

## Freedom of Information request 7-23

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### Request

1. If you treat Bardet-Biedle Syndrome, how many unique patients have you treated in the last 12 months?
2. What % of these patients get a genetic diagnosis prior to them being referred onto specialist centres?
3. If you do not treat Bardet-Biedle Syndrome, could I request where these patients are referred to?

### Response

1. NHS Borders has treated <5 patients with Bardet-Biedle Syndrome in the last 12 months.
2. All (100%) of these patients get a genetic diagnosis prior to them being referred on to specialist centres.
3. NHS Borders does treat patients with Bardet-Biedle Syndrome.

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](mailto: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 **7-23** 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.