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Engaging multiple stakeholder groups in the development of standards for multiple sclerosis care: a modified Delphi process

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Background

- Although broad guidelines exist for multiple sclerosis (MS) care,^{1,2} there is no benchmark for timely care.
 - The need for prompt diagnosis and early treatment of MS was highlighted by the widely endorsed policy report *Brain health: time matters in multiple sclerosis*.³
- The current study aimed to engage multiple stakeholder groups in defining standards for the timing of key steps in the MS care pathway.
- These standards will inform the content of tools to help MS clinics strive for the highest level of care.

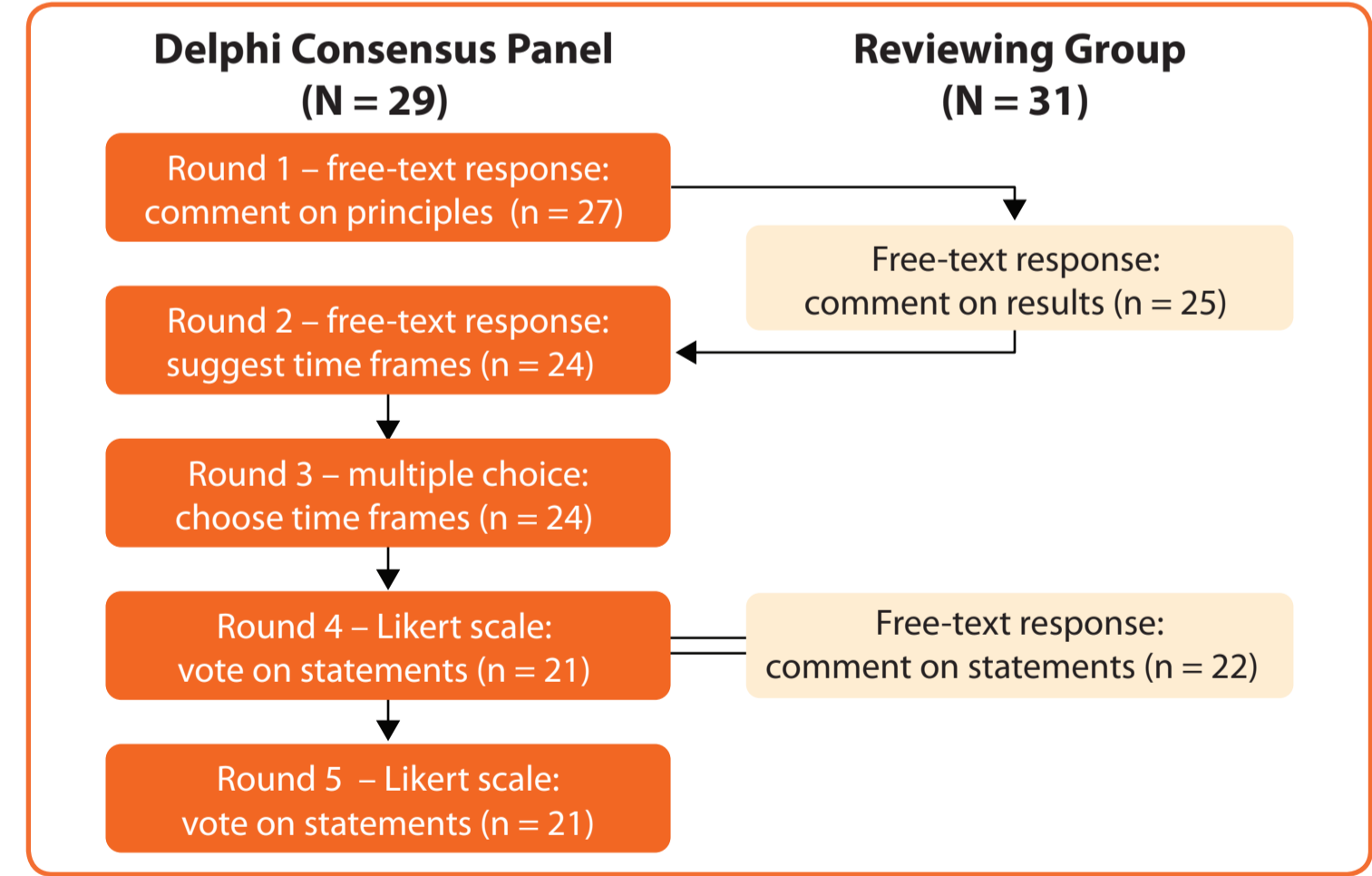
Developing standards for MS care

Methods

- A modified Delphi process was conducted, including both a core Delphi Consensus Panel and an additional Reviewing Group (Figure 1).
- Responses were collected via online surveys; the Panel remained anonymous to analysts and Chairs throughout.

