

Date 04/12/2025  
Your Ref  
Our Ref 10801

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Dear

## FREEDOM OF INFORMATION – PRIMARY IMMUNODEFICIENCY

I write in response to your request for information in relation to Primary Immunodeficiency.

### Question:

1. The number of unique patients with a recorded diagnosis of Primary Immunodeficiency (PID) in Q3'25(July, August, and September 2025)
  - a. Of these PID patients, what is the number of PID patients treated with Immunoglobulin in Q3'25(July, August, and September 2025) If possible, segment patients by brand used e.g 5 patients on Cuvitru
  - b. How of these Ig treated PID patients are naïve (new starts) in Q3'25(July, August, and September 2025)?
2. The number of unique patients with a recorded diagnosis of Secondary Immunodeficiency (SID) in Q3'25(July, August, and September 2025)
  - a. Of these SID patients, what is the number of SID patients treated with Immunoglobulin Q3'25(July, August, and September 2025) If possible, segment patients by brand used?
  - b. How of these Ig treated SID patients are naïve (new starts) in Q3'25(July, August, and September 2025)?
3. The number of unique patients with a recorded diagnosis of Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) in Q3'25(July, August, and September 2025)
  - a. Of these SID patients, what is the number of CIDP patients treated with Immunoglobulin Q3'25(July, August, and September 2025) If possible, segment patients by brand used?
  - b. How of these Ig treated CIDP patients are naïve (new starts) in Q3'25(July, August, and September 2025)?

### Definition: (ICD Codes)

For reference, the following ICD-10 codes apply to the indications listed above:

Primary Immunodeficiency (PID): D80 (Immunodeficiency with predominantly antibody defects)

Secondary Immunodeficiency (SID):

- D84.81 (Immunodeficiency due to conditions classified elsewhere)
- D84.821 (Immunodeficiency due to drugs)

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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*

- D84.822 (Immunodeficiency due to external causes)
- D84.9 (Immunodeficiency, unspecified)

Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP): G61.8 (Other inflammatory polyneuropathies)

**Answer:**

As advised previously, this level of detail requested is not held in a centrally extractable format. 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.

**Question:**

4. The number of immunoglobulin vials/volume in grams distributed to NHS Lothian in each month for July, August, and September 2025, broken down by product (see below). I would also like to request the number of patients NHS Lothian by brand if available
- Vigam
  - Flebogamma DIF
  - Gammaplex
  - Gamunex-C
  - Octagam
  - Gamten
  - Kiovig
  - Intratect
  - Privigen
  - Iqymune
  - Gammanorm
  - Subcuvia
  - Subgam
  - Hizentra
  - Hyqvia
  - Cuvitru
  - Panzyga
  - Xembify
  - Cutaquig
  - Yimmugo
  - Vyvgart (Efgartigimod) (if available)

Answer:

Medication	July 2025 - September 2025								
	Patient Count	July Number of Dose Units Issued	Total Volume Issued (g)	Patient Count	August Number of Dose Units Issued	Total Volume Issued (g)	Patient Count	September Number of Dose Units Issued	Total Volume Issued (g)
Vigam	0	0	0	0	0	0	0	0	0
Flebogamma	5<	5<		0	0	0	0	0	0
Gammaplex	0	0	0	0	0	0	0	0	0
Gamunex	10	50	790	14	66	1010	11	71	1120
Octagam	0	0	0	0	0	0	0	0	0
Gamten	6	34	455	14	74	1085	18	118	1875
Kiovig	19	71	1165	24	133	2055	28	111	1885
Intratect	0	0	0	0	0	0	0	0	0
Privigen	46	197	2945	42	158	2650	25	140	2090
Iqymune	0	0	0	0	0	0	0	0	0
Gammanorm	0	0	0	0	0	0	0	0	0
Subcuvia	0	0	0	0	0	0	0	0	0
Subgam	0	0	0	0	0	0	0	0	0
Hizentra	8	117	332	6	112	288	5<	8	32
Hyqvia	0	0	0	0	0	0	0	0	0
Cuvitru	10	106	488	7	40	224	6	99	428
Panzyga	0	0	0	0	0	0	0	0	0
Xembify	12	212	636	7	130	318	16	297	955
Cutaquig	10	122	408	5<	24	112	6	64	220
Vyvgart	0	0	0	0	0	0	0	0	0

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](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