MS Brain Health global quality standards: MS nurses' role in development and implementation

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Background

- 'Time matters at every stage of multiple sclerosis (MS)' is the key message of the MS Brain Health initiative, which emerged from the evidence-based policy report, *Brain health: time matters in multiple sclerosis*.[1]
- Building on the widely endorsed recommendations from that report,[1] an international group of MS neurologists defined global consensus standards for timely diagnosis and treatment.[2]
- The current analysis aimed to show the contribution of MS nurses to the Reviewing Group that participated in the wider research.

Key points

- In a modified Delphi process to define consensus standards for brain health, a group of MS nurses, who were an integral part of the research, agreed with the time frames for care that were recommended by a panel of MS neurologists.
- A nurse-led pilot of a prototype **MS Brain Health quality improvement (QI) tool**, based on the standards, showed that local benchmarking can prompt service improvement.
- A refined prototype of the tool will be trialed more widely. **To find out about participating in the pilot study, email MS Brain Health: info@msbrainhealth.org**.
- MS nurses are likely to play a pivotal role in disseminating the consensus standards more widely and promoting their use locally for improving care for people with MS.

Developing standards for MS care

Methods

- A modified Delphi process was conducted including a **Delphi Panel** of 29 MS neurologists and a **Reviewing Group** of 31 MS nurses, people with MS and allied healthcare professionals. The process was led by four Chairs.[2]
  - Nine MS nurses from eight countries participated in the Reviewing Group.
- Details of the methodology have been published previously[2] and are summarized below.
  - In total, 21 time-related principles were derived from the recommendations in the report *Brain health: time matters in multiple sclerosis*.[1]
  - In five rounds of online surveys, the Delphi Panel commented on these principles, suggested time frames for 'core', 'achievable' and 'aspirational' standards (reflecting minimum-, good- and high-quality MS care, respectively), and voted on consensus statements (**Figure 1**).
    - Panel members remained anonymous to analysts and Chairs throughout.
    - The predefined threshold for consensus on each standard was agreement by at least 75% of the Panel, with a minimum of 66% of panelists from round 1 responding to all surveys.
  - During the process, the Reviewing Group advised the Chairs, providing early insights and feedback on whether the final standards matched their expectations (**Figure 1**).
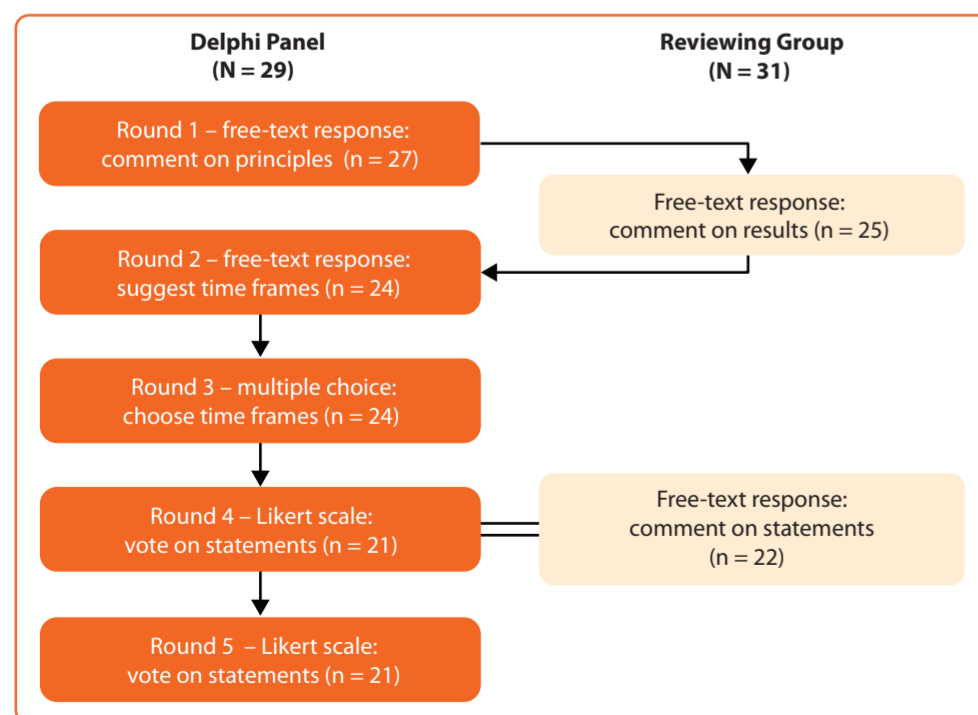

