

Our ref: IG/FOI/FOI.159.25

21 February 2025

Sent via email to: [REDACTED]

Dear [REDACTED]

## **Request under the Freedom of Information Act 2000**

I write further to your request for information which was received on 8 January 2025 and subsequent clarification received on 24 January 2025, to confirm, in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Teaching Health Board (PTHB) partly holds the information that you require. For ease of reference your request is set out below and my response follows.

### Your Freedom of Information (FOI) Request:

I am writing to you under the Freedom of Information Act 2000 to request the following information. Please may you provide me with answers to the following questions. For each of the last 5 financial years (2019-2020, 2020-2021, 2021-2022, 2022-2023, 2023-24) please provide the following:

#### Commissioning Process:

1. A description of the care and support commissioning process for people living with MND, including key stages and decision-making criteria.
2. The average duration of the commissioning process from initial proposal to the awarding of contracts for care and support people living with MND.

#### Commissioned Services:

3. A list of all care and support services commissioned for people living with MND, including the name of the service provider, the location of the service provider, the type of service provided, and the duration of the contract.
4. The total number of new contracts awarded, and the number of contracts renewed for people living with MND.

#### Budget and Expenditure:

5. The total budget allocated for care and support commissioning for people living with MND.

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Brecon, Powys LD3 0LU  
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6. The actual expenditure on commissioned care and support services for people living with MND, broken down by service type.

MND Diagnosis:

7. How many people have been diagnosed with a neurological condition.

8. How many people have been diagnosed with MND.

9. Average length from initial presentation to formal diagnosis of MND.

10. Average length of time from formal diagnosis to registration of death for people with MND.

11. How many hospital admissions have you had for someone living with MND.

Neurological support:

12. How much money has been spent on neurological support for people living with MND.

13. How many consultant neurologists have you employed that support people living with MND.

Psychological support:

14. How much money has been spent on psychological support for people living with MND.

15. How many psychologists have you employed that support people living with MND.

Genetic testing:

16. How many people with an MND diagnosis have received genetic testing.

17. How many family members of people with MND have received genetic testing.

18. What is the average length of time between requesting genetic testing and receiving the results.

Clarification requested:

Q1. Please can you confirm what is meant by description of the care and support commissioning process? Do you require the information generically on the commissioning process given there is not a specific process for individuals living with Motor Neurone Disease (MND).

Q2, Q3 & Q4. Please can you confirm which contracts you wish to have information on. Do you require the information for organisations we specifically commission services for individuals living with MND.

Q5 & Q6. Please can you confirm if you wish to have the breakdown expenditure for all services for people with MND or only specifically relating to contracts where we commission services specifically for people living with MND.

Q12, Q13, Q14 & Q15. Please can you confirm what is meant by neurological support and from whom e.g. Provider/ Commissioner Basis?

Clarification received:

Q1. Yes please, the commissioning process for any care and support services that are utilised by people living with MND.

Q2 - Q4. Any contracts commissioned in the timeframe that have been utilised for people with MND.

Q5 - Q6. All services for people with MND please.

Q12 - Q15. Any support providers that provide neurological services for people with MND.

Powys Response:

Please Note: Powys Teaching Health Board (PTHB) does not hold population prevalence data.

Q1 – Q4: Unfortunately, PTHB does not hold the specific detail to be able to answer these questions. Processes we undertaken are too generic in terms of our Long-Term and Short-Term Agreements to be able to extract the level of information you require. Any processes for new contracts would be taken through our national procurement process.

Q5. I can confirm there is no specific budget for care and support commissioning for people living with Motor Neurone Disease (MND). These costs are contained within our overall commissioning and provider spend portfolios.

Q6. Please see the table below for the expenditure on commissioned care and support services for individuals living with MND. Please Note: This data includes all hospital admissions for PTHB patients where the patient has a diagnosis of MND as signified by diagnosis code G122.

Year of discharge	Total number of admissions	Total cost of admissions
2019-2020	13	£38,787
2020-2021	20	£111,866
2021-2022	19	£182,012
2022-2023	15	£52,773
2023-2024	26	£98,503
<b>Grand Total</b>	<b>93</b>	<b>£483,940</b>

These are divisible as follows between Activity provided in Powys and activity commissioned from other providers.

Year of discharge	PTHB provider number of admissions	PTHB provider cost of admissions
2019-2020	3	£23,620
2020-2021	4	£82,480
2021-2022	3	£149,262

2022-2023	3	£32,143
2023-2024	3	£69,296
<b>Total</b>	<b>16</b>	<b>£356,801</b>

Year of discharge	Other provider number of admissions	Other provider cost of admissions
2019-2020	10	£15,167
2020-2021	16	£29,386
2021-2022	16	£32,750
2022-2023	12	£20,630
2023-2024	23	£29,206
<b>Total</b>	<b>77</b>	<b>£127,139</b>

Q7 – Q10. I can confirm this data is held with General Practitioners (GP). For GP data you will need to contact the GP Practices directly. The link below provides Powys GP contact details: [General Practices - Powys Teaching Health Board \(nhs.wales\)](https://www.nhs.uk/healthboard/powys/General-Practices)

Q11. Please see question 6 above for the number of hospital admissions PTHB have received for an individual living with MND.

Q12. I can confirm PTHB are working with MND society to develop a MND care coordinator. PTHB are unable to identify any specific spend, however this does not mean we have not provided any support, but we are unable to distinguish from other neurological support provided at the current time.

Q13. I can confirm PTHB does not have any Consultant Neurologists employed by PTHB to support people living with MND.

Q14. I can confirm PTHB has a Clinical Consultant Psychologist for Neurological conditions in which MND clients can access this service. I can confirm there is no post specific for MND. As per Q12 above, PTHB are unable to identify any specific spend, however this does not mean we have not provided any support, but we are unable to distinguish from other neurological support provided at the current time.

Q15. I can confirm PTHB has one psychologist that support individuals living with MND.

Q16 – Q18. I can confirm reliable figures held for generic testing would not be held within PTHB data. The data will be held with the neurologists commissioned from outside of Powys.

Under the terms of the Health Board's Freedom of Information procedure, individuals seeking access to recorded information held by the Health Board are entitled to request an internal review of the handling of their requests. If you would like to complain about the Health Board's handling of your request, please contact us directly at the address below or register your complaint via [Powys.foi@wales.nhs.uk](mailto:Powys.foi@wales.nhs.uk)

If after Internal Review you remain dissatisfied you are also entitled to refer the matter to the information commissioner at the Information Commissioner's Office (Wales), 2nd Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH. Telephone Number: 0330 414 6421.

Yours sincerely



**David Farnsworth**  
**Assistant Director, Community Services Group**

Rydym yn croesawu derbyn gohebiaeth yng Nghymraeg. Byddwn yn ateb y fath ohebiaeth yng Nghymraeg ac ni fydd hyn yn arwain at oedi.

We welcome receiving correspondence in Welsh. We will reply to such correspondence in Welsh and this will not lead to a delay.