Participants

- Four Chairs directed the process; they represented neurology, patient-reported outcomes, nursing/policy and the patient perspective.
- Participants were invited from regions where MS prevalence is high:⁴ North America, Northern Europe, Western Europe, Southern Europe, Eastern Europe and Russia, Australia and New Zealand, Middle East and North Africa.
 - In total, 41 MS neurologists from 22 countries were invited to participate in the **Delphi Consensus Panel** (Figure 1); 29 agreed to participate.
 - Thirty-nine MS nurses, people with MS and allied healthcare professionals were invited to participate in the **Reviewing Group** to advise the Chairs; 31 agreed to participate (Figure 1).



Round 1 – principles

- We derived 21 time-related principles from the recommendations in the report *Brain health: time matters in multiple sclerosis*.³
- 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 Reviewing Group reviewed the results and provided feedback.
- Variables describing the principles in clinical practice were developed for round 2. Some principles identified were not considered time dependent; these were taken straight to round 4.

Disclosures

T Vollmer has received consulting fees from AbbVie, DeltaQuest, EMD Serono, F. Hoffman-La Roche, Genentech, Novartis, Novartis Canada, Oxford PharmaGenesis, Rocky Mountain MS Center, Teva Neuroscience and WebMD/Medscape; and has received grant/research support from Acorda, Avanir, Biogen, EMD Serono, Genentech, Genzyme, Janssen Research & Development, MedImmune, NIH/NINDS, Ono, Rocky Mountain MS Center, TG Therapeutics and Teva. 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 PharmaGenesis and Teva. A Bowen has nothing to disclose. L Eberhard is an employee of PharmaGenesis London. G Pepper has received consulting fees from Biogen, Novartis, Oxford PharmaGenesis and Teva. G Giovannoni has received consulting fees from AbbVie, Atara Biotherapeutics, Almiral, Biogen, Celgene, GlaxoSmithKline, MedDay Pharmaceuticals, Merck and Company (USA), Merck Group (Europe), Novartis, Oxford PharmaGenesis, Roche, Sanofi Genzyme, Synthon, Takeda, Teva Pharmaceutical Industries Ltd. and UCB; and has received grant/research support from Biogen, Sanofi Genzyme and Takeda. Support for MS Brain Health activities and materials has been provided by Oxford Health Policy Forum and Oxford PharmaGenesis, Oxford, UK, funded by grants from AbbVie, Actelion, Celgene and Sanofi Genzyme and by educational grants from Biogen, F. Hoffmann-La Roche and Merck KGaA, all of whom had no influence on the content.

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.
- Consensus statements related to symptom onset, referral, diagnosis, treatment decisions, lifestyle, monitoring and managing new symptoms were developed based on these results.

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.

Rounds 4 and 5 – consensus statements

- In round 4, the Panel voted on the consensus statements, indicating agreement (or otherwise) on a five-point scale.

