

23 May 2017

**Our Ref:** RFI 20311

Dear

**Freedom of Information Act 2000  
Information in Relation to Huntington's Disease Provision within the Trust  
etc**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for the information relating to the above which you requested on 5 May 2017.

A response to each of the questions raised has been provided by the Hospital Services Directorate and is attached in Appendix A. Please note that information is not available in respect of Question 4.

Under the terms of the legislation, if you are unhappy with this response you have the right to seek a review within the Trust in the first instance. If you wish to do so, please write to me at the address below.

If after such a review you are still unhappy with the response, you have the right to appeal to the Information Commissioner who will undertake an independent review. The Information Commissioner can be contacted at The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

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**L McAree (Miss)  
Head of Information Governance &  
Directorate Support**

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Appendix A

Q1. *How many specialist Huntington's Disease posts do you have within the trust?*

A1. There are no specialist Huntington's posts within the Trust.

Q2. *If there is no HD specialist provision within the trust, can patients access the service outside the trust area? If so please provide details.*

A2. Patients with HD are referred to the Belfast Health & Social Care Trust (Belfast Trust).

Q3. *If another Trust provides that service how much does the South Eastern Trust have to contribute towards the cost of that provision?*

A3. This provision is regionally funded by the Health and Social Care Board and not by Trusts.

Q4. *For the most recent year available how many patients have been seen by a HD specialist nurse/referred to another trust to see a Huntington's Disease specialist nurse?*

A4. In order to retrieve this information a manual review of all referrals made to the Belfast Trust is required as the information is not collated on our information systems. The Trust considers that the cost of retrieving this information would be above the 'Appropriate Limit' as defined by the Freedom of Information Act 2000 under Section 12(1), so it will not be possible to make this information available to you.

*12.(1) Section 1(1) does not oblige a public authority to comply with a request for information if the authority estimates that the cost of complying with the request would exceed the appropriate limit.*

In accordance with the Freedom of Information Act 2000 this letter acts as a Refusal Notice.

Q5. *How many patients are waiting to be seen by a Huntington's Disease specialist nurse for an initial appointment/review appointment?*

A5. The Trust does not hold this information. This information may be held by the Belfast Trust. If you wish to pursue this question the Belfast Trust can be contacted at [publicliaison@belfasttrust.hscni.net](mailto:publicliaison@belfasttrust.hscni.net)

Q6. *If there is a waiting list, what is the waiting time?*

The Trust does not hold this information. This information may be held by the Belfast Trust. If you wish to pursue this question the Belfast Trust can be contacted at [publicliaison@belfasttrust.hscni.net](mailto:publicliaison@belfasttrust.hscni.net)