

**Freedom of Information Act 2000****The Royal Cornwall Hospitals NHS Trust Response to Information request****Date Request Received: 06 May 2024****FOI Ref No: 24622****Requested Information****Postural Tachycardia Syndrome PoTS**

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 annually with a suspected diagnosis of PoTS and how many diagnosed PoTS patients are under active care under specialties within local hospitals? Please provide data for the last 5 financial years if available.
- 2) Is there evidence of an increase in referrals of PoTS patients since May 2020 due to patients suffering with long-Covid?
- 3) How many patients with a suspected or confirmed diagnosis of PoTS are seen annually in Emergency Departments or admitted as an emergency? Please provide data for the last 5 financial years if available.
- 4) To which individual specialty or specialties are PoTS patients referred for investigation, diagnosis and longer-term management?  
e.g., cardiology, neurology, care of the elderly, paediatrics.  
Please specify separately for children and adults, where applicable.
- 5) 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 condition?  
If so, please provide details of specialised adult and paediatric services in place.
- 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.
- 7) If no specialist PoTS services are in place locally, 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).

- 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?

## Response

- 1) Regrettably, RCHT would not be able to answer questions 1 and 3 as there is no means of identifying referrals for suspected PoTS, and no reliable means of capturing patients with a diagnosis under the care of the Trust as they are not held on specific clinics or waiting lists and the ICD10 code available is not exclusively used for this condition. The patients are referred in with a diagnosis and put onto a general cardiology list. If thought appropriate following that consultation, they are referred on to Jamie Fultons POTS clinic at University Hospitals Plymouth (UHP).
- 2) Clinical opinion is that we are seeing an increase in incidence due to long Covid. However, this may be artefactual as we are currently working our way through our longest waiting 1<sup>st</sup> OPA patients list with the aid of an external medical company under the terms of a waiting list clearance initiative. As such, we are clearing large numbers of long waiting patients, several of whom have POTS. The increasing numbers of POTS patients we are seeing referred on, may of course be due in part to increased activity in waiting list clearance
- 3) Regrettably, RCHT would not be able to answer questions 1 and 3 as there is no means of identifying referrals for suspected PoTS, and no reliable means of capturing patients with a diagnosis under the care of the Trust as they are not held on specific clinics or waiting lists and the ICD10 code available is not exclusively used for this condition.

Q4-7 RCHT has no specialised clinic or service for POTS. Patients are referred to UHP as detailed in response to Q1 after being initially seen in a general cardiology clinic.

- 8) We code PoTS to the following ICD-10 code:  
I49.8 - Other specified cardiac arrhythmias  
Please note this code is not exclusively for this condition and may be coded to represent another condition.

**Attachment(s):**

None.

**Date Response sent: 02 July 2024**