

20240312 FOI ref 560-2324

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.

#### Clarified:

Thank you for your response requiring clarification of the timeframe for this request. Please could you provide information from the last 5 financial years if possible i.e. from 2018/19 onwards.

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?  
Identifying suspected or confirmed PoTS cases would require reviewing all out patient records, which would make this an unreasonable request. Section 12 exemption as detailed in the attach letter
2. Is there evidence of an increase in referrals of PoTS patients since May 2020 due to patients suffering with long-Covid?  
Identifying changing trends in suspected or confirmed PoTS cases would require reviewing all out patient records, which would make this an unreasonable request. Section 12 exemption as detailed in the attach letter
3. How many patients with a suspected or confirmed diagnosis of PoTS are seen annually in the Emergency Department or admitted as an emergency?  
Since the ICD10 code for PoTS was introduced in 2022, 49 patients have been admitted to UHNM on a Non-Elective basis with a primary Diagnosis of PoTS.
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.

While PoTS patients may be referred to, and be seen by, other specialities dependent on the referral symptoms and pathway, we can confirm that PoTS patients are seen by the Heart Centre at UHNM. Section 12 exemption as detailed in the attach letter

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.

While there is not a dedicated specialist PoTS service for adult patients, there are a number of consultants within the Cardiology department that have experience in treatment for 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.

There is no dedicated PoTS service at UHNM.

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).

If a PoTS patient is referred to the Cardiology department, the referral is triaged and is listed under one of the consultants with experience in treatment for PoTS.

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?

Outpatient activity is coded as a first or follow up activity. Inpatient care is coded as per the ICD10 and HRG coding system.