

Dear

FREEDOM OF INFORMATION – PRESCRIBING

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

Question:

- In the past 3 months [latest 3 months available] how many patients have received the following treatments [for any disease]:
 - Berinert (Human C1-esterase inhibitor)
 - Cinryze (Human C1-esterase inhibitor)
 - Orladeyo (Berotralstat)
 - Takhzyro (Lanadelumab)
 - Ruconest (Recombinant human C1-esterase inhibitor)
 - Firazyr (Icatibant injection)
 - Icatibant - any brand except Firazyr

Answer:

January 2026 - March 2026	
Medication	Patient Count
Berinert (Human C1-esterase inhibitor)	Information Unavailable
Cinryze (Human C1-esterase inhibitor)	5<
Orladeyo (Berotralstat)	0
Takhzyro (Lanadelumab)	6
Ruconest (Recombinant human C1-esterase inhibitor)	0
Firazyr (Icatibant injection)	0
Icatibant - any brand except Firazyr	11

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).

Question:

2. In the past 3 months how many patients have received the following treatment for any disease:

- Octagam
- Gamunex
- Intratect
- Kiovig
- Gamten
- Panzyga
- Xembify
- Cuvitru
- Cutaquig
- Hyqvia

Answer:

January 2026 - March 2026	
Medication	Patient Count
Octagam	0
Gamunex	41
Intratect	0
Kiovig	33
Gamten	86
Panzyga	5
Xembify	28
Cuvitru	13
Cutaquig	10
Hyqvia	0

Question:

3. In the past 3 months, how many patients have received any immunoglobulin treatment for the following diseases:

- Primary immunodeficiency (PID)
- Secondary immunodeficiency (SID)
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Answer:

I am advised we cannot link medicines supply data to the indication for treatment.

Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form



and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

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