

Date: **17 September 2019**

Our reference: **FOIRQ5352**

Dear Sir/Madam,

Thank you for your request for information processed under the Freedom of Information Act 2000. Please see our response to your requests for information below:

Your Request and Our Response (in bold)

I am writing to you today to formally request information relating to the diagnosis and treatment of Homozygous Familial Hypercholesterolaemia (HoFH) at Great Ormond Street Hospital for Children NHSFT.

Specifically, I am after the following information:

1. *Does Great Ormond Street Hospital for Children NHSFT 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 Great Ormond Street Hospital for Children 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.*
 - 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)*

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

2. Does Great Ormond Street Hospital for Children NHSFT 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 Great Ormond Street Hospital for Children NHSFT? 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 Great Ormond Street Hospital for Children NHSFT? 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 Great Ormond Street Hospital for Children NHSFT? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients.

Our Request for Clarification

We explained the information requested in Q.1(b) and Q.2(c) is not centrally recorded information where you asked for the last calendar year. We asked you to specify what calendar year you are requesting?

Your Response to Our Request for Clarification

You responded and stated the time period is June 2018 to June 2019 for the information request, or alternatively if you need it to be a full calendar year please use the time period of January 2018 to January 2019.

Our Response

Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is a single site, specialist tertiary paediatric trust. The information you have requested is not centrally recorded; but we have made enquiries with the relevant teams to enable to us to respond (in bold) to your following request for information:

1. *Does Great Ormond Street Hospital for Children NHSFT diagnose patients with Homozygous Familial Hypercholesterolaemia (HoFH)?*
Y/N **Yes**
 - a. *If yes, does your trust diagnose adult patients, paediatric patients or both?* **We only treat paediatric patients at GOSH**
 - 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?* **We are unable to provide this information. Please see note below****

Please Note: **The Trust is unable to provide a breakdown of the information where there have been five or less data subjects (<5) for the period specified. Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is withholding this information under Section 40 (Personal Information) of the Freedom of Information Act (FOIA) 2000 in order to reduce the risk of identifying an individual. The Trust is of the view that disclosure of information would significantly increase the risk of individuals being identified and would therefore constitute a breach of their personal data.

The Trust believes that Sections 40(2) of the FOIA is applicable in withholding the information as disclosure could lead to individuals being identified, which is a breach of their rights under the Data Protection Act (DPA) 2018. The grounds for applying this exemption are as follows:

- In the context of your request, this data is third party information. The Trust categorises the information about our patients' health as information falling within paragraph (e) of the definition of "sensitive personal data" in s.2 of the DPA 2018. As such, Section 40(2) of the FOIA applies to this information, as does the Trust's duty of confidentiality. Therefore under s.2(3)(f)(ii) of the FOIA, there is an absolute exemption from disclosure on the grounds that it would contravene the First Data Protection Principle.
- The Trust has a duty under the DPA 2018 and the First Data Protection Principle to process personal data regarding the Trust's patients fairly and lawfully and, in particular, not process data unless at least one of the conditions in Schedule 2 DPA is met, and in the case of sensitive personal data, at least one of the conditions in Schedule 3 DPA is also met.
- The Act has defined "sensitive personal data" to include data on the "physical or mental health or condition" of a person (s.2)(e) (DPA). Any medical information about specific individual falls within this category and disclosure of this data to a FOI applicant would be processing sensitive personal data of those patients.

In line with the guidance from the Information Commissioner's Office based upon the requirements of the Data Protection Act

the Trust has considered first whether it would be “fair” to process and disclose the requested information, and whether it would be lawful to disclose the requested information before considering whether any Schedule 2 and Schedule 3 conditions have been met. Disclosing medical information to the public regarding the Trust’s patients is likely to lead to emotional distress of the patients and their families. It is also the Trust’s position that there is a reasonable expectation on the part of the Trust’s patients and their families that their sensitive personal data would not be disclosed to FOI applicants.

A breach of this expectation would have the effect of the data being processed unfairly. The information that forms part of the medical records of an individual is therefore implicitly confidential. The courts and the Information Commissioner have long recognised the strong public interest inherent within keeping confidential medical information confidential. The Trust holds the view that Section 41 (1) of the FOIA is applicable for the reasons that: the information was obtained by the Trust; it has the necessary quality of confidence (being neither generally accessible nor trivial); and disclosure of this information to an FOI applicant would give rise to an actionable breach of confidence.

c. *Which of the following tests/diagnostic procedures do you use at Great Ormond Street Hospital for Children 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.*

- vii. *Cascade Genetic/DNA Tests*
- viii. *Dutch Lipid Clinic Network (DLCN) criteria*
- ix. *Simon Broome diagnostic criteria*
- x. *Family History*
- xi. *Cholesterol/LDL Blood Testing*
- xii. *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	Y	N/A
Dutch Lipid Clinic Network (DLCN) criteria	N	N	The Trust does not use the DLCN criteria for diagnosing Homozygous Familial Hypercholesterolaemia
Simon Broome Diagnostic Criteria	Y	Y	N/A
Family History	Y	Y	N/A
Cholesterol/LDL Blood Testing	Y	Y	N/A
Other (please specify)	N/A	N/A	N/A

2. Does Great Ormond Street Hospital for Children 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? **We only treat paediatric patients at GOSH**

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 Great Ormond Street Hospital for Children NHSFT? Please provide where available (and applicable) a breakdown by Adult and/or Paediatric Patients. **The Trust is unable to provide this information. Please see our note to Q.1(b) above.**

- d. *For HoFH patients requiring Apheresis, are you able to carry out this procedure at Great Ormond Street Hospital for Children NHSFT?*
Y/N

Yes - but patients are referred to the Evelina hospital for Apheresis as the service is well established at their hospital.

- 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.*
Please see our response to Q2 (d)
- ii. *If yes, how many HoFH patients in the past calendar year have been treated by Apheresis by Great Ormond Street Hospital for Children NHSFT? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients.* **0**

Please note:

The information provided under the Freedom of Information Act 2000 is the information held on the date your request was received by the Trust.

We trust the information provided is sufficient and helpful in answering your questions or any issues and concerns. Should you have any further queries in relation to this request, please do not hesitate to contact the FOI Team and quote the above reference number on any related correspondence.

Re-use of information

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Yours sincerely

Freedom of Information team

Great Ormond Street Hospital for Children NHS Foundation Trust

Email: foiteam@gosh.nhs.uk

[Enclosed – Your rights – see next page]

Your Rights

If you are dissatisfied with the response you have received to your request for information, please contact the FOI team and quote your reference number on all correspondence relating to your request.

You can also write to the Head of Quality & Safety at the following address:

Quality & Safety team
Great Ormond Street Hospital
LONDON
WC1N 3JH

If you are still not satisfied with your response, you also have the right to appeal to the Information Commissioner.

You can contact the Information Commissioner's Office at the following address:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF