NHS Borders
Communications & Engagement

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Freedom of Information request 608-23

Request & Response

I have a freedom of information request I would like to raise with the trust, I would be grateful if you could please answer the following questions:

Q1. Within your trust, how many patients currently have a diagnosis for:

- Fabry Disease / Gaucher Disease   **<5***
- Pompe Disease (ICD10 Code E74.02)   **0**
- Pompe Disease (ICD10 Code E74.02)
  Infantile-onset (Patients Diagnosed before age 1)   **0**
- MPS II (Hunter Syndrome) (ICD10 code E76.1)   **0**

Q2. Of the patients above, how many patients have been newly diagnosed within the past 3 months for:

- Fabry Disease (ICD10 code E75.21)   **0**
- Gaucher Disease (ICD10 code E75.22)   **0**
- Pompe Disease (ICD10 Code E74.02)   **0**
- Pompe Disease (ICD10 Code E74.02)
  Infantile-onset (Patients Diagnosed before age 1)   **0**
- MPS II (Hunter Syndrome) (ICD10 code E76.1)   **0**

Q3. How many patients have been treated in the last 3 months with the following products:

- Replagal (agalsidase alfa)   **0**
- Fabrazyme (algalsidase beta)   **0**
- Galafold (migalastat)   **0**
- Elfabrio (pegunigalsidase alfa)   **0**
- VPRIV (velaglucerase alfa)   **0**
- Cerezyme (imiglucerase)   **0**
- Cerdelga (eliglustat)   **0**
- Zavesca (miglustat)   **0**
- Myozyme (alglucosidase alfa)   **0**
- Nexviazyme (avalglucosidase alfa)   **0**
- AT-GAA (cipaglucosidase alfa/miglustat)   **0**

Q4. Do you participate in any clinical trials for Pompe Disease? If so, can you please provide the name of each trial along with the number of patients taking part?   **No**

Clarification

Q1 and Q2 - Unfortunately, NHS Borders cannot provide diagnosis data. However, we can provide data on the number of patients treated for the named diseases, if held.

I would be happy to receive the suggested data for Q1 and Q2.

* TrakCare diagnosis coding is only 4 point therefore only E75.2 can be identified

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 **608-23** 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.