Reference:	FOI.16317.25
Subject:	Motor Neurone Disease (MND)
Date of Request:	8 January 2024

Requested:

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.

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.

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with the information requested for questions 7 and 9 of your request, 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 and the 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.

In order to provide you with the information requested for question 7 of your request, the UHB would need to undertake a manual trawl of all patient records, to identify those patients who have been diagnosed with a neurological condition.

The UHB can confirm that there are (199) one hundred and ninety-nine people who have been diagnosed with MND during the time period of your request. Therefore, to provide you with the exact information being requested for question 9, conducting the search would far exceed the 'appropriate limit', costing the UHB the following:

199 @ 15 minutes per item = 49.75 hours
49.75 hours @ £25 per hour = £1,243.75

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (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, the UHB has a duty to provide advice and assistance. Therefore, the UHB provides the accessible information it holds below.

Commissioning Process:

1. Hywel Dda University Health Board (UHB) is part of NHS Wales and is an integrated Local Health Board responsible for the planning and provision of primary, community and in hospital services, based on the needs of the local community across three (3) counties. NHS Wales does not commission care in the same way as NHS England and therefore, the UHB does not hold the information in the way it is requested. The UHB provides MND within its core clinical services.

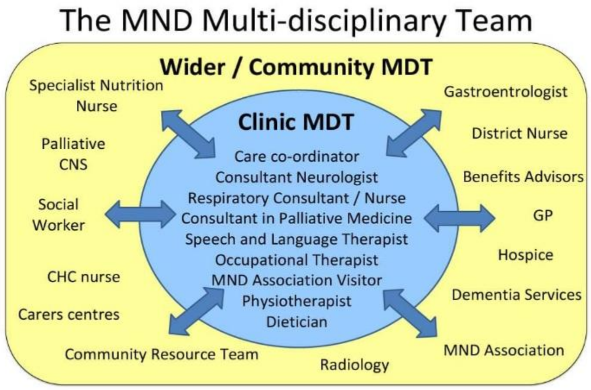
   In South Wales, there is the South Wales MND Care and Research Network and as part of this network (5) five Health Boards, including the UHB, work together to provide services looking after people living with and affected by MND. The Network is supported by (5) specialist care coordinators, who provide a single point of access in each of the (5) five local Health Boards, liaising and working within a localised and pre-existing Multi-Disciplinary Team (MDT) in both a clinic and community setting, from diagnosis to death. Primary and secondary care are also involved in caring for this patient group, as well as charities, most notably the MND Association.

   The MND Association works with the Network in various ways. MND Association volunteers attend clinics to greet patients as they arrive. Also, patients who request Association volunteers are referred by the Network, and patients are also signposted to their website and the grants that they offer. Additionally, Network specialist care coordinators often liaise with local branches of the MND Association and will go and speak at their open days.

2. The UHB does not hold the information requested. However, it can confirm that the current commissioning contract was submitted in November 2022 and was confirmed by the UHB in November 2024.

Commissioned Services:

3. The UHB does not hold the information requested. However, it can provide you with the following graphic demonstrating how the MND MDT works. The Network's care coordinators work as part of the MND MDT to provide services to people living with and affected by MND.
   The way in which the MDT works with people living with and affected by MND is demonstrated in the graphic below:



4. The UHB can inform you that it has awarded (2) two contracts and (1) one contract extension for people living with MND between 2019 to present day, as follows:

- The UHB as part of the Network awarded a (4) four-year contract from 2019 – 2023
- The UHB as part of the Network awarded a (12) twelve-month contract extension from 2023 – 2024
- The UHB as part of the Network awarded a (4) four-year contract from 2024 – 2028

Budget and Expenditure

5.&6. The UHB considers that Section 43 of the FoIA applies to some of the requested information, as answering would be prejudicial to commercial interests. Section 43(2) exempts information, where disclosure would or would be likely to prejudice the commercial interests of any company. Commercial interests may be prejudiced where disclosure would, or would be likely to:

- Weaken a company's position in a competitive environment by revealing market sensitive information or information of potential usefulness to its competitors
- Damage a company's business reputation or the confidence that customers/users, suppliers or investors may have in it.

