# Expert consensus on standards for multiple sclerosis care: results from a modified Delphi process

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## Background

- The need for prompt diagnosis and early treatment of multiple sclerosis (MS) was highlighted by the widely endorsed policy report *Brain health: time matters in multiple sclerosis.*<sup>1</sup>
- The current study aimed to define international standards for the timing of key steps in the MS care pathway.
- These standards will inform the content of tools to help MS services strive for the highest level of care.

## Methods

- The Delphi process is a structured communication technique for gaining consensus among experts.
- Here, the Delphi process was modified to include both a core Delphi Consensus Panel and an additional Reviewing Group (**Figure 1**).

#### **Participants**

- Four Chairs directed the process; they represented neurology, patientreported outcomes, nursing/policy and the patient perspective.
- In total, 39 MS neurologists from 26 countries were invited to participate in the **Delphi Consensus Panel** (**Figure 1**); 29 agreed to participate. All were currently based in an MS clinic and were spending at least half of their clinical time seeing patients with MS.
- Panel members were required to take part in each round to remain in the process.
- Responses were collected via online surveys, and participants remained anonymous to analysts and Chairs throughout.
- Thirty-nine MS nurses, people with MS and allied healthcare professionals were invited to participate in the **Reviewing Group**; 31 agreed to

## Subset of achievable consensus standards

	Reporting	first symptom	S	
Referral and diagnosis	ł	10 days	<ul> <li>Anyone who reports symptoms that might be related to MS to a healthcare professional should be referred to a neurologist within 10 days</li> </ul>	
	Referral			
		2 weeks	<ul> <li>An initial MRI scan should be performed within 2 weeks of first referral to a neurologist for diagnosis (if not performed earlier)</li> </ul>	
	_	4 weeks	The MS team should complete a diagnostic workup for MS within 4 weeks of referral to a neurologist	
			An accurate diagnosis of (uncomplicated) MS should be made within 4 weeks of referral to a neurologist	
	Completion of diagnostic workup			
		10 days	<ul> <li>The results from a diagnostic workup for MS should be discussed within 10 days of completion, during an appointment with the patient</li> </ul>	
	<b>↓</b>	45 minutes	<ul> <li>Following MS diagnosis, patients should be offered an initial appointment of at least 45 minutes to discuss the implications of the diagnosis</li> </ul>	
	Diagnosis			
Treatment decisions		2 weeks	The MS team should discuss the aims of treatment with each patient within 2 weeks of MS diagnosis	
		3 weeks	The MS team should discuss the pros and cons of early treatment with a DMT with patients within 3 weeks of diagnosis	
	<b>↓</b>		<ul> <li>The MS team should assess within 3 weeks of an MS diagnosis whether the patient is eligible for treatment with a suitable DMT</li> </ul>	
	Patient be	comes eligible	for DMT	
	Patient de	3 weeks cides to start [	A DMT should be offered to a patient with MS within 3 weeks of their becoming eligible for one OMT	
	$\downarrow$	2 weeks	<ul> <li>Treatment with a DMT should commence within 2 weeks of a patient with MS agreeing this approach with their neurologist</li> </ul>	
	Q	Every 6 months	<ul> <li>The MS team should review at least once every 6 months whether each patient with MS who is not receiving a DMT is eligible for one, based on applicable guidelines</li> </ul>	
	Routine co	onsultations		
Monitoring	$\bigcirc$	Every	The MS team should perform a follow-up clinical evaluation of each patient at least once every 6 months	
		6 months	The MS team should review with each patient at least once every 6 months the aims of their treatment for MS	
	<b>O</b>		<ul> <li>The MS team should review with each patient at least once every 6 months their currently prescribed DMT and consider alternatives if appropriate</li> </ul>	
	$\frown$	Every 1 year	<ul> <li>All patients with MS should be offered an MRI scan at least once every year</li> </ul>	
		Regularly	<ul> <li>The MS team should regularly enter patient data into an MS database</li> </ul>	
	Suboptimal response to DMT			
		4 weeks	<ul> <li>If a patient's response to their current DMT is judged to be suboptimal, an appropriate, alternative DMT should be offered within 4 weeks</li> </ul>	
	New or wo	orsened sympt	oms	
w symptoms	Ļ	7 days	<ul> <li>Patients with MS should report new or worsened symptoms to their MS team within 7 days of experiencing these symptoms</li> </ul>	
	Reporting	new or worse	ned symptoms	
		2 days	The MS team should respond within 2 days to a patient with MS reporting an acute deterioration of symptom	
	Ļ	3 days	<ul> <li>Patients with MS who experience an acute deterioration of symptoms should be seen by the relevant member of their MS team within 3 days of reporting these symptoms</li> </ul>	



Figure 1. Modified Delphi process flow chart.

