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: 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, who represented neurology, patient-reported outcomes, nursing/policy and the patient perspective.

In total, 28 MS neurologists from 26 countries were invited to participate in the Delphi Consensus Panel (Figure 1). 29 agreed to participate. All were currently in a 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 Chair throughout.

Thirty-nine MS nurses, people with MS and allied healthcare professionals were invited to participate in the Reviewing Group (Figure 1).

Consensus thresholds

The predefined thresholds for consensus were at least 75% agreement and at least 60% participation compared with round 1.

Disclosures

Butzkueven HB has received consultation fees from Boehringer Ingelheim, Roche, Merck Serono, Biogen Idec, Genzyme, Novartis, and Sanofi-Aventis. A. Bowen received consultation fees from Genzyme and Merck & Co. J. Hobart has received consulting fees from Genzyme, Merck & Co. and Fujifilm. J. Eberhard has received consulting fees from Genzyme. A. Bowen, J. Hobart, L. Eberhard, G. Pepper and G. Giovannoni have received multiple speaker’s honoraria from Biogen, Genzyme, Roche, sanofi-aventis, and Merck Serono. G. Giovannoni has received research support from Biogen, Genzyme, Roche, sanofi-aventis, and Merck Serono. A. Bowen, J. Hobart and L. Eberhard have received research support from Genzyme but invest time in the Delphi process only as time permitting. G. Pepper and G. Giovannoni have received research support from Biogen, Genzyme, Roche, sanofi-aventis, and Merck Serono. A. Bowen, J. Hobart, L. Eberhard and G. Giovannoni receive research support for the completion of this project from the Australian Multiple Sclerosis Foundation, Multiple Sclerosis Society of Australia and the National Health and Medical Research Council of Australia.

Results

We summarize here the results from round 1 and round 4 and compare these with 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% (2/7) agreement:

‘Early discussion with patient about the aims of treatment’

‘Regularity of follow-up clinical evaluation’

‘Time to achieve a brain-healthy lifestyle’

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 care (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, 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 herein, and those to follow, will inform the development of an MS Brain Health quality improvement tool that will help establish and developing MS clinics in different countries strive for the best possible standard of care.

Alongside the clinical tool, the standards also provide the basis for a checklist that will help MS professionals to bring about improvements in care.

Reference


Subset of achievable consensus standards

Table 1. Definitions used for consensus standards

<table>
<thead>
<tr>
<th>Principle</th>
<th>Variable</th>
<th>Definition</th>
<th>Treatment decisions</th>
<th>Referral and diagnosis</th>
<th>Reporting first symptoms</th>
</tr>
</thead>
</table>
| Round 1 – principles | We derived 21 time-related principles from recommendations in the report Brain: 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. The Panel was asked if each principle was ‘an appropriate description of a good standard of care’.
| Round 2 – time frames | For gaining consensus among experts. The Panel was asked if each principle was ‘appropriate and accurate description of a good standard of care’.
| Round 3 – choose time frames | Regardless of the local healthcare system, and will provide a minimum standard for different countries.
| Round 4 – Likert scale | The predefined thresholds for consensus were at least 75% agreement and at least 60% participation compared with round 1.
| Round 5 – Likert scale | The predefined thresholds for consensus were at least 75% agreement and at least 60% participation compared with round 1.

Figure 1. Modified Delphi process flow chart.

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

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.