

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

### **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 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?

**Response: We don't routinely code for this diagnosis - these patients would usually be seen as part of general paediatric or cardiology clinics. Would be impossible to tell numbers without a prospective audit.**

2. Is there evidence of an increase in referrals of PoTS patients since May 2020 due to patients suffering with long-Covid?

**Response: Anecdotally this is definitely the case. I haven't got any data to back that up, but my experience is absolutely yes**

3. How many patients with a suspected or confirmed diagnosis of PoTS are seen annually in the Emergency Department or admitted as an emergency?

**Response: Please see spreadsheet.**

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.

**Response: In general the more severely affected patients are likely to be referred to paediatric cardiology for exclusion of more sinister causes of tachycardia. We have a specialist paediatric cardiology clinic run by Dr Hassan locally. Investigations would normally be a 24 hr ECG to exclude more worrying causes for tachycardia. We do not routinely do tilt table testing. Diagnosis is based on 10-minute stand test normally. Currently we do not follow up patients with a confirmed diagnosis of POTS if this is the only medical diagnosis. They are offered nonpharmacological advice and discharged to GP care. If there are**

**complicating symptoms (ME, hypermobility and chronic pain) then these would be managed by the child's paediatrician with specialist referral as needed.**

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 condition?  
If so, please provide details of specialised adult and paediatric services in place.

**Response: No specialist clinic exists in our region for children with POTS**

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.

**Response: Not applicable - no dedicated service**

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).

**Response: This depends on the reason for referral. If a patient is referred for help with managing a known diagnosis of POTS it is likely the referral would be rejected (no expertise or specialist service available). If a patient was referred because of symptoms of tachycardia and syncope then we would usually see them in a general paediatric clinic.**

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: Currently diagnostic code not routinely collected for POTS. They would be coded as a general paediatric or cardiology outpatient activity**