

Reference:	FOI.18002.25
Subject:	Narcolepsy Services
Date of Request:	5 August 2025

Requested:

Please provide the following information regarding narcolepsy services provided or commissioned by your organisation:

1. Do you provide or commission narcolepsy services?
2. If yes, please provide:
 - a. The name and location of the service
 - b. The current Referral to Treatment Time (RTT)
 - c. The number of patients seen by the service during the most recent full financial year (to April 2025)
 - d. The number of patients the service is contracted to see
 - e. The key performance indicators (KPIs) or outcome measures are used to monitor the service. Additionally, how the services performed against the set KPIs (outcome measures) for the latest available period of time.
 - f. Whether the service is commissioned through a block contract (Yes/No).
3. If not, please specify:
 - a. The organisation or provider to which patients with suspected or confirmed narcolepsy are referred to.

Response:

1. Hywel Dda University Health Board (UHB) confirms Adult Narcolepsy patients are seen through its general Neurology clinics.
- 2a. The UHB confirms general Neurology services are delivered at Prince Philip Hospital (PPH) in Llanelli and Glangwili General Hospital (GGH) in Carmarthen.
- 2b. The UHB confirms the longest wait to see a general Neurologist is forty-nine (49) weeks.
- 2c. The UHB confirms no patients were added to the waiting list with a referral reason of Narcolepsy during the 2024/25 financial year.
- 2d. The UHB confirms the Neurology service is not contracted to see a set number of Narcolepsy patients. However, the Neurology Service does insource for approximately one hundred and thirty-two (132) general patients per month; see response to 2f. below.
- 2e. The UHB confirms its key performance indicators (KPIs) for stage one (1) patients, awaiting a first appointment with Neurology is fifty-two (52) weeks. The UHB has zero (0) patients

breaching 52 weeks, and it has maintained this position throughout this calendar year to date, 1 January to 15 August 2025.

2f. The UHB confirms the Neurology service commissions a private company to deliver general neurology clinics as a block contract. This is due to the Neurology service having very limited consultants, so it insources to deliver core activity.

3a. Not applicable.