Disorders)

SEVERE  MODERATE  MILD

< 18  ≤ 18  >18

0 : 4

4 : 9

10 : 19

20 : 29

30 : 39

40 : 49

50 : 59

60 : 69

70+

**Study Period:**

Apr 2016 to Mar 2017

Apr 2015 to Mar 2016

Apr 2014 to Mar 2015

Apr 2013 to Mar 2014

Apr 2012 to Mar 2013

OTHER Click or tap here to enter text.

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# Final Product (select one)

DATA ONLY

DATA WITH STATISTICAL ANALYSIS

DATA WITH STATISTICAL ANALYSIS & CLINICAL INTERPRETATION

# Are the results of the analyses intended for publication, if so where? (N.B. no results to be made public without prior agreement of UKHCDO)

NO

YES, AND WILL BE PUBLISHED IN THE FOLLOWING JOURNALS:

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# Bespoke requirements for the report

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# Additional Comments

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# Date report required 01/01/2018

# Explain why the data is required by a specific date and what are the implications if your date is not met

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**Additional Information**

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 patients)*

The NHD collects data on diagnosis, management and complications of all UK patients with congenital or acquired bleeding disorders. NHD data is collected on a quarterly basis and is available for analysis 4 months following the end of the quarter.

***Haemtrack Data*** *(patient reported treatment)*

Haemtrack is a home therapy reporting system. The majority of Haemtrack users have severe haemophilia A or B. Haemtrack data is available for analysis one month after entry.

***Important***: In order to measure compliance, Haemtrack records are compared 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.

**Examples of available analyses**

1. Market share of products (anonymised and your own product), e.g. quarterly, six monthly or yearly.1 or 2.
   1. Break down by severity, i.e. severe and moderate1 or 2
   2. Break down by treatment type, i.e. on-demand and prophylaxis2
2. Demographics of patients (the whole and/or your own product). 1 or 2
   1. Number of patients by severity1 or 2
   2. Number of patients by age group (>=18 and <18, if not specified) 1 or 2
3. Treatment patterns by product type (e.g. standard rFVIII and or your own product) 2
   1. Aggregated dosage per treatment by treatment type 2
   2. Aggregated weekly usage 2
   3. Aggregated number of infusions per week2
4. Annualised bleeding rates (your own product) 2
   1. Break down by severity and/or age group (>=18 and <18, if not specified) 2
   2. Break down by treatment regimen, i.e. on prophylaxis and on-demand2

1 NHD data

2 Haemtrack data