

Freedom of Information Act 2000 - Request Reference FoI/20/062

Multiple Sclerosis (MS)

Request details

We have a Freedom of Information request regarding prescribing in Neuroscience.

Could you please provide us with the numbers of patients in relation to the questions mentioned below, for a period of last 12 months:

1. In your trust how many patients have a diagnosis of Multiple Sclerosis (MS), regardless of whether they are currently on treatment?

Cardiff and Vale University Health Board (the UHB) have had 366 individual patients coded with a diagnosis of Multiple Sclerosis (MS) following an inpatient or daycase stay for the period 1/2/2019 to 31/1/2020.

This data does not represent activity outside of the inpatient or daycase setting (e.g. outpatient data).

2. Of these MS patients, how many have been diagnosed with relapsing (RRMS), primary progressive (PPMS) or secondary progressive (SPMS) MS;

If you do not code your MS patients in this way, do you have plans to do this?

RRMS

PPMS

SPMS

Not known

In completing a search for the information requested, the UHB has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual search through individual records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the Section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 18 hours, to comply with a request and the cost limit set within the fees regulations for this amount of work (18 hours) is £450 for the UHB. The fees regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.

3. How many patients with Multiple Sclerosis have been treated with disease modifying drugs in the past 6 months. Please include all patients whose treatment is ongoing, even

those with infrequent dosing schedules (e.g. Lemtrada, Mavenclad, Ocrevus). Please provide the total number of patients by treatment for the following disease modifying drugs:

Aubagio (teriflunomide)
Avonex (interferon beta-1a)
Betaferon (interferon beta-1b)
Brabio (glatiramer acetate)
Copaxone (glatiramer acetate)
Extavia (beta interferon-1b)
Gilenya (fingolimod)
Lemtrada (alemtuzumab)
Mavenclad (cladribine)
Mayzent (siponimod)
Ocrevus (ocrelizumab)
Plegridy (peginterferon beta-1a)
Rebif (beta interferon-1a)
Tecfidera (dimethyl fumarate)
Tysabri (natalizumab)
Vumerity (diroximel fumarate)
Zinbryta (daclizumab)
Ampyra (fampyra)
Ozanimod

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4. Of the patients who are receiving Ocrevus (Ocrelizumab), how many are primary progressive (PPMS)? If unknown, please state unknown.

Please refer to Question 2.

5. How many patients have been treated with these drugs in the past 6 months, regardless of diagnosis.

- Aubagio (teriflunomide)**
- Avonex (interferon beta-1a)**
- Betaferon (interferon beta-1b)**
- Brabio (glatiramer acetate)**
- Copaxone (glatiramer acetate)**
- Extavia (beta interferon-1b)**
- Gilenya (fingolimod)**
- Lemtrada (alemtuzumab)**
- Mavenclad (cladribine)**
- Mayzent (siponimod)**
- Ocrevus (ocrelizumab)**
- Plegridy (peginterferon beta-1a)**
- Rebif (beta interferon-1a)**
- Tecfidera (dimethyl fumarate)**
- Tysabri (natalizumab)**
- Vumerity (diroximel fumarate)**
- Zinbryta (daclizumab)**
- Ampyra (fampyra)**
- Ozanimod**

Please note that Section 40 of the Freedom of Information Act 2000 has been applied where information in the below table has been replaced with an asterisk. The UHB will not provide these exact numbers due to the low numbers of individuals involved (5 or less). The UHB believes there is a potential risk of individuals being able to be identified, when considered with other information already available within the public domain, if this was disclosed. Therefore, the data is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.

Aubagio (teriflunomide)	*
Avonex (interferon beta-1a)	0
Betaferon (interferon beta-1b)	0
Brabio (glatiramer acetate)	6
Copaxone (glatiramer acetate)	0
Extavia (beta interferon-1b)	0
Gilenya (fingolimod)	51
Lemtrada (alemtuzumab)	13
Mavenclad (cladribine)	*
Mayzent (siponimod)	0

Ocrevus (ocrelizumab)	60
Plegridy (peginterferon beta-1a)	12
Rebif (beta interferon-1a)	*
Tecfidera (dimethyl fumarate)	119
Tysabri (natalizumab)	69
Vumerity (diroximel fumarate)	0
Zinbryta (daclizumab)	0
Ampyra (fampyra)	0
Ozanimod	0