

Freedom of Information request 27-23

Request

I would like to please request the following information, with regards to the treatment of Epilepsy in your trust/ board.

In the last 12 months of available data:

1a. What number of unique patients have been treated for Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex? Please give answers for each condition separately.

1b. For each indication (Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex), what number of these have been treated in a paediatric environment?

2a. How many patients have been treated with Epidyolex in a paediatric environment?

3a. Can you please detail which NHS Trusts/ Health Boards these patients have been referred from?

Response

1. The number of unique patients treated in NHS Borders is:

Condition	Number of Patients	Paediatric
Lennox-Gastaut Syndrome	<5	<5
Dravet Syndrome	0	0
Tuberous Sclerosis Complex	0	0

2. There are <5 patients treated with Epidyolex in a paediatric setting.

3. No patient(s) referred to in Q1 have been referred from outwith the NHS Borders area.

As the number of events in some areas are very small and in accordance with the Code of Practice for Official Statistics any number that is less than five, actual numbers and potentially identifiable information is withheld to help maintain patient confidentiality due to potential risk of disclosure. Further information is available in the [ISD Statistical Disclosure Control Protocol](#).

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the

reference number **27-23** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.