

<b>Reference:</b>	FOI.1175.19
<b>Subject:</b>	Genetic haemochromatosis
<b>Date of Request:</b>	17 July 2019

**Requested**

1. For the period 1st January 2018 to 31st December 2018 (or the most recent 12 month period available), the number of patients diagnosed with genetic haemochromatosis under your care.
2. For the period 1st January 2018 to 31st December 2018 (or the most recent 12 month period available), the average time in days from first referral from primary care to the patient's first appointment within your trust.
3. A copy of the protocol and/or patient pathway applicable to the care of people with genetic haemochromatosis.
4. The date that your protocol/patient pathway for genetic haemochromatosis was last reviewed or revised.
5. A copy of your clinical protocol(s) for therapeutic venesection.
6. The date that your protocol(s) for therapeutic venesection were last reviewed or revised.

**Response:**

Hywel Dda University Health Board (UHB) is unable to provide you with the information for questions 1 and 2 as it is estimated that the cost of answering your request would exceed the "appropriate level" as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. The "appropriate level" represents the estimated cost of one person spending 18 hours or (2 ½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with the requested information, the UHB would need to undertake a manual search of all hemochromatosis gene (HFE) tests performed to identify any information that fulfils your request. Within 2018, 129 HFE tests were performed; it is therefore estimated that completing this part of your request would cost:

129 @ 15 minutes per patient record notes = 32.25 hours  
 32.25 hours @ £25 per hours = £806.25

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (FOI), which provides an exemption from a public authority's obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

The UHB provides a copy of "integrated care pathway for venesection of patients with hemochromatosis or polycythaemia" used for patient care, Attachment 1. The document was last reviewed and updated 4 April 2019 to reflect the national British Society for Haemochromatosis (BSH) clinical guidelines for patient care.

The BSH clinical guidelines can be found on the haemochromatosis webpage:  
<https://www.haemochromatosis.org.uk/clinical-guidelines>