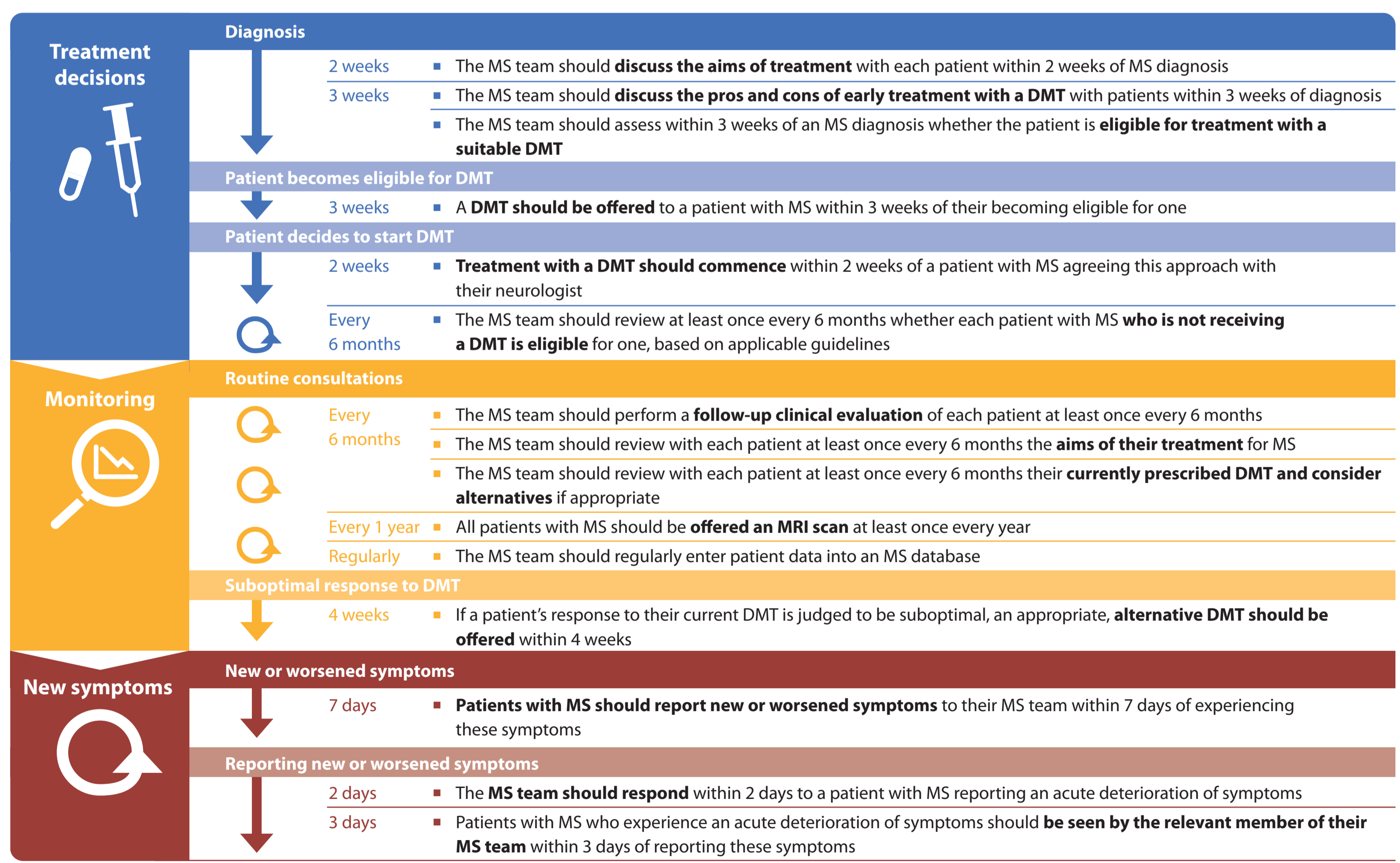


Figure 2. Subset of 'achievable' standards that gained at least 75% agreement from the Delphi Consensus Panel. DMT, disease-modifying therapy; MRI, magnetic resonance imaging

- The predefined threshold for consensus was at least 75% agreement, with a minimum of 66% of participants from round 1 completing the process.
- In round 5, the Panel were asked to vote again on statements from round 4 for which consensus was not reached, taking the results into consideration.
 - Those who did not agree with the statements were asked to give reasons.
- The Reviewing Group were asked to review the statements and vote regarding the ambition of each using a three-point scale (not ambitious enough, about right or too ambitious).

Results

Defining a good standard of care

- For all 21 principles, over 75% of the 27 Panel members agreed in round 1 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.'

Timings for key steps in the patient pathway

- Rounds 4 and 5 were completed by 21/27 (78%) of the Delphi Consensus Panel.
- Here, we present standards related to treatment decisions, monitoring and managing new symptoms, which the Panel agreed should be achievable (Figure 2).

