

Reference Number: FOIAH2324/702
From: Other
Date: 11 March 2024
Subject: Postural Tachycardia Syndrome (PoTS) referrals, diagnosis and management

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.

- Q1 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?
- A1 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. We are unable to provide the breakdown requested as the patients are coded as other disorders of autonomic nervous system and not a specific diagnosis of PoTS.
- Q2 Is there evidence of an increase in referrals of PoTS patients since May 2020 due to patients suffering with long-Covid?
- A2 Information not held as per A1.
- Q3 How many patients with a suspected or confirmed diagnosis of PoTS are seen annually in the Emergency Department or admitted as an emergency?
- A3 Information not held as per A1.
- Q4 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.
- A4 Cardiology, Paediatrics
- Q5 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.
- A5 a) Information not held - Alder Hey Children's NHS Foundation Trust is a specialist children's hospital and does not treat adult patients.
b) No

- Q6 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.
- A6 Not applicable as per 5b
- Q7 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).
- A7 Accept referrals under general acute services - Cardiology, Paediatrics
- Q8 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?
- A8 Information not held as per A1