

Date 22/08/2025  
Your Ref  
Our Ref 10373

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Dear

## FREEDOM OF INFORMATION – HAEMOPHILIA

I write in response to your request for information in relation to Haemophilia.

### Question:

1. In the past 12 months [latest 12 months available], how many patients have been diagnosed with the each of the following conditions in your Trust:
  - a. Haemophilia A
  - b. Acquired Haemophilia A (AHA)
  - c. Congenital Haemophilia A with inhibitors (CHAwI)

### Answer:

a.	5<
b.	5<
c.	5<

### Question:

2. In the last twelve months[latest 12 months available], how many pts with Haemophilia A, have been treated with each of the following products in your Trust:
  - a. Factor Eight Inhibitor Bypass Activity (FEIBA)
  - b. Hemlibra (standalone)
  - c. Hemlibra in combination with NovoSeven RT
  - d. Hemlibra in combination with Cevenfacta
  - e. NovoSeven RT
  - f. Obizur
  - g. Cevenfacta

### Answer:

a.	5<
b.	39
c.	5<
d.	5<

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Chair Professor John Connaghan CBE  
Chief Executive Professor Caroline Hiscox  
*Lothian NHS Board is the common  
name of Lothian Health Board*

e.	5<
f.	5<
g.	5<

Question:

3. In the last twelve months[latest 12 months available], how many patients with Acquired Haemophilia A, have been treated with each of the following products in your Trust:

- a. Factor Eight Inhibitor Bypass Activity (FEIBA)
- b. NovoSeven RT
- c. Obizur
- d. Cevenfacta

Answer:

a.	5<
b.	5<
c.	5<
d.	5<

Question:

4. In the last twelve months[latest 12 months available], how many pts with Congenital Haemophilia A with Inhibitors have been treated with each of the following products in your Trust?

- a. Factor Eight Inhibitor Bypass Activity (FEIBA)
- b. Hemlibra (standalone)
- c. Hemlibra in combination with NovoSeven RT
- d. Hemlibra in combination with Cevenfacta
- e. Hemlibra in combination with FEIBA
- f. Helimbra in combination with Factor VIII
- g. NovoSeven RT
- h. Obizur
- i. Cevenfacta

Answer:

a.	5<
b.	7
c.	5<
d.	5<
e.	5<
f.	5<
g.	5<

h.	5<
i.	5<

Question:

5. What is the total Prothrombin Complex Concentrate usage in International Units (IUs) for your Trust over the last 12 months [latest 12 months available] for each of the products below in your Trust?

- a. Prothromplex
- b. Beriplex
- c. Octaplex

Answer:

a.	Nil
b.	33,000 internal Units
c.	Nil

Question:

6. Can you share the Prothrombin Complex Concentrate usage in International Units for your Trust in the last 12 months [latest 12 months available] within each of the following departments, and which PCC is used?

- a. Prothromplex
- b. Beriplex
- c. Octaplex

Answer:

We cannot answer this as the issues were all made to the blood bank / blood transfusion service. They may have record of what they use where, and they may also acquire products from other sources – if so, then if our figures are included in final response, there is a potential for duplication. I am not sure if there are multiple pathways for purchase of these products through the organisation.

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the tables above. Since we do not have their consent to release this data from their records, the information is exempt under section 38(1)(b) of the Freedom of Information (Scotland) Act i.e. to provide it would breach the Data Protection Act (2018).

I hope the information provided helps with your request. I am sorry we cannot help further with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at [www.itspublicknowledge.info/Appeal](http://www.itspublicknowledge.info/Appeal). If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

**ALISON MACDONALD**  
**Executive Director, Nursing**  
Cc: Chief Executive