

Ref: FOIA Reference 2019/20-236

Date: 9th August 2019

Email foi@uhn.nhs.uk

Dear

I am writing in response to your email dated 25th July 2019 requesting information under the Freedom of Information Act (2000) regarding Homozygous Familial Hypercholesterolaemia.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 Does University Hospitals of North Midlands NHS Trust diagnose patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y/N

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

- c. Which of the following tests/diagnostic procedures do you use at University Hospitals of North Midlands NHS Trust 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			
Dutch Lipid Clinic Network (DLCN)			

criteria			
Simon Broome Diagnostic Criteria			
Family History			
Cholesterol/LDL Blood Testing			
Other (please specify)			

A1 UHNM has had no patients with Homozygous Familial Hypercholesterolaemia (HoFH)

Q2 Does University Hospitals of North Midlands NHS Trust treat patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y/N

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.

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

d. For HoFH patients requiring Apheresis, are you able to carry out this procedure at University Hospitals of North Midlands NHS Trust? Y/N

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 University Hospitals of North Midlands NHS Trust? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients

A2 As answer 1.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

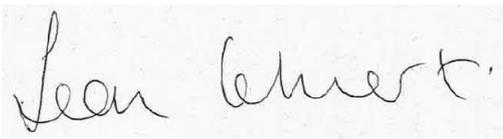
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 676474.

Yours,



Jean Lehnert
Information Governance Manager