

Freedom of Information Request

Ref: UHB 19-461

2 August 2019

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

1. Does University Hospitals Bristol NHSFT diagnose patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y/N
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.
None.
 - c. Which of the following tests/diagnostic procedures do you use at University Hospitals Bristol NHSFT 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.

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	N	Bristol Genetics Laboratory (North Bristol Trust)
Dutch Lipid Clinic Network (DLCN) criteria	Y (Welsh Modification)	Y	
Simon Broome Diagnostic Criteria	Y	Y	
Family History	Y	Y	
Cholesterol/LDL Blood Testing	Y	Y	
Other (please specify)	N	N/A	

2. Does University Hospitals Bristol NHSFT treat patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y/N

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.

N/A.

- b. If yes, does your trust treat adult patients, paediatric patients or both?

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.

N/A.

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

Six adults.

- d. For HoFH patients requiring Apheresis, are you able to carry out this procedure at University Hospitals Bristol NHSFT? Y/N

Yes.

- 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.

N/A.

- ii. If yes, how many HoFH patients in the past calendar year have been treated by Apheresis by University Hospitals Bristol NHSFT? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients.

Five adults.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Trust Secretary
University Hospitals Bristol NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

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To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

FOI Team
UH Bristol NHS Foundation Trust