

8 September 2021

Multiple Sclerosis (MS) Coding, Treatment and Waiting Times

- 1. Are your patients coded for the different sub types of MS (multiple sclerosis) - relapse remitting, primary progressive and secondary? Please answer Yes, No, coding planned, partial coding, all patients coded.**

No

This information is not held centrally and therefore Belfast Trust is unable to respond. To provide the information would require a manual trawl of all patient records and it is anticipated that this would be in excess of 18 hours.

The Trust considers that the cost of retrieving the information would be above the 'Appropriate Limit', as defined by the FOI Act under Section 12. Section 12 of the Freedom of Information Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit. The limit has been specified as £450 for public authorities such as Belfast Trust. This represents the cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.

Most patients attend MS clinics but there are many more patients who attend General clinics, as all Consultants manage patients with MS. Therefore, there is no way of defining how many patients we have in Belfast Trust with MS.

- 2. For secondary progressive MS are your patients coded? Please answer No coding, coding planned, partial coding, all patients coded.**

No coding.

This information is not held centrally and therefore Belfast Trust is unable to respond. To provide the information would require a manual trawl of all patient records and it is anticipated that this would be in excess of 18 hours.

- 3. What proportion of your MS patients have a diagnosis of secondary progressive MS (within all MS diagnosed patients? Please answer Unknown, <10%, 10-20%, 21-30%, 31-40%, >50%**

Unknown.

Again, this information is not held centrally and therefore Belfast Trust is unable to respond. To provide the information would require a manual trawl of all patient records and it is anticipated that this would be in excess of 18 hours.

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- 4. For MS patients requiring an MRI, what is the average waiting time? Please answer <1 month, 2 – 3 months, 4 – 6 months, >6 months**

> 6 months

The average waiting time for an MRI is approximately 6 months for a routine scan.

- 5. For MS patients requiring an OCT, what is the average waiting time? Please answer <1 month, 2 – 3 months, 4 – 6 months, >6 months**

< 1 month

The average waiting time for a patient who requires OCT is less than one month.

- 6. For MS patients what is the average waiting time for IV MS treatment? Please answer <1 month, 2 – 3 months, 4 – 6 months, >6 months**

2 – 3 Months

The average waiting time for a patient who requires an IV MS treatment is dependent on many factors, which include whether a washout period is required prior to initiation of a different treatment option.

For patients who are symptomatic and require IV steroids, the waiting time is less than one month.

- 7. When a patient has been diagnosed with MS, what is the average time from diagnosis of MS to initiate treatment?**

The average time from diagnosis of MS to initiation of treatment is dependent on various factors, which include waiting time for the results of diagnostic testing and the suitability for various treatment options. On average, a patient may wait for up to 13 weeks.

- 8. How many unscheduled admissions have there been for patients with a diagnosis of MS in any position between April – June 2021? Please answer with the number of admissions.**

This information is not held centrally and therefore Belfast Trust is unable to respond. To provide the information would require a manual trawl of all patient records and it is anticipated that this would be in excess of 18 hours.

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9. How many MS patients are being treated in neurology rehab? Please answer the number of patients.

This information is not held centrally and therefore Belfast Trust is unable to respond. To provide the information would require a manual trawl of all patient records and it is anticipated that this would be in excess of 18 hours.

10. Of the patients in Question 8, how many are being treated with an MS disease-modifying drug? Please answer with the number of patients.

This information is not held centrally. To provide the information would require a manual trawl of all patient records. Belfast Trust would estimate that this would take in excess of 18 hours to complete.

11. How many MS patients are in the following EDSS (Expanded Disability Status Scale) groups? 1 – 3.5, 3.5 – 6.5, >7

Unknown

This information is not held centrally and therefore Belfast Trust is unable to respond. To provide the information would require a manual trawl of all patient records and it is anticipated that this would be in excess of 18 hours.

12. How many of your physicians can initiate MS disease modifying drug treatment? If possible please supply the physicians name

All Consultant Neurologists can prescribe a disease modifying treatment for a patient with MS. Depending on the complexity of the patient's needs, some patients are referred directly to the MS Service for treatment options. Belfast Trust has three Consultant Neurologists who have a specialist expertise in the management of patients with MS.