

18 December 2023

**Our Ref:** RFI 54849

Dear

**Freedom of Information Act 2000  
Information in Relation to Postural Tachycardia Syndrome PoTS**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above which you requested on 21 November 2023.

A response to each of the questions raised has been provided by Medicine, Unscheduled Care & Cancer Directorate and the Surgery, Elective Care, Maternity & Paediatrics Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital ([informationgovernance@setrust.hscni.net](mailto:informationgovernance@setrust.hscni.net)) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

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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**Robyn Watterson**  
**Information Governance Officer**

- Q1. What is your estimate of the incidence of PoTS in the population of Ards, Down, Lisburn and North Down and how many patients have been diagnosed with the condition over the last 5 years?**
- Q2. Is there evidence of a growth in PoTS diagnoses since May 2020 due to patients suffering with long covid?**

A1,2. The Trust do not clinically code their outpatient clinics, therefore the information requested is not collated centrally and an extensive trawl of records would be required to try to locate, gather and verify this.

This would exceed the 'Appropriate Limit' as defined by the Freedom of Information Act 2000. This represents the cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information. The Trust therefore exempts the release of this information under Section 12(1).

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 for question 1 and 2.

- Q3. To which speciality within secondary care are PoTS patients referred for investigation, diagnosis and longer-term management?**

A3. The Trust do not have a specific PoTs services. Patients may be referred to cardiology or general medicine services for investigation, diagnosis and longer-term management.

- Q4. Are there established patient pathways in place for the referral, diagnosis and management of the below with PoTS in your local population:**

- a) Adult patient**
- b) Paediatric patients**

A4a. The Trust do not have a specific PoTs services. Patients may be referred to cardiology or general medicine services for investigation, diagnosis and longer-term management.

A4b. PoTS is diagnosed by the cardiology or neurology service and those services for Paediatrics are centralised in the Belfast Health & Social Care Trust (Belfast Trust). You may wish to contact the Belfast Trust at [publiciasion@belfasttrust.hscni.net](mailto:publiciasion@belfasttrust.hscni.net)

**Q5. Do adult patients and paediatric patients diagnosed with PoTS have access to specialised PoTS clinics or services for treatment by dedicated clinicians with an interest/expertise in the condition? If so, please provide details of individual adult and paediatric services patients are referred to.**

A5. The Trust do not have a specific PoTs services for adults. Patients may be referred to cardiology or general medicine services for investigation, diagnosis and longer-term management.

As above, Paediatrics is a centralised service in the Belfast Trust. You may wish to contact the Belfast Trust at [publicliasion@belfasttrust.hscni.net](mailto:publicliasion@belfasttrust.hscni.net)

**Q6. How is activity coded for adult and paediatric patients with a diagnosis of PoTS?**

A6. The Trust do not clinically code their outpatient clinics, therefore the information requested is not collated centrally and an extensive trawl of records would be required to try to locate, gather and verify this.

This would exceed the 'Appropriate Limit' as defined by the Freedom of Information Act 2000. This represents the cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information. The Trust therefore exempts the release of this information under Section 12(1).

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 for question 6.

As above, Paediatrics is a centralised service in the Belfast Trust. You may wish to contact the Belfast Trust at [publicliasion@belfasttrust.hscni.net](mailto:publicliasion@belfasttrust.hscni.net)