

Dear

FREEDOM OF INFORMATION – HEREDITARY ANGIOEDEMA

I write in response to your request for information in relation to hereditary angioedema in NHS Lothian.

Question:

Please provide the following data for the Royal Hospital for Children and Young People, Edinburgh.

1. Total patients with hereditary angioedema (HAE, ICD-10-CM D84.1) were registered at the institution as of the end of June 2026?
2. How many patients were:
 - a) types 1
 - b) type 2
 - c) type 3 (normal C1 inhibitor)
3. How many patients in each age range:
 - a) <12 years
 - b) 12-18 years
 - c) 19-45 years
 - d) >45 years
4. How many were:
 - a) male
 - b) female

Answer:

The information is not collected centrally. This is because diagnosis coding is not applied to outpatient appointments on our electronic system. Information may be held in individual patient records, but in order to provide the information you request it would be necessary to review each patient record over the period you have specified, requiring significant resources. Under section 12 of the Freedom of Information (Scotland) Act 2002, NHS Lothian is not required to respond to your request if the resources required to do so equate to more than £600 in cost.

Coding is recorded for some emergency attendances and inpatient admissions. There has been no recorded diagnosis coded ICD10 code D84.1 for any emergency attendances, and since 1 January 2025 there have been fewer than 5 inpatient admissions with this diagnosis. I am not able to provide the exact number, or break this down as requested, as this information could lead to the identification of the individuals involved. Since we do not have their consent to release their personal data, the information is exempt under section 38 of the Freedom of Information (Scotland) Act 2002 as to provide it would breach the principles of the Data Protection Act 2018.

Question:

5. Volume of medication dispensed and/or consumed from January 1st to June 30th, 2026, for each product below. If it is more convenient to specify the number of vials, pre-filled syringes, or tablets, that would also be very helpful.

List of Medications:

lanadelumab (Takzhyro - SC)
 pdC1-inhibitor (Cinryze - IV)
 pdC1-inhibitor (Berinert - IV and SC)
 rC1-inhibitor (Ruconest - IV)
 icatibant (Firazyr and generic - SC)
 berotralstat (Orladeyo cap)
 sebetralstat (Ekterly cap)
 garadacimab (Andembry - SC)

Answer:

The information you have requested is detailed in the table below:

Patient treatment, 1 January – 30 June 2026, NHS Lothian	
Medication	Dose unit issued
lanadelumab (Takzhyro - SC)	0
pdC1-inhibitor (Cinryze - IV)	0
pdC1-inhibitor (Berinert - IV and SC)	≤5
rC1-inhibitor (Ruconest - IV)	0
icatibant (Firazyr and generic - SC)	0
berotralstat (Orladeyo cap)	0
sebetralstat (Ekterly cap)	0
garadacimab (Andembry - SC)	0

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 <https://www.foi.scot/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 reviewer at the address at the top 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>

Yours sincerely

ALISON MACDONALD
Executive Director of Nursing Midwifery and AHPs
Cc: Chief Executive