Delphi Panel (N = 29) / **Reviewing Group (N = 31)**

- Round 1 – free-text response: comment on principles (n = 27)
- Free-text response: comment on results (n = 25)
- Round 2 – free-text response: suggest time frames (n = 24)
- Round 3 – multiple choice: choose time frames (n = 24)
- Round 4 – Likert scale: vote on statements (n = 21)
- Free-text response: comment on statements (n = 22)
- Round 5 – Likert scale: vote on statements (n = 21)

Figure 1. Modified Delphi process flow chart.

Results

- The consensus standards spanned six aspects of the MS care pathway: symptom onset, referral and diagnosis, treatment decisions, brain-healthy lifestyle, disease monitoring and management of new symptoms.[2]
- Consensus was reached on a total of 76 'core', 'achievable' and 'aspirational' time frames for key steps in the care pathway.[2]
- For 74% of the standards (n = 56/76), the majority of MS nurses in the Reviewing Group considered the agreed timings to be 'about right'.
- The participating MS nurses did not consider that any of the 'core' standards were too ambitious, nor that any 'aspirational' standards were not ambitious enough.

Developing and piloting a QI tool

- The consensus standards defined by a multinational group of neurologists provide benchmarks for MS services, and they can be used to assess performance at a local level.
- The standards were therefore incorporated into an Excel-based QI tool to allow MS teams to compare services at their center with the international quality standards.[3]
- The first prototype of this tool was piloted in three MS centers:
  - Eastern Health (Melbourne, Australia)
  - University Hospital Carl Gustav Carus (Dresden, Germany)
  - Plymouth University Peninsula Schools of Medicine and Dentistry (Plymouth, UK).[3]
- Investigators at each participating center reviewed the medical records of 12 adults (aged ≥ 18 years) with a confirmed diagnosis of MS and entered the required information into the QI tool.[3]
  - To collect information spanning the MS care pathway, the investigating teams selected three patient records from each of four patient populations (**Table 1**) for review.
  - For MS centers in which there were no patients with relapsing–remitting MS who did not receive treatment with a disease-modifying therapy, four patient records were examined from each of the other three populations.
  - Investigators selected eligible cases for review chronologically from a list of patients who attended the center at least once during the study period (January 1, 2016–June 30, 2018), thereby minimizing selection bias.
- The findings and recommendations from all three centers were gathered and used to prepare a refined prototype of the QI tool which will be piloted more widely.

Patient population	Definition
Patients with newly diagnosed RRMS	RRMS diagnosed between January 1, 2016 and June 30, 2017
Patients with RRMS already receiving a DMT	Diagnosis of RRMS, monitored for ≥ 1 year and **receiving a DMT**
Patients with RRMS not receiving a DMT	Diagnosis of RRMS, monitored for ≥ 1 year and **not receiving a DMT**
Patients with progressive MS	Diagnosis of PPMS or SPMS

Table 1. Definitions used for patient populations.

DMT, disease-modifying therapy; PPMS, primary progressive MS; RRMS, relapsing–remitting MS; SPMS, secondary progressive MS.

Case study: using the QI tool to facilitate local change

A nurse-led QI program

- A local MS nurse led a QI program for the Eastern Health MS service, Australia, based on data that were gathered in the QI tool during the initial pilot study.
- The program included analyzing the results from the service evaluation, identifying gaps in service delivery, developing key performance indicators and implementing strategies for care improvement based on the findings (**Figure 2**).

