

Dear

## FREEDOM OF INFORMATION – PRESCRIBING

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

Question:

1. How many patient's does the trust have with a recorded diagnosis of Dravet Syndrome (DS).

- a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?
- b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

Answer:

a.	NHS Lothian are not able to link indication with prescribing activity without complex manual configurations, therefore this is out with the scope of an FOI request
b.	NHS Lothian are not able to link indication with prescribing activity without complex manual configurations, therefore this is out with the scope of an FOI request

Question:

2. How many patient's does the trust have with a recorded diagnosis of Lennox-Gasteau Syndrome (LGS).

- a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?
- b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

Answer:

a.	NHS Lothian are not able to link indication with prescribing activity without complex manual configurations, therefore this is out with the scope of an FOI request
b.	NHS Lothian are not able to link indication with prescribing activity without complex manual configurations, therefore this is out with the scope of an FOI request

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.

We ran searches for primary care prescribing activity for both products (from July-Dec 2023):

- there were no results found for Fenfluramine (Fintepla).
- there have been 5 patients who have received at least one prescription (July-Dec 2023) for Cannabidiol (Epidyolex) within NHS Lothian (again, we are unable to provide any information on the indication this was prescribed for).

We ran a search of secondary care / hospital prescribing data (again, we are unable to provide any information on the indication this was prescribed for).

August 2023 - January 2024	
Medication	Patient Count
Cannabidiol (Epidyolex)	18
Fenfluramine (Brand Not Specified)	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 am sorry I 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, Midwifery and AHPs**  
Cc: Chief Executive