

Freedom of Information request 225-20

Request

I am writing to you under the Freedom of Information Act 2000 to request the following information from the Borders Health Authority:

Information regarding the population of individuals with Smith-Magenis Syndrome, this is identified by a mutation or deletion of RAI1 gene on chromosome 17p11.2:

1. Total population covered by the health authority
2. The total number of people diagnosed with Smith-Magenis syndrome within this population
3. Year of Birth
4. Male / Female

Response

1. The total population of the Scottish Borders is approx. 115,270.
2. NHS Borders do not have an electronic record of anyone diagnosed with Smith-Magenis syndrome in this area.
3. Not applicable.
4. Not applicable.

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 **225-20** 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.