Insights from the service evaluation

- Analysis of results from the service evaluation showed that patient records contained limited data on some of the events in the care pathway.
- Information was not routinely documented for standards relating to the length of appointments, brain-healthy lifestyle discussions, management of comorbidities and reviewing treatment aims.
- If events had been consistently documented in the medical records, it was often MS nurses who had entered the records, highlighting their key role in monitoring standards of care.
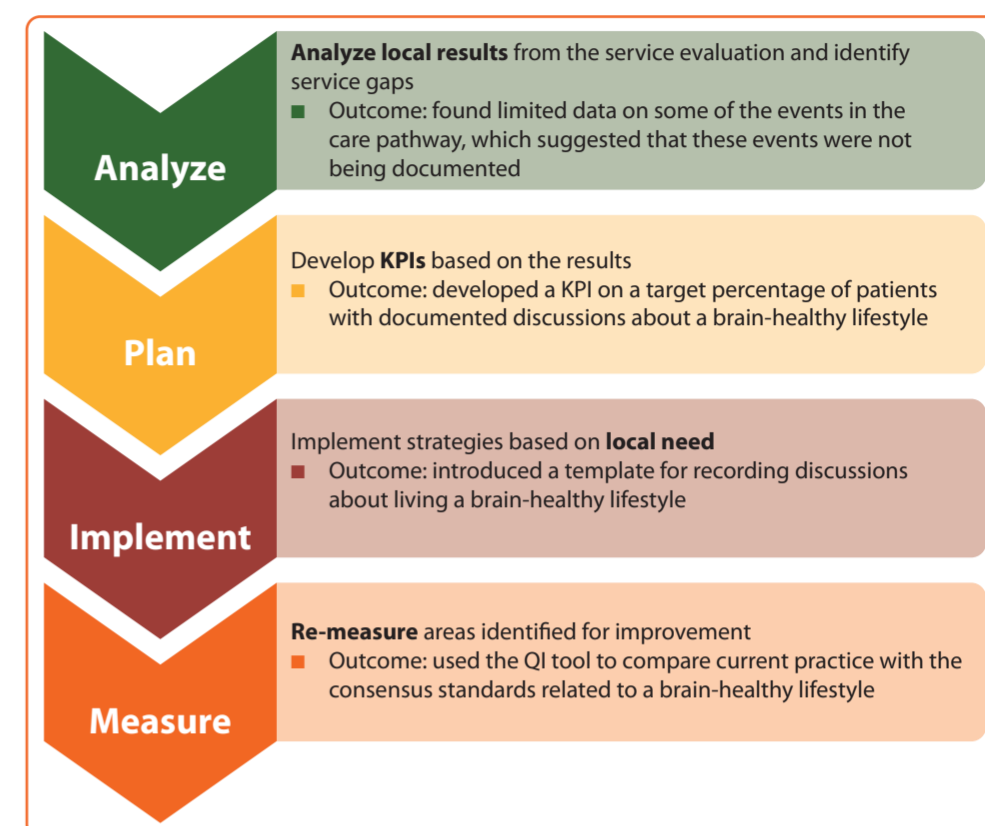

Analyze – **Analyze local results** from the service evaluation and identify service gaps
- Outcome: found limited data on some of the events in the care pathway, which suggested that these events were not being documented

Plan – Develop **KPIs** based on the results
- Outcome: developed a KPI on a target percentage of patients with documented discussions about a brain-healthy lifestyle

Implement – Implement strategies based on **local need**
- Outcome: introduced a template for recording discussions about living a brain-healthy lifestyle

Measure – **Re-measure** areas identified for improvement
- Outcome: used the QI tool to compare current practice with the consensus standards related to a brain-healthy lifestyle

Figure 2. Stages in the nurse-led QI program.

KPI, key performance indicator; QI, quality improvement.

