

# Implementing a brain health-focused approach to multiple sclerosis care: global and local MS Brain Health initiatives

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## Background

- A strategy to maximize lifelong brain health by minimizing delays in the multiple sclerosis (MS) care pathway was described in the widely endorsed policy report, *Brain health: time matters in multiple sclerosis*.<sup>1</sup>
- MS Brain Health aims to encourage implementation of the recommendations from this policy report by engaging with stakeholders at global and local levels.
- The current work aimed to define international standards for the timing of key events in MS care and to assess interest in quality improvement tools to compare local care with these standards.

## Conclusions

- An international group of MS neurologists, MS nurses, allied healthcare professionals and people with MS has been involved in a modified Delphi process to define standards relating to early diagnosis and treatment.
- Tools to support MS services in achieving these standards of care would be welcomed by many MS healthcare professionals worldwide.
- An Australian MS Brain Health Community has been set up to encourage local implementation of the report recommendations and uptake of future tools. This is a model that we hope other countries will follow.

## Developing standards for MS care

### Methods

- A modified Delphi process was led by four Chairs. A core Delphi Panel of 29 MS neurologists and a Reviewing Group of 31 MS nurses, people with MS and allied healthcare professionals agreed to take part (Figure 1).
- Responses were collected via online surveys; the Panel remained anonymous to analysts and the Chairs throughout.
- The predefined threshold for consensus was at least 75% agreement, with a minimum of 66% of participants from round 1 completing the process.

### Modified Delphi process

- Details of the methodology have been published previously and are briefly outlined below.<sup>2</sup>
  - A total of 21 time-related principles were derived from the recommendations in the report *Brain health: time matters in multiple sclerosis*.<sup>1</sup>
  - Variables describing the principles in clinical practice were developed and the Panel suggested timings for 'core', 'achievable' and 'aspirational' standards for each variable (to reflect minimum, good and high standards of MS care, respectively).

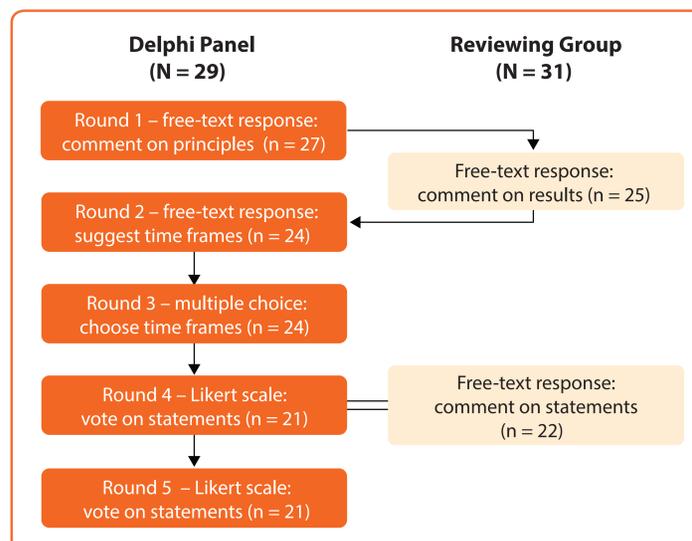


Figure 1. Modified Delphi process flow chart.

Brain-healthy lifestyle	Diagnosis	
	Within 4 weeks	■ The <b>importance of a brain-healthy lifestyle</b> should be discussed with each patient with MS within 4 weeks of diagnosis
Within 3 months	■ Patients with MS who need additional support to make lifestyle modifications, beyond that offered by the MS team, should be <b>referred to appropriate services</b> within 3 months of diagnosis	
Routine consultations		
Every 6 months	■ The MS team should engage patients with MS in an active, documented <b>discussion about living a brain-healthy lifestyle</b> at least once every 6 months	
	■ All patients with MS should have a check-up with an appropriate healthcare professional to screen for and/or <b>manage comorbidities</b> at least once every 6 months	

Figure 2. 'Achievable' standards related to a brain-healthy lifestyle that gained at least 75% agreement from the Delphi Consensus Panel in round 4.