#### **Consensus thresholds**

The predefined thresholds for consensus were at least 75% agreement and at least 66% participation compared with round 1.

### **Round 1 – principles**

- We derived 21 time-related principles from recommendations in the report *Brain health: time matters in multiple sclerosis*.<sup>1</sup>
- The Panel were asked if each principle was 'an appropriate and accurate description of a good standard when considering brain health in people with MS' and were invited to suggest additional principles for inclusion.
- We then developed variables that describe the principles in clinical practice (**Figure 2**).



Early discussion about the importance of living a brain-healthy lifestyle

#### Variable

Time **from** MS diagnosis **to** discussion about the importance of living a brain-healthy lifestyle

**Figure 3.** 'Achievable' **standards** related to referral, diagnosis, treatment decisions, monitoring and managing new symptoms, that gained at least 75% agreement from the Delphi Consensus Panel in round 4.

DMT, disease-modifying therapy; MRI, magnetic resonance imaging

### Rounds 2 and 3 – timings

- In round 2, the Panel suggested timings for 'core', 'achievable' and 'aspirational' standards (**Table 1**) for each variable, by free text.
- In round 3, the Panel were shown box plots of the round 2 data and asked to choose timings from given options, taking into account the responses from the rest of the Panel. We developed consensus statements based on these results.
- Some principles were not time dependent, so these were not included in rounds 2 and 3 but taken forward to round 4.

#### Rounds 4 and 5 – consensus statements

- In round 4, the Panel voted on consensus statements related to symptom onset, referral, diagnosis, treatment decisions, a brain-healthy lifestyle, monitoring and managing new symptoms; participants indicated agreement (or otherwise) on a five-point Likert scale.
- In round 5, the Panel were shown the results for all statements from round 4

- 'Timely offer of cognitive testing after MS diagnosis' gained the lowest agreement (78%; 21/27).
- Ten additional principles were included based on suggestions from both groups.

### **Consensus on key steps in the patient pathway (round 4)**

- Consensus was reached on the majority of core (22/27), achievable (25/27) and aspirational (18/27) standards with timings and on four statements that did not include timings. Where consensus was not reached, the statements were taken forward to round 5; this is ongoing.
- Here, we present the standards on referral, diagnosis, treatment decisions, monitoring and managing new symptoms, which the Panel agreed should be **achievable** (Figure 3).

### Next steps

Additional consensus standards will be presented at a future date. These

#### **Consensus statement**

The **importance of a brain-healthy lifestyle should be discussed** with each patient with MS within (...) of diagnosis

Figure 2. Example of progression from principle to consensus statement.

Standard	Definition
Core	This should currently be achieved by most MS teams worldwide, regardless of the local healthcare system, and will provide a <b>minimum standard</b>
Achievable	This is a realistic target for most MS teams and reflects a <b>good standard of care</b>
Aspirational	This might be achieved by only a few MS teams, where the local healthcare system allows, but should <b>set the standard for high-quality care</b>

Table 1. Definitions used for consensus standards.

where consensus was not reached and were asked to vote again.

 Those who did not agree with the statements were asked to give reasons in a free-text box.

## Results

We summarize here the results from round 1 and round 4 and present a subset of the **achievable** standards where consensus was reached.

#### **Participants**

 21/27 (78%) of the Delphi Consensus Panel completed round 4 (Figure 1), thus meeting the threshold for participation.

#### Defining a good standard of care (round 1)

- For all 21 principles, over 75% of the Panel (n = 27) agreed that the principle was an appropriate and accurate description of a good standard.
- Three statements gained 100% (27/27) agreement:
  - 'Early discussion with patient about the aims of treatment'
  - 'Evaluation of suitability/eligibility for treatment shortly after MS diagnosis'
  - 'Regular review of the aims of treatment'.

include:

- achievable standards related to symptom onset and a brain-healthy lifestyle
- core and aspirational consensus standards
- round 5 consensus standards.

## Conclusions

- An international group of MS neurologists has agreed standards for the timing of key steps in the MS care pathway which relate to brain health.
- The standards presented here, and those to follow, will inform the development of an MS Brain Health quality improvement tool that will help established and developing MS clinics in different countries strive for the best possible standard of patient care.
- Alongside the clinical tool, the standards also provide the basis for a checklist that will help people with MS to bring about improvements in care.

## Reference

1. Giovannoni G *et al.* Brain health: time matters in multiple sclerosis. *Mult Scler Relat Disord* 2016;9 Suppl 1:S5–S48.

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