

Reference:	FOI.13149.23
Subject:	Postural Tachycardia Syndrome (PoTS)
Date of Request:	15 November 2023

Requested:

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. What is your estimate of the incidence of PoTS in the population of Carmarthenshire, Ceredigion and Pembrokeshire?
 - a. How many patients have been diagnosed with the condition over the last 5 years?
2. Is there evidence of a growth in PoTS diagnoses since May 2020 due to patients suffering with long-Covid?
3. To which specialty within secondary care are PoTS patients referred for investigation, diagnosis and longer-term management?
4. Are there established ICB patient pathways in place for the referral, diagnosis and management of a) adult patients and b) paediatric patients with PoTS in your local population?
5. 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 individual adult and paediatric services patients are referred to.
6. How is activity coded for adult and paediatric patients with a diagnosis of PoTS?

Response:

1. The Freedom of Information Act 2000 (FoIA) covers any recorded information that is held by a public authority; recorded information includes printed documents, computer files, letters, emails, photographs, and sound or video recordings. The FoIA does not cover information on estimates, opinions or recommendations. The UHB has an obligation to provide information already in recorded form but cannot create new information to answer a question.
 - 1a. The UHB is unable to provide you with the information requested, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

The UHB does not centrally record this information, as PoTS does not have an individual clinical code for recording this condition in the Welsh Patient Administration System (WPAS). Therefore, the UHB would need to undertake a manual trawl of all Cardiology patient records, to identify any information that would fulfil your request.

The UHB is therefore applying an exemption under Section 12 of the FoIA, which provides an exemption from a public authority's obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

2. The UHB can confirm that there is anecdotal evidence of a small increase in the number of referrals, often by patients who have raised the possibility of this diagnosis with their GPs. However, this has not been formally quantified.
3. The UHB confirms that most PoTS patients would be referred to the Cardiology Department. However, some may be referred to the Endocrine Department to exclude Addison's disease and some may be referred to the Neurology Department for investigation of syncope.
4. The UHB confirms that it has no specific pathways for PoTS in place.
5. The UHB confirms that it does not have specific PoTS clinics or services for adults or children and young people (CYP).
 - a. However, for adults, Active Stand Test protocol has been circulated among the UHB's cardiologists and used to provide information that in the presence of other factors might support a diagnosis of POTS.
 - b. For CYP, each county in the UHB's geographical area, has a consultant Paediatrician with Expertise in Cardiology (PEC). The PEC will refer CYP patients in Carmarthenshire and Pembrokeshire, with any abnormality, including suspicion of PoTS, to tertiary care based at the University Hospital for Wales, within Cardiff and Vale University Health Board (CAVUHB). CYP patients in Ceredigion are referred to Alder Hey Children's NHS Foundation Trust.
6. The UHB confirms that it does not have a specific code for PoTS; all activity is recorded on individual patient notes.