

Title

Postural Tachycardia Syndrome PoTS

Reference Number: RDF2410-24

Date of Response: 09/04/24

Further to your Freedom of Information Act request, please find the Trust's response(s) below:

Under the Freedom of Information (FOI) Act 2000 please could you respond the questions below.

Postural tachycardia syndrome (PoTS) is a neurovascular condition characterised as an abnormal response by the autonomic nervous system to upright posture. The condition causes affected patients of all ages to experience a range of symptoms requiring extensive clinical investigations involving neurology and cardiology specialties to inform a positive diagnosis.

Please consult with cardiology, neurology, emergency medicine, care of the elderly and paediatrics specialties to provide the information requested.

- 1. How many patients are referred to your Trust annually with a suspected diagnosis of PoTS and how many diagnosed PoTS patients are under active care under specialties within the Trust?* - The Trust is unable to respond to this question. The Information is not held in a reportable format within the Trust.

The only data that is held is part of a patient's medical record held within the Electronic Patient Record (EPR). This data it would not be appropriate to release under FOI as it is personal data and would not be lawful or transparent to patients to view their records for this purpose. As such it is exempt under Section 40(2) of the FOI Function as it is in breach of Principle 1 of the UK GDPR
- 2. Is there evidence of an increase in referrals of PoTS patients since May 2020 due to patients suffering with long-Covid?* Answer: Yes, with increasing awareness from primary care, both as a post Covid phenomenon and otherwise.
- 3. How many patients with a suspected or confirmed diagnosis of PoTS are seen annually in the Emergency Department or admitted as an emergency?* Answer: The Trust is unable to respond to this question. The Information Is not held in a reportable format within the Trust. The only data that is held is part of a patient's medical record held within the Electronic Patient Record (EPR). This data it would not be appropriate to release under FOI as it is personal data and would not be lawful or transparent to patients to view their records for this purpose. As such it is exempt under Section 40(2) of the FOI Function as it is in breach of Principle 1 of the UK GDPR

4. *To which individual specialty or specialties are PoTS patients referred for investigation, diagnosis and longer-term e.g., Cardiology Neurology care of the elderly, paediatrics.*

Please specify separately for children and adults, where applicable. Answer: Health Care for Older people.

There is sometimes some crossover with faints/vasovagal/POTS. These sort of patient referrals often come through Cardiology (but also Neurology) However, the Trust does not currently run a syncope clinic. If the referral is purely for postural hypotension then the referral should not come to cardiology.

5. *Within your Trust do a) adult patients and b) paediatric patients diagnosed with PoTS have access to a specialised PoTS clinic or service for treatment by dedicated clinicians with an interest/expertise in the If so, please provide details of specialised adult and paediatric services in place.-* No, the trust does not have a specialist PoTS service. Senior Clinicians have a specialist interest with a view to employing someone with specialist interest in POTs/dysautonomia.

6. *Where dedicated PoTS services are available within your Trust, are there any restrictions in place around acceptance of new referrals or longer-term management of patients? Please specify any restrictions imposed.* Answer: No specialist service. However, GPs have to perform and active stand test prior to referring to HfOP. If the active stand test is not performed the referral will be rejected

7. *If no specialist PoTS services are in place within your Trust, do you reject referrals (back to referring GP), accept referrals under general acute services e.g., cardiology / neurology (please specify) or refer on to a known specialist service elsewhere? (please specify where) Answer:*

No specialist service. However, GPs have to perform and active stand test prior to referring to Health Care for Older people. If the active stand test is not performed the referral will be rejected.

When triaging our referrals, if the main question from the referrer is query POTs i.e., dizziness on standing, the referral is rejected with a generic advice and guidance letter.

The Trust is not aware of any local services to refer to at present. Sometimes cardiology may see these patients and sometimes refer to us for a tilt table. However, if the referral is just for POTs i.e., dizziness on standing, the referral is rejected, and a tilt procedure would be organised if there is syncope/LOC.

8. *How is activity coded for adult and paediatric patients with a diagnosis of PoTS attending for a first or follow up outpatient appointment or admitted to inpatient care? –* The Trust is unable to respond to this question. The Information Is not held in a reportable format within the Trust.