

Reference:	FOI.1230.19
Subject:	Homozygous Familial Hypercholesterolemia (HOFH)
Date of Request:	25 July 2019

Requested

1. Does Hywel Dda University Health Board 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 Hywel Dda University Health Board 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 Hywel Dda University Health Board treat patients with Homozygous Familial Hypercholesterolemia (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 subgroup 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 Hywel Dda University Health Board? 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 Hywel Dda University Health Board? 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 Hywel Dda University Health Board? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients.

Response:

1. Hywel Dda University Health Board (UHB) confirms if a patient presented with the appropriate clinical symptoms for HoFH a diagnosis would be made.
 - a. The UHB confirms both adult and paediatric patients would be diagnosed.
 - b. The UHB confirms it does not currently have any patients with HoFH.
 - c. Not applicable
2. The UHB does not have any patients being treated for HoFH at the time of your request, therefore I regret to inform you that we do not hold the information you requested.