- Consensus statements were developed based on these timings. The Panel voted on the consensus statements, indicating agreement (or otherwise).
- Of the survey respondents, 64% (78/121) worked in clinics that invited patients to give feedback on the care they receive and 70% (92/131) worked in clinics that regularly assess performance against standards agreed to within their practice; 60% (78/131) use international standards as a benchmark for assessments.
- In total, 93% (122/131) of respondents would consider using a tool to compare current practice in their clinic with internationally recommended standards and 91% (116/127) would find it helpful to receive patient feedback relating to those standards.

## Survey: assessing global interest in tools

- A survey was conducted at theECTRIMS–ACTRIMS 2017 congress and online. Questions related to quality assessments, the collection of patient feedback in the respondents' current practice and the respondents' interest in tools to compare local MS care with international standards.
- A total of 131 people from six continents completed the survey (note, not all questions were answered by all participants); 55% (70/127) of the respondents practiced in Europe and 9% (11/127) practiced in North America.
  - Overall, 72% (91/127) were neurologists, 17% (21/127) were nurses and 2% (3/127) were allied healthcare professionals.

## Case study: facilitating local change

### MS Brain Health in Australia

- The global MS Brain Health Steering Committee is encouraging individual countries to set up local groups, with the aim of helping to drive the implementation of the MS Brain Health report recommendations<sup>1</sup> and use of quality improvement tools locally.
- The Australian MS Brain Health Community, formed in 2017, is the first local MS Brain Health group (Figure 3).
  - Membership includes MS nurses, MS neurologists, representatives from MS Australia (the national MS society of Australia), people with MS and community healthcare professionals.

- MS Australia has played an active role in promoting MS Brain Health recommendations, by:
  - asking the major political parties at the 2016 general election to commit to funding the implementation of the recommendations
  - making a pre-budget submission to the 2017 federal budget to fund a project to help implement the recommendations.
- We encourage other countries to adopt a similar local model.



- Promote the implementation of MS Brain Health recommendations
- Identify challenges and barriers to the implementation of these recommendations in Australia
- Deliver projects to target these barriers
- Actively identify and recruit MS Brain Health champions (advocates of the strategy to maximize lifelong 'brain health')

Figure 3. Aims and scope of Australian MS Brain Health Community.

## References

- Giovannoni G et al. *Mult Scler Relat Disord* 2016;9 Suppl 1:S5–S48.
- Hobart J et al. Expert consensus on standards for multiple sclerosis care: preliminary results from a modified Delphi process [poster]. Presented at the 7th JointECTRIMS–ACTRIMS meeting, 25–28 October 2017, Paris, France.

## Disclosures

J Haartsen has received consulting fees from Biogen, Merck and Roche. J Hobart has received consulting fees, honoraria, support to attend meetings or research support from Acorda, Asubio, Bayer Schering, Biogen Idec, F. Hoffmann-La Roche, Genzyme, Merck Serono, Novartis, Oxford Health Policy Forum, Oxford PharmaGenesis and Teva. A Bowen has nothing to disclose. L Eberhard is an employee of Oxford PharmaGenesis. G Pepper has received consulting fees from Biogen, Novartis, Oxford Health Policy Forum, Oxford PharmaGenesis and Teva. G Giovannoni has received consulting fees from AbbVie, Atara Biotherapeutics, Almirall, Biogen, Celgene, GlaxoSmithKline, MedDay Pharmaceuticals, Merck and Company (USA), Merck Group (Europe), Novartis, Oxford Health Policy Forum, Oxford PharmaGenesis, Roche, Sanofi Genzyme, Synthon, Takeda, Teva Pharmaceutical Industries Ltd and UCB; and grant/research support from Biogen, Sanofi Genzyme and Takeda.

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To read *Brain health: time matters in multiple sclerosis*, visit [www.msbrainhealth.org](http://www.msbrainhealth.org)