Using standards to improve care

Our vision

- The quality standards from the Delphi process will be used as the basis of practical tools to support the implementation of recommendations from *Brain health: time matters in multiple sclerosis*.³
- Established and developing MS clinics in different countries will be encouraged to compare their services to the core, achievable or aspirational standards, as appropriate.

Quality improvement tool for clinics

- An MS Brain Health quality improvement tool is proposed that will help MS clinics strive for the best possible standard of patient care (Figure 3).
- Leading MS specialist neurologists will be part of a collaborative effort to design the tool and pilot it in their clinics.

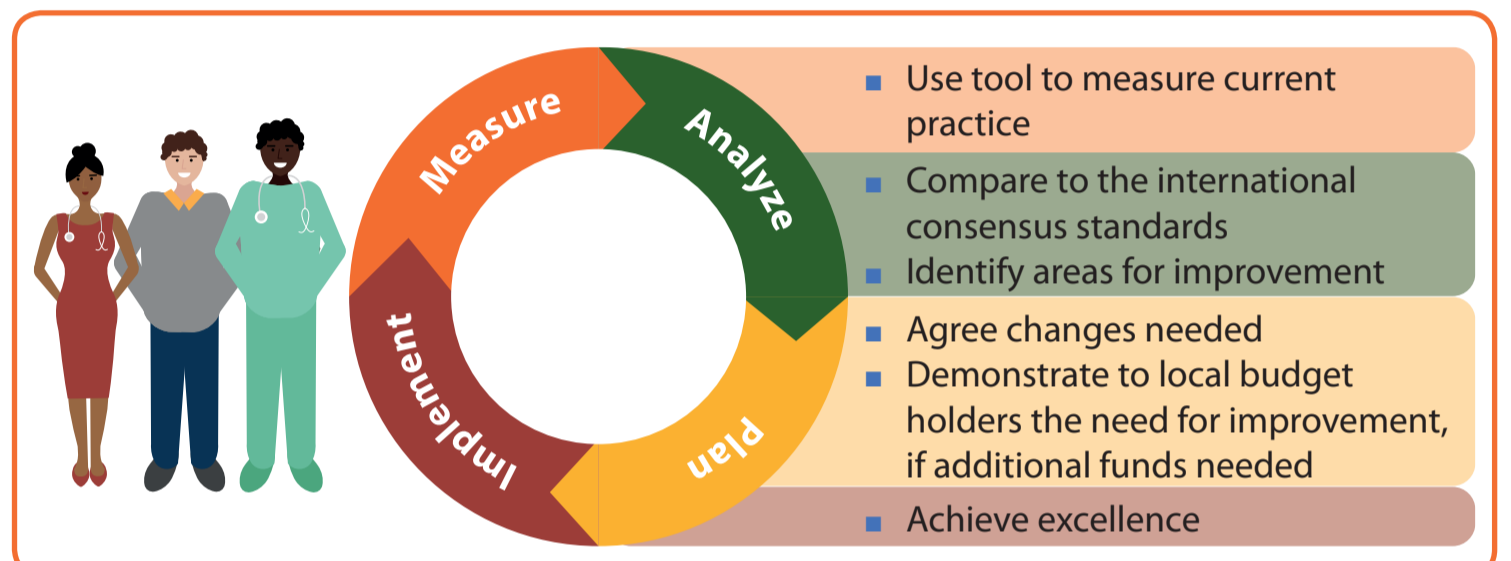


Figure 3. Proposed MS Brain Health quality improvement cycle.

Tool to empower people with MS

- Resources for people with MS will be developed in close consultation with representatives from patient organizations (Figure 4).
- We will explore whether it would be possible to collect information on what patients actually experience and provide feedback to participating clinics.



Figure 4. Our vision for planned MS Brain Health tools for people with MS.

Conclusions

- An international group of MS neurologists, MS nurses, allied healthcare professionals and people with MS have been involved in a modified Delphi process to develop quality standards for MS care.
- These quality standards describe the timings of key steps in the MS care pathway and will provide a new benchmark for MS clinics globally.
- Tools will be developed to help multiple stakeholders improve care and deliver these standards in practice.

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