

Ref. No: 0771
Date: 11/03/24
Subject: Postural Tachycardia Syndrome

REQUEST

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.

- 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?**
- 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 the Emergency Department or admitted as an emergency?**
- 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. 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.**
- 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 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).

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?

Clarification:

PoTS is classifiable under the ICD system.

I can confirm that G90 is the ICD 10 code for autonomic disorders, and G90 A is the code for postural orthostatic tachycardia syndrome

The new ICD 11 code appears to be 8D89-2, but I am not sure if this code is in use in the UK yet.

The link below describes common symptoms.

<https://icd.who.int/browse/2024-01/mms/en#1533647472>

RESPONSE

St Helens and Knowsley Teaching Hospitals NHS Trust and Southport and Ormskirk Hospital NHS Trust became a single legal entity known as Mersey and West Lancashire Teaching Hospitals NHS Trust on 1st July 2023, as such parts of the response may be provided in two sections relating to the hospital sites of each of the legacy organisations.

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?

St Helens and Knowsley Paeds

Unable to identify as paediatric referrals are not specific to a suspected diagnosis of PoTS. Patients are referred in either to a paediatrician with expertise in cardiology or to a general paediatrician. Normally patients are referred by their GP due to palpitations or collapse/syncope.

Southport and Ormskirk:

We are unable to identify this as referrals are not specific to PoTS, patients are referred into General Cardiology.

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

We are unable to identify as referrals are not specific to PoTS. However, there does appear to be wider GP awareness of this condition as our paediatrician with expertise in cardiology has noted an increase in the number of referrals from GPs in this regard, into the general cardiology clinic as well as the general paediatric clinics.

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

St Helens and Knowsley:

<5 patients

Southport and Ormskirk:

<5 patients

Section 40: personal information

We are unable to provide precise figures when those figures refer to individuals in volumes of 5 or less due to the risk that individuals will be re-identified, as we are required to protect their identity under the General Data Protection Regulations & Data Protection Act 2018. In such circumstances Section 40(2) and Section 40(3) of the Freedom of Information Act apply. In this case, our view is that disclosure would breach the first data protection principle which states that personal data should be processed "lawfully, fairly and in a transparent manner". It is the lawful aspect of this principle which, in our view, would be breached by disclosure, and in such circumstances, Section 40 confers an absolute exemption on disclosure.

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.

Patient would be seen within our Cardiology / General Paediatrics / General Medicine clinics.

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.

There is no specialised POTS clinic / service.

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.

N/A

- 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).**

MWL Response

We do not have a dedicated PoTS service, but these referrals would be accepted by us, with the patient being seen within our Cardiology / General Paediatrics clinics – if the patient was however found to have a complex co-morbidity, such as an underlying cardiac problem, then they would be referred on to the local tertiary hospital, Alder Hey.

- 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?**

Postural Orthostatic Tachycardia Syndrome (POTS) is not specifically classifiable within the ICD-10 Classification.