This exemption is qualified; therefore, even if information falls within Section 43, public authorities must then apply the public interest test set out in Section 2(2)(b). The information can only be withheld if the public interest in maintaining the exemption outweighs the public interest in disclosure.

The UHB has therefore considered the following:

In **favour of disclosure**: There is a public interest in transparency and in the accountability of public funds. Furthermore, it is in the public's interest that public funds be used effectively and that public sector bodies obtain the best value for money when contracting for the provision of services. Organisations engaging in commercial activities with the public sector must expect some information about those activities to be disclosed. The UHB sought the views of the MND Association on disclosure of the requested information. Their view was that they were content with the disclosure of the requested information.

Against Disclosure: Disclosure of the information being requested, when used in conjunction with other information accessible within the public domain could result in the calculation of the financial contribution from the MND Association. Disclosure of the information requested could impact negatively on the UHB's relationship with the MND Association should they not have an expectation that their funding contributions be released into the public domain, thus affecting our service delivery.

Decision: - The UHB has considered that releasing the information under the FoIA, to which the UHB is subject, would not impede upon the UHB's relationship with the MND Association or negatively impact the commercial activities of the MND Association. The UHB believes that there is greater public interest in the effective use of public funds and the knowledge that the UHB is obtaining the best value for money when contracting service provision. Also, the MND Association is content to disclose the requested information. Therefore, the public interest in disclosing the requested information is greater than the interests in withholding the requested information.

The UHB can inform you that the South Wales MND Care and Research Network has received funding from the MND Association since 2012. Funding between 2019-2023 followed a tapering arrangement, with the MND Association contributing 52% of the running costs and the remaining 48% being split between the LHBs – this reduced by 2% for the Association and increased by 2% for the LHBs each financial year.

The partnership agreement for 22/23 was 50% MND Assocation and 50% LHBs, which amounted to £15,857 from each of the LHBs and totalled at £70,829 for the four-year period. 2024-2028 follows a period of adjusted tapering during the 2024-28 grant cycle where the LHBs' contribution rises to full funding for the core service at an estimated contribution of £40,309 per year, per Health board.

Dec 23 – Nov 24	60%	£24,185
Dec 24- Nov 25	70%	£28,217
Dec 25- Nov26	80%	£32,248
Dec 26-Nov 27	90%	£36,279
Dec 27 onwards	100%	£40,309

MND Diagnosis

7. The UHB has applied a section 12 exemption to your request.

8. The UHB provides within the table below, the number of people who have been diagnosed with MND by calendar year during the time period requested, with the exception of 2024, which includes information held from January to September.

Health Board	2019	2020	2021	2022	2023	2024	Total
HDUHB	47	38	36	27	36	15	199

9. The UHB has applied a section 12 exemption to your request.

10. The UHB does not hold the information requested.

11. The UHB provides within the table below, the number of hospital admissions recorded on the Welsh Patient Administration System (WPAS) with a diagnosis for MND, by financial year, during the time period requested.

It should be noted that patients with MND may not be admitted to hospital for symptoms related to MND.

Year	2019/2020	2020/2021	2021/2022	2022/2023	2023/2024	Total
Number	78	21	42	44	64	249

Neurological Support

12. The UHB does not hold the information requested.

13. Due to long term sickness between 2019-2021, Neurology cover in the UHB was sporadic. At this time, diagnosis was made by neurologists based in the UHB and Swansea Bay University Health Board (SBUHB) and care was then delivered by the MND team. Since 2022, the MND service within the UHB has had (1) one Locum Consultant who supports the MDT to deliver (3) three different clinics, with on average (2) two sessions per month.

Psychological Support

14. The UHB does not hold the information requested.

15. The UHB has (0) zero psychologists employed that support people living with MND.

Genetic Testing

16. The UHB is unable to provide you with the requested information, as there is a potential risk of identifying individuals if this was disclosed due to the low number of cases (5 and under). The UHB is therefore withholding this detail under Section 40(2) of the FoIA. This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations, as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

17. The UHB has (0) zero records held of family members of people with MND who have received genetic testing.

18. The UHB does not hold the information requested.