



**The Clatterbridge  
Cancer Centre**  
NHS Foundation Trust

Clatterbridge Road  
Bebington  
Wirral  
CH63 4JY

Tel: 0151 556 5000  
Web: [www.clatterbridgecc.nhs.uk](http://www.clatterbridgecc.nhs.uk)

Date: 26 July 2019

**Re: Freedom of Information Request**  
**Ref: 206- 2019**

Thank you for your email dated 25th July 2019 requesting information in relation to Homozygous Familial Hypercholesterolaemia (HoFH).

The information that you require is as follows:

**Specifically, I am after the following information:**

1. **Does The Clatterbridge Cancer Centre 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 The Clatterbridge Cancer Centre 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)**

**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)**

- 2. Does The Clatterbridge Cancer Centre 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 The Clatterbridge Cancer Centre 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 The Clatterbridge Cancer Centre 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 The Clatterbridge Cancer Centre NHSFT? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients.**

**I can confirm that our Trust does not hold any information in this regard. Our Trust is a tertiary specialist cancer treatment centre and does not diagnose or treat Homozygous Familial Hypercholesterolaemia. Therefore, the information you have requested is not applicable to our Trust in this instance.**

Should you require any further information please do not hesitate to contact me on the email address provided below.

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

If you are dissatisfied with the handling of your request, you have the right to ask for this to be investigated internally.

If you are dissatisfied with the information you have received, you have the right to ask for an internal review.

Both processes will be handled in accordance with our Trust's Freedom of Information Policy and the Freedom of Information Act 2000.

Internal investigation and 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: Freedom of Information Review, The Clatterbridge Cancer Centre NHS Foundation Trust, Clatterbridge Road, Bebington, Wirral, CH63 4JY

If you are not satisfied with the outcome of the internal investigation/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.

**In order for us to ensure customer satisfaction and to monitor compliance with the Freedom of Information Act 2000, we would be grateful if you could take a couple of minutes to complete a short feedback form via the link below:**

<https://www.surveymonkey.co.uk/r/H39RFMM>