

Freedom of Information request 350-19

Request and Response

I am writing to you today to formally request information relating to the diagnosis and treatment of Homozygous Familial Hypercholesterolaemia (HoFH) at NHS Borders.

Specifically, I am after the following information:

1. Does NHS Borders diagnose patients with Homozygous Familial Hypercholesterolaemia (HoFH)?

Yes

- a. If yes, does your trust diagnose adult patients, paediatric patients or both?

Both

- b. How many patients in the last calendar year have you diagnosed with this condition? Please provide where available (and applicable) a breakdown by Adult and/or Paediatric Patients.

This information is not held electronically, it would only be held in a patient's notes and this would require a manual trawl of all records and the cost of carrying out this work would exceed the limit set in the Fees Regulations of the FOI(S)A 2002 and under Section 12 we are not required to provide.

- c. Which of the following tests/diagnostic procedures do you use at NHS Borders in relation to the diagnostics of HoFH? For these tests, which ones are you able to carry out "in house"? Of those carried out elsewhere, where are patients referred to have the testing carried out? For answers please use table below.
 - i. Cascade Genetic/DNA Tests
 - ii. Dutch Lipid Clinic Network (DLCN) criteria
 - iii. Simon Broome diagnostic criteria
 - iv. Family History
 - v. Cholesterol/LDL Blood Testing
 - vi. Other (please specify details of name of test in the FOI return)

Test Name	Test used for HoFH diagnosis at this trust Y/N	Test carried out by trust In-house for diagnosis of HoFH Y/N	Details of referral organisation/location for those tests that cannot be carried out by the trust.
Cascade Genetic/DNA Tests	Y	-	NHS Lothian / Aberdeen
Dutch Lipid Clinic Network (DLCN) criteria	N	-	
Simon Broome Diagnostic Criteria	Y	-	
Family History	Y	-	
Cholesterol/LDL Blood Testing	Y	-	
Other (please specify)			

2. Does NHS Borders treat patients with Homozygous Familial Hypercholesterolaemia (HoFH)?

Yes

- a. If no, please specify where patients diagnosed with HoFH are referred to for treatment. Please specify Trust/Organisation Name and Hospital Name where possible.
- b. If yes, does your trust treat adult patients, paediatric patients or both?
 - i) If your trust doesn't treat a subgroup (Adult or Paediatric), to which organisation are this sub group referred to for treatment? Please specify Trust/Organisation Name and Hospital Name where possible.

Both with Paediatric referrals treated by NHS Lothian.

- c. How many patients in the last calendar year have received treatment for HoFH at NHS Borders? Please provide where available (and applicable) a breakdown by Adult and/or Paediatric Patients.

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- d. For HoFH patients requiring Apheresis, are you able to carry out this procedure at NHS Borders?

Not applicable.

- i. If no, to which organisation(s) do you refer patients to for Apheresis treatment and how many patients are referred to these sites? Please list by trust name and hospital site where available, and where possible/applicable please breakdown patient referrals by Adult and Paediatric.
- ii. If yes, how many HoFH patients in the past calendar year have been treated by Apheresis by NHS Borders? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients.

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 **350-19** 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.