Expert consensus on standards for multiple sclerosis care: preliminary 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: how 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, 41 MS neurologists from 22 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 66% of their 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).

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: how time matters in multiple sclerosis.1 The Panel were asked if each principle was ‘appropriate’ and ‘achievable’, and supported a minimum standard. We then developed variables that describe the principles in clinical practice (Figure 2).

Results

We summarize here the results from round 1 and round 2 and present a subset of the achievable standards where consensus was reached.

Participants

To reach agreement, all principles were presented to the Panel. Panel members could agree or disagree with a principle and respond to any comments made by other Panel members. An “agreement” was counted as a “positive” or an “agreement + disclosure” as a “negative” (GetAltText).

Delphi Consensus Panel (N = 29)

Reviewing Group (N = 31)

Round 1 – free-text response on principles (n = 27)

Round 2 – free-text response on principles (n = 24)

Round 3 – multiple-choice question (n = 24)

Round 4 – Likert scale: agree/disagree (n = 23)

Round 5 – Likert scale: support to attend meetings or research support from (n = 23)

Variable

Core

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

Achievable

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

Apirational

Discussion of the importance of a brain-healthy lifestyle should be discussed with each patient with MS within (…) of diagnosis

Table 1. Definitions used for consensus standards.

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-test. In round 3, the Panel was presented with the 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 disagreement 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 2 and present a subset of the achievable standards where consensus was reached.

Participants

21/27 (77.8%) of the Delphi Consensus Panel completed round 4 (Figure 1), thus meaning the threshold for participation.

Defining a standard of care (round 1)

For all 21 principles, the Panel agreed (n = 27) that the principle was an appropriate and accurate description of a good standard. Three standards gained 100% (27/27) agreement.

Aversible

‘Early discussion with patient about the aims of treatment’

‘Early discussion with patient about the aims of treatment’

‘Regular review of the aims of treatment’

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 consensus among experts. The Panel were asked if each principle was ‘appropriate’ and ‘achievable’ and supported a minimum standard. The Panel agreed to proceed if consensus was not reached, the statements were taken forward to round 4; 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
- care and aspirational consensus standards
- round 5 consensus standards

Disclosures

All authors have reviewed the final submitted version, have made substantial contributions to the study, and agree to be accountable for the research and accuracy of the data. The Committee on Publication Ethics guidelines were followed.

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 between the Delphi consensus Panel in round 4.