

Under the Freedom of Information (FOI) Act 2000 please could you respond to the question causes affected patients of all ages to experience a range of symptoms requiring 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.

Patients with a suspected or confirmed diagnosis of PoTS are seen in the Emergency Department or admitted as an emergency?

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

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?