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.*[1]
- 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, patient-reported 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 participate (**Figure 1**).

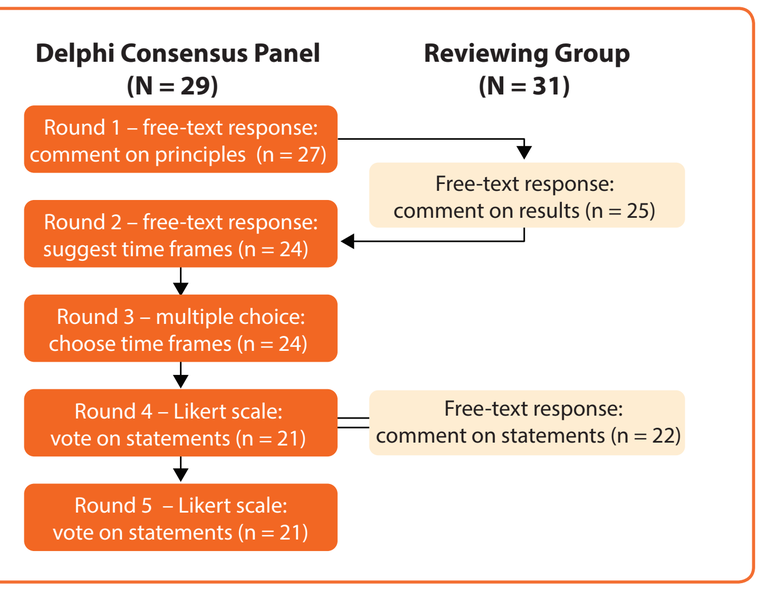

Figure 1. Modified Delphi process flow chart.

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*.[1]
- 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**).

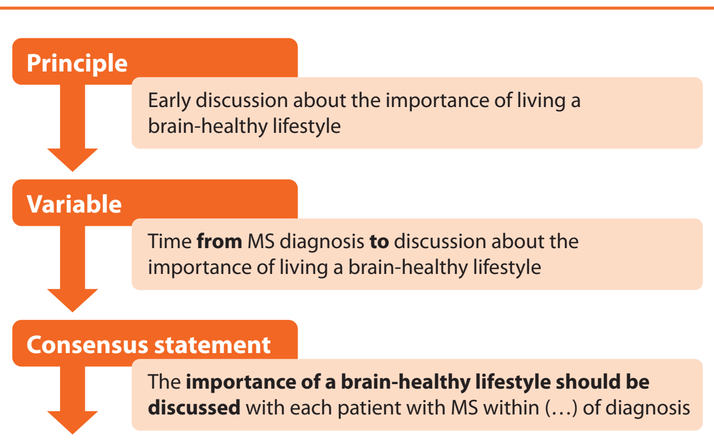

Figure 2. Example of progression from principle to consensus statement.

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

Table 1. Definitions used for consensus standards.

Subset of achievable consensus standards

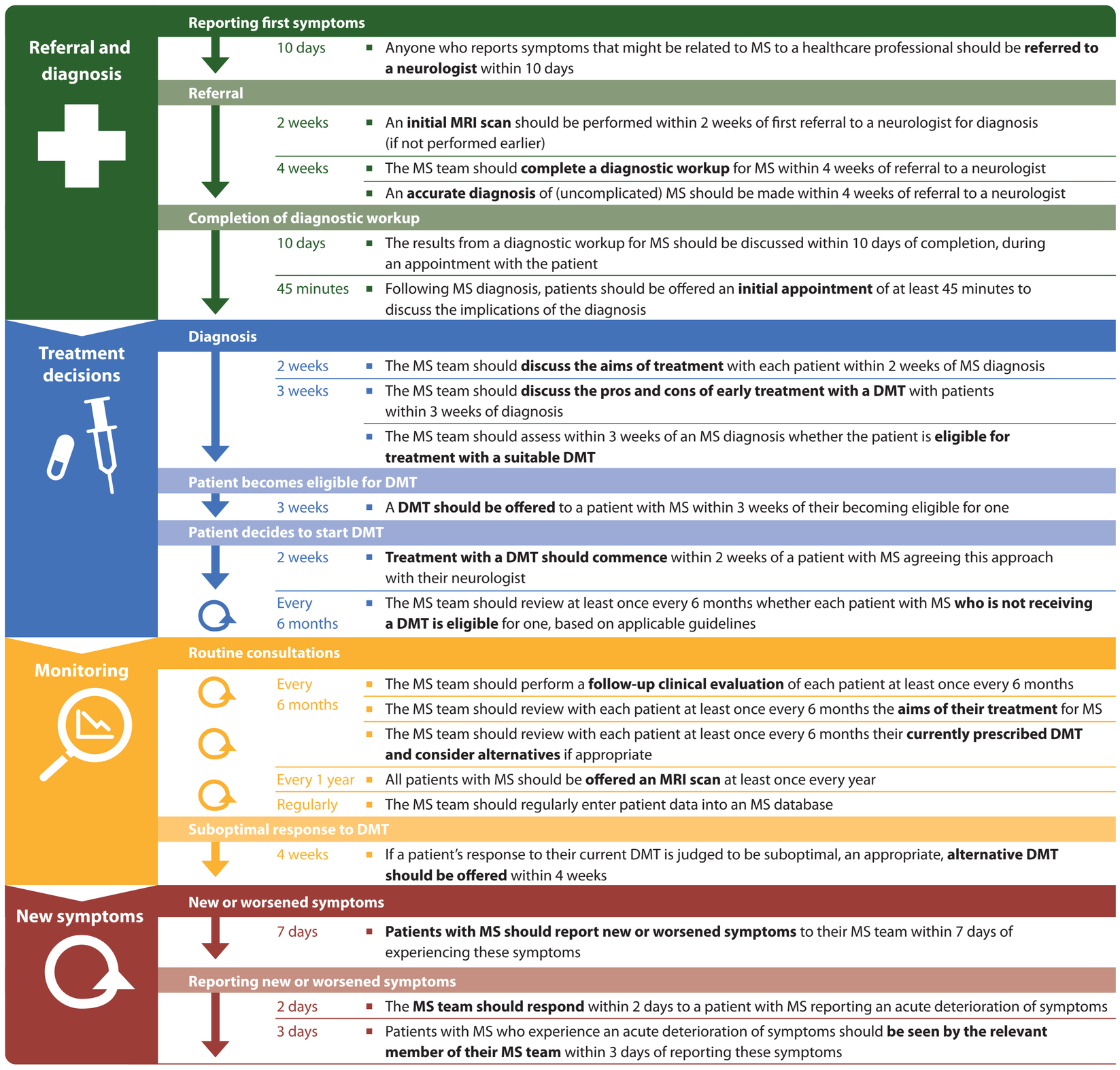

Figure 3. 'Achievable' **standards** related to referral, diagnosis, treatment decisions, monitoring and managing new symptoms, that gained at least 75% agreement from the Delphi Consensus Panel in round 4.

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 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'.
- '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 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.

Disclosures

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Time Matters

To read *Brain health: time matters in multiple sclerosis*, visit **www.msbrainhealth.org**