

Reference:	FOI.21354.26
Subject:	Neuromuscular healthcare provision
Date of Request:	17 August 2026

Requested:

Please note our remit, and thus the remit of this FOI, does not include Motor Neuron Disease (MND). A full list of relevant conditions and ICD-10 codes is attached for your reference.

We are writing to seek access to the following information:

1. Please confirm whether your health board has any strategies or transformation programmes relevant to neurological services.
 - a. If so, please provide the relevant strategy documents.
2. Does your health board provide community-based neurology services?
 - a. If yes, can you confirm whether the community-based neurology services treats people with neuromuscular conditions? Please provide the referral criteria used by each team, including a list of conditions which are accepted/covered by the team.
3. Within the past three years (2023-24, 2024-25, 2025-26), have you reviewed improvement in care and pathways for neuromuscular conditions?
 - a. If yes, what did this review find? Please provide any relevant reports or discussion papers.
 - b. If no, please confirm whether and when your organisation has plans to review this.
4. Over the same time period, have you reviewed the care and support needs of people living with a neuromuscular condition within your local population, and planned services to meet these needs?
 - a. If yes, what did this review find? Please provide any relevant reports or discussion papers.
 - b. If not, are there plans to do so?
5. Please confirm the total number of children and adults with a known diagnosis of a neuromuscular condition within the population covered by your health board.
6. Please provide the total annual funding provided for adult and paediatric neurology for the financial year 2022-23, 2023-24, 2024-25, and 2025-26.
7. Please provide the total annual funding provided for neuromuscular care for the financial year 2022-23, 2023-24, 2024-25, and 2025-26. If exact figures are not available, please provide an approximation based on the records you hold.
8. Please confirm whether your health board includes people with lived experience of neurological conditions in decision-making about the commissioning of neurological services.
 - a. If yes, please provide further details.
 - b. If not, please outlines the barriers

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with the information requested for question 5, as it is estimated that the cost of answering your request would exceed the "appropriate limit" as stated in the Freedom of Information Act 2000 (Appropriate Limit and Fees)

Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2 ½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with the information requested, the UHB would need to manually search the records of all Neurology patients for both adults and children and young people (CYP), to identify any information that would fulfil this part of your request, as it is not recorded centrally.

The UHB can confirm that it currently has two thousand, three hundred and twenty-five (2,325) adult Neurology patients on the follow-up waiting list. It is estimated that a manual search of these records alone would exceed the 18 hours stipulated within the Freedom of Information Act 2000 (FoIA). Based on the number of records identified, conducting a search, taking a minimum of five (5) minutes per record, would exceed the ‘appropriate limit’, costing the UHB the following:

2,325 @ 5 minutes per record = 193 hours and 45 minutes
193 hours and 45 minutes @ £25 per hour = £ 4,843.75

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.

However, under Section 16 of the FoIA, we are required as a public authority, to provide advice and assistance so far as it is reasonable to individuals who have made a request under the FoIA, this can include assisting a requestor to further refine their request.

Unfortunately, the UHB is unable to provide advice on how you can refine your request further. This is due to the UHB still requiring a manual trawl of all Neurology patient records for the 2022/23 to 2025/26 financial years to be undertaken, to identify any information that would fulfil your request.

Under Section 16, the UHB provides the accessible information it holds below.

1. The UHB does not hold the information requested, as it does not have strategies or transformation programmes running for its Neurological services. For clarity, Neurological services for adults are generally provided by the Neurology service, while paediatric patients are seen within the wider Paediatric service as the UHB does not have a dedicated Paediatric Neurology service. Patients are managed locally where possible with referrals made to specialist regional centres when required.
2. The UHB does not have a specific community-based Neurology Service. Patients are seen and treated on an individual needs basis and are referred to the most appropriate treatment route, including referrals to Allied Health Professionals, which can include community-based treatments/therapies.
3. The UHB does not hold the requested information, as it does not have a pathway dedicated to Neuromuscular conditions.
4. The UHB does not hold the requested information. Neurology patients are seen and treated on an individual needs basis, receiving care locally where possible, from the most appropriate service for their needs. Patients requiring care that cannot be provided locally, e.g. more

specialist care, can be referred to other care providers to ensure their individual needs are met.

5. An exemption under Section 12 of the FoIA has been applied.
6. & 7. The UHB does not hold the information exactly as requested, as the budgets are allocated across the wider Neurology and Paediatric services. However, the UHB provides within the table below, the budget for adult Neurology services, for the 2022/23 to 2025/26 financial years.

Financial year	Budget
2022/23	£387,690.00
2023/24	£979,261.00
2024/25	£1,039,463.00
2025/26	£1,074,515.00

8. The UHB does not hold the requested information as it has not undertaken a work programme of this nature. However, it is standard procedure for patients and service users to feed into programmes of work relating to service development or service change.