# National Haemophilia Database Dataset

**Information required to:**

**Register a Patient:**

NHS number
NHD number
Forenames(s)
Surname
Previous surname
Date of birth
Gender
Post code
GP practice code
Usually resident overseas (yes/no/unknown)
Date first seen
Reason seen (diagnosis/registration/clinical assessment/other)
Clinical bleeding history (no/yes/unknown)
Home delivery provider
Diagnosis
Factor Levels

**Amend patient details:**

Forename
Surname
NHS number
Postcode
DOB
Factor (type/denominator/level/units)
Genetic mutation known/date
GP practice code
Other

**De-register a patient:**

NHD number
NHS number
Forename
Surname
Date
Reason (transferred/lost to follow up/diagnosis is no longer current/moved away)

**Adverse Events Reports:**

Death event:

NHS number
NHD number
Forename
Surname
Date of death
Cause of death

Other Adverse Events, including HIV_transmission, Hepatitis B transmission; Transfusion reaction; Non-A, Non -B or Hepatitis C transmission, Thrombotic Event/DIC report; Other Event

NHS number
NHD number
Forename
Surname
About the event:
Event date
Details of transmission

**New inhibitor:**

NHS number
Forenames
Surname
Date of birth
Hospital record number
Reporting consultant details:
Title (Mr/Mrs/ Miss/Ms/Dr/Prof)
Forename (initials)
Surname
Treatment details:
Coagulation disorder
Severity (lab details) – (percentage)
Genotype (if known)
Relatives with inhibitors (Yes/No)
Details of above
First inhibitor detection date
Reason for test (routine screen/surgery/post response)
Inhibitor potency (Bethesda units):

Anti human:

- Date of first detection
- Value at first detection
- Date of maximum value
- Maximum value

Anti porcine:

- Date of first detection
- Value at first detection
- Date of maximum value
- Maximum value

Any change in baseline VIIIC or IXC? (Yes/No)
Has there been any change in bleeding pattern? (Yes/No)
Treatment before inhibitor development (none/routine on-demand/routine prophylaxis/intensive)
Time interval between first replacement and the development of the inhibitor (months/weeks/days)
Treatment days before inhibitor development

## Clinical studies

### First 50 exposure days

NHD no
Ethnicity
Factor Levels
- Type
- Level
- Units

Family History of inherited bleeding disorders
Screened at Birth: Yes/No
- If no, age at diagnosis: Months

Pregnancy and Delivery

Born at obstetric unit affiliated to Haemophilia centre: Yes/No
Gestation at delivery: Weeks
Mode of delivery
Duration of labour (if known): Hours

Pre-Natal History

Cranial USS performed?
If yes, what age performed?
Indication
Period end date
Has the patient received any vaccinations in the last period?
- If yes which ones?

Bleeds

Total number of bleeds in the period for the following: Haemarthrosis, Other Bleeding (definite or suspected)
If bleeding, provide details:
USS Result: Normal/Abnormal If abnormal, provide details:
Vitamin K given?
Route: IM/IV/PO
Breast Fed?
Prophylaxis with factor concentrate following delivery?
Indication: Preterm/Routine/Trauma
Comments:
Bleeding during 1st month of life?
Severity of bleed

*All patients with severe haemophilia over the age of 10 who have up to 50 exposures will have the following data requested on a 3 monthly basis:*

Period start date
Soft tissue Mucosal (minor bleeds), intracranial or other life-threatening bleed (specify)

Exposure days

Day number
Date
Product Name
Dose (IU)
Weight (Kg)
If surgery was it by continuous infusion?
Was extravasation possible?
Intercurrent Infection:Yes/No

**vCJD patient exposure assessment form**

Name
NHD number
Date of birth
NHS number
Date first seen
Centre
Risk status:

Did the patient receive ANY UK sourced pooled factor concentrates or Antithrombin between 1980 and 2001? (Yes/No)

Details of product and volume received:

Brand
Batch number
Release date
First dose
Last dose
Total dose

Has the patient asked to know if they received the implicated batch(s)? (no/yes/unknown)

Date patient notified
Assessor's name
Date of assessment

**Hepatitis C Look-back Exercise**

Has the patient been exposed to plasma components, platelets or red cells prior to September 1991? (Yes/No)

Has the patient been treated with clotting factor concentrates prior to 1988? (Yes/No)

Is the patient still alive? (Yes/No)

What is the result of the hepatitis C test?

| | |
|---|---|
| Antibody | Unknown<br>+ve<br>-ve |
| Antigen/HCV RNA/HCV PCR | Unknown<br>+ve<br>-ve |

Where did the patient contract the infection?

England
Scotland
Wales
N. Ireland
UK
Non-UK

| | |
|---|---|
| Has Hepatitis C (HCV) been resolved? | Spontaneously<br>Following treatment<br>No |

| | |
|---|---|
| Hepatitis C Genotyping | 1a<br>1b<br>2<br>3<br>4<br>5<br>Unknown |
| What was the result of the patient's most recent liver function test? | |
| | Unknown<br>Normal<br>Abnormal |
| Cirrhosis | Yes<br>No<br>First Date (Year) |
| Liver failure | Yes<br>No<br>First Date (Year) |
| Hepatocellular carcinoma | Yes<br>No<br>First Date (Year) |
| Liver transplant | Yes<br>No<br>First Date (Year) |
| Treated for Hepatitis C | Yes<br>No |
| What was the outcome? | Successful<br>Unsuccessful<br>On-going<br>Pending |
| What was the treatment? | Interferon<br>Interferon + Ribivarin<br>Peginterferon +Ribavarin |
| Is the patient still under regular review at your centre? | |
| | Yes<br>No |

Comments

### Inhibitor Surveillance Data Collection

Test date
Was this done via a screening method? (Yes/No)
What was the result of the screening method test? (Positive/Negative)
Was this test done via a quantitative method (e.g. Bethesda, Nijmegen modified?) (Yes/No)
What assay was used?
What was the result of the test?
Does your Centre consider the result above to be Positive or Negative?
Next test date

## Quarterly Treatment Returns Data

Every quarter Haemophilia Centres are required to submit information to the National Haemophilia Database about the treatment issued to patients, including products delivered to the patient's home. The following information is collected:

### Quarterly Returns Information

Patient information:

Post code
GP practice code
NHS number
Patient's weight
No longer seen date
Mutation (unknown/no/yes/pending)
Inhibitor known
Year detected
Current inhibitor
Patient receives home delivery (Yes/No)
Home delivery provider
Patient has died (Yes/No)
Date of death

Specific information for haemophilia A and B:

Severity
Ethnicity
If the patient has had surgery with 2 or more nights as an inpatient – type of surgery; continuous infusion; total product usage for the first 2 weeks post-surgery
Family history of an inhibitor in a first degree relative
Malignancy diagnosed in this quarter
Auto-immune disease diagnosed in this quarter
Interferon received in this quarter

Treatment details

Name of product
Number of units issued

Visitor information

Name
DOB
NHD number
Diagnosis
Product
Units

Product usage per diagnosis

Diagnosis
Product name
Total usage