

Dear

FREEDOM OF INFORMATION – NARCOLEPSY DIAGNOSIS

I write in response to your request for information in relation to narcolepsy diagnosis in NHS Lothian.

Question:

Could you please tell me how many people within your NHS area are diagnosed with Narcolepsy? This can be those with both Type 1 Narcolepsy (with Cataplexy) and those with Type 2 Narcolepsy (without Cataplexy), reported as one figure, I don't need it broken down to Type 1 and Type 2.

If possible, I would like the data reported by Council area but if that is not possible then NHS area will be sufficient.

Answer:

This information is not collected centrally. We could provide information on patients who have had an inpatient stay with the diagnosis of narcolepsy recorded, but this would not include patients who have been diagnosed or treated in another setting, such as by their GP or at an outpatient clinic, or patients who have been living with the condition without recent contact with healthcare services.

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.

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.nhslothian.scot/FOI>

Yours sincerely

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