Action to improve local processes

- As a result of the service evaluation, the MS center made improvements to local processes for care delivery and record keeping, and raised awareness of the global consensus standards among team members (**Figure 3**).
- Central to enabling these changes to take place was engaging and securing support from the multidisciplinary team, as well as from the decision-makers and budget holders in the center.
- The MS nurse who led the QI program highlighted that the data captured in the QI tool had aided them in demonstrating the need for improvement.
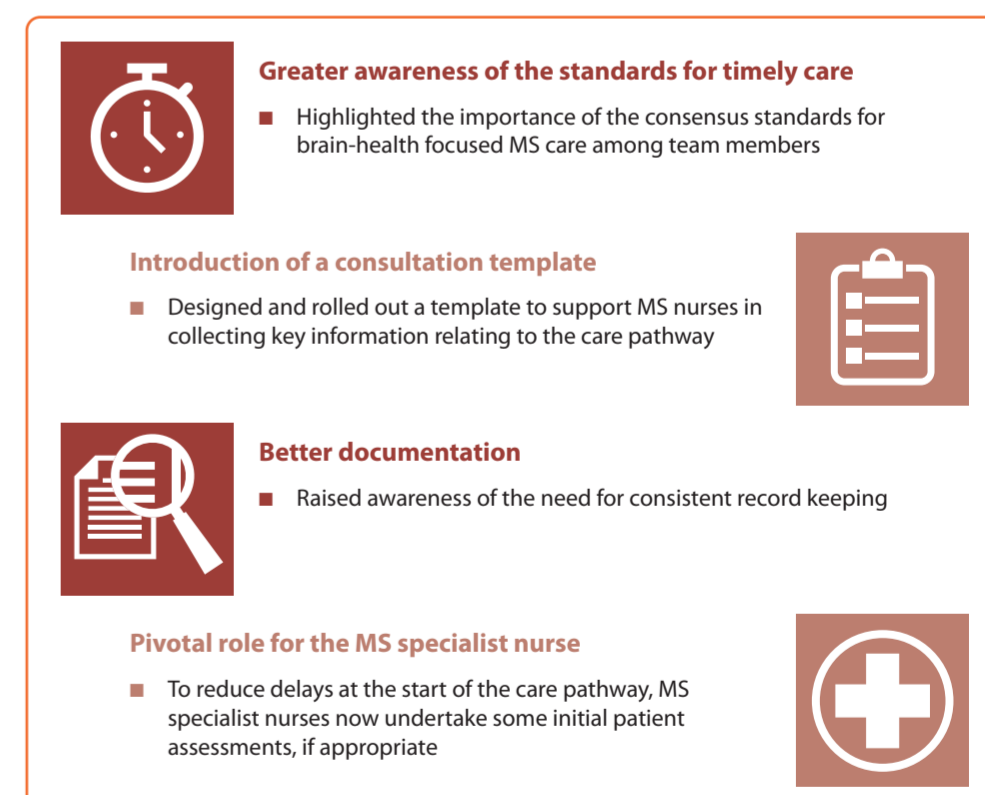

Greater awareness of the standards for timely care
- Highlighted the importance of the consensus standards for brain-health focused MS care among team members

Introduction of a consultation template
- Designed and rolled out a template to support MS nurses in collecting key information relating to the care pathway

Better documentation
- Raised awareness of the need for consistent record keeping

Pivotal role for the MS specialist nurse
- To reduce delays at the start of the care pathway, MS specialist nurses now undertake some initial patient assessments, if appropriate

Figure 3. Impact of the nurse-led quality improvement program.

References

1. Giovannoni G et al. Mult Scler Relat Disord 2016;9 Suppl 1:S5–48.
2. Hobart J et al. Mult Scler 2019;25:1809–18.
3. Hobart J et al. Timely Intervention, Monitoring and Education MATTERS in Multiple Sclerosis (TIME MATTERS in MS): developing a globally applicable quality improvement tool. Poster presented at the 34th congress of the European Committee for Treatment and Research in Multiple Sclerosis, October 10–12, 2018, Berlin, Germany.

MS Brain Health Time Matters