

Freedom of Information Request: Our Reference CTMUHB_511_23

You asked:

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 Bridgend, Merthyr Tydfil, Rhondda and Cynon Taf and how many patients have been diagnosed with the condition over the last 5 years?

Due to the way the Health Board records information, we are unable to respond to the question above as we only record the number of inpatients discharged with any appropriate diagnosis.

However to assist with your request, we have provided below the number of inpatient cases:

Year	2019	2020	2021	2022	2023	Total
Inpatients	11	7	20	18	34	92

2. Is there evidence of a growth in PoTS diagnoses since May 2020 due to patients suffering with long-Covid?

We can confirm that the Health Board does not centrally record this information. The information you require would be recorded within an individual patient's health record as part of their ongoing care. To provide you with this information, would require a manual trawl and significantly exceed the 18 hours time and £450 cost limit set out within Section 12 of the Freedom of Information Act.

3. To which specialty within secondary care are PoTS patients referred for investigation, diagnosis and longer-term management?

Usually Cardiology.

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?

No.

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.

No.

6. How is activity coded for adult and paediatric patients with a diagnosis of PoTS?

The condition is very rare and is not currently indexable within ICD-10 codes for outpatients.