

Date 28/04/2025
Your Ref
Our Ref 9954

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION – HAEMOPHILIA A

I write in response to your request for information in relation to haemophilia A.

Question:

1. How many haemophilia A patients are registered with your centre, and how many of these patients are classified as exhibiting mild, moderate, or severe disease.

Answer:

Mild	72
Moderate	16
Severe	56

Question:

2. In the last three months, how many Haemophilia A patients, including on-demand patients, have been treated with the following products?

Answer:

- Altuvect – 5<
- Advate - 15
- Adynovi – 5<
- Elocta – 5<
- Esperoct - 20
- Factor Eight Inhibitor Bypass Activity (FEIBA) – 5<
- Hemlibra (Emicizumab) - Standalone - 28
- Hemlibra (Emicizumab) in combination with any Factor VIII - 8
- NovoEight – 5<
- NovoSeven RT – 5<
- Nuwiq – 5<
- Obizur – 5<
- Refacto AF – 5<
- Any other products – 5<

Headquarters
Mainpoint
102 West Port
Edinburgh EH3 9DN

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

- Hympavzi (Marstacimab) – 5<
- CEVENFACTA – 5<

Question:

- For patients treated with Advate in the last three months, please provide:

Answer:

- The number of haemophilia A patients treated prophylactically – 5<
- The number of haemophilia A patients treated for any other reason (e.g. surgery, on-demand, breakthrough bleeds) - 11

Question:

- In the last three months, how many patients were treated with the following products for severe Haemophilia A ONLY?

Answer:

- Altuvect – 5<
- Advate - 8
- Adynovi - 5<
- Elocta – 5<
- Esperoct - 15
- Factor Eight Inhibitor Bypass Activity (FEIBA) – 5<
- Hemlibra (Emicizumab) - Standalone - 28
- Hemlibra (Emicizumab) in combination with any Factor VIII - 8
- NovoEight – 5<
- NovoSeven RT – 5<
- Nuwiq – 5<
- Obizur – 5<
- Refacto AF – 5<
- Any other products – 5<
- Hympavzi (Marstacimab) – 5<
- CEVENFACTA – 5<

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the table 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.

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. 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