

Freedom of Information request 541-22

Request

1. The number of people in your ICB/ICP area who have been diagnosed with Epidermolysis Bullosa during the past five years.
2. The number of people with Epidermolysis Bullosa referred to one of the UK's specialist EB treatment centres in the past five years.

Note: Specialist centres include children's services at Birmingham Women's and Children's Hospital, Glasgow Royal Hospital for Children and GOSH and adult services at Glasgow Royal Infirmary, Guy's and Thomas' Hospital and Solihull Hospital.

3. How many GPs and frontline healthcare professionals have received training on Epidermolysis Bullosa diagnosis and care within your area. Please refer to training undertaken where possible.

Response

1. There have been no NHS Borders patients diagnosed with Epidermolysis Bullosa during the past five years.
2. NHS Borders does not receive this information within the Commissioning Team. Patients who are treated by specialist centres such as the one in Glasgow would be referred usually from the tertiary services in NHS Lothian. Costs and patient activity levels at a specialist centre would be sent onto National Service Division (NSD) direct as the funders of specialist treatment centres. The information NHS Borders does receive from NHS Greater Glasgow and Clyde does not detail the patient conditions to the level of Epidermolysis Bullosa. Therefore, this information is not held, as defined in Section 17, Freedom of Information (Scotland) Act 2002.
3. There has not been any training delivered to GP's and frontline Healthcare Professionals on Epidermolysis Bullosa diagnosis and care.

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 **541-22** 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.