Progress in MS care through the last decade and into the next: an update to the 2013 consensus of the MS in the 21st Century Steering Group

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MS in the 21st Century

Scan to find out more about MS in the 21st Century

Introduction

- The MS in the 21st Century (MS21) initiative is an international collective of health care professionals (HCPs), people living with multiple sclerosis (PwMS) and patient advocacy group (PAG) representatives who collaborate to understand the real-world unmet needs in MS and develop practical tools to support MS care.
- In 2013, the MS21 initiative established consensus recommendations for MS standards of care with an overall vision of "full access to personalised treatment, with reimbursement, to achieve freedom from disease," based on 7 overarching principles[1].

Objective

To reflect on and update a 2013 consensus statement by considering the advances made towards better MS care provision and priority areas for further improvement, from the perspective of both HCPs and PwMS.

Methods

- Delphi process with 2 rounds of anonymised voting was conducted between July 2023 and August 2024.
- Voting panels (N=30) included PwMS, PAG representatives and HCPs (**Figure 1**).
- An initial set of 43 statements was based on **3 key themes**:

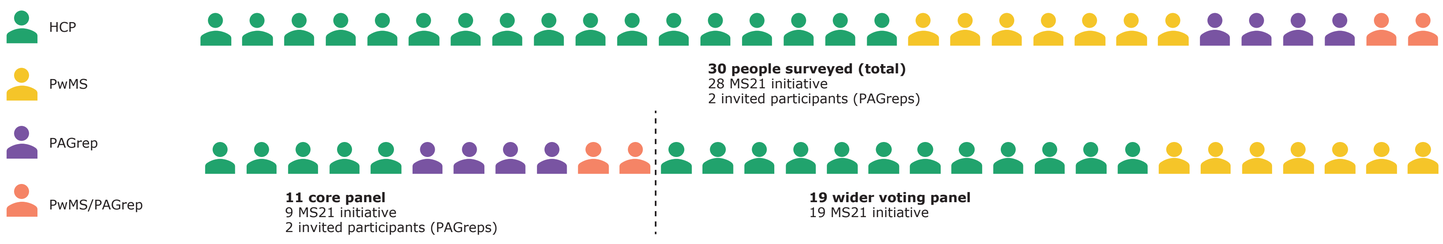
01 Optimising the current MS care provision

02 Facilitating shared decision making and patient education

03 Continuing MS research and development

- Statements were revised after each round of voting.
- A consensus threshold was set *a priori* as ≥75% agreement.

Figure 1. The MS21 Delphi consensus voting panel



HCP, health care professional; MS21, MS in the 21st Century; PAGrep, patient advocacy group representative; PwMS, people living with multiple sclerosis

Table 1. Demographics of panel members with complete responses at rounds 1 and 2 of voting

Characteristic	Round 1 (n=21)	Round 2 (n=21)
HCPs In service >10 years (or did not respond)	11 8 (3)	12 12 (0)
PwMS Time since diagnosis 6–10 years Time since diagnosis >10 years	7 1 6	6 1 5
PAG representatives	3	3
Age, years 26–34 35–50 51–65 >65	 – 6 12 3	 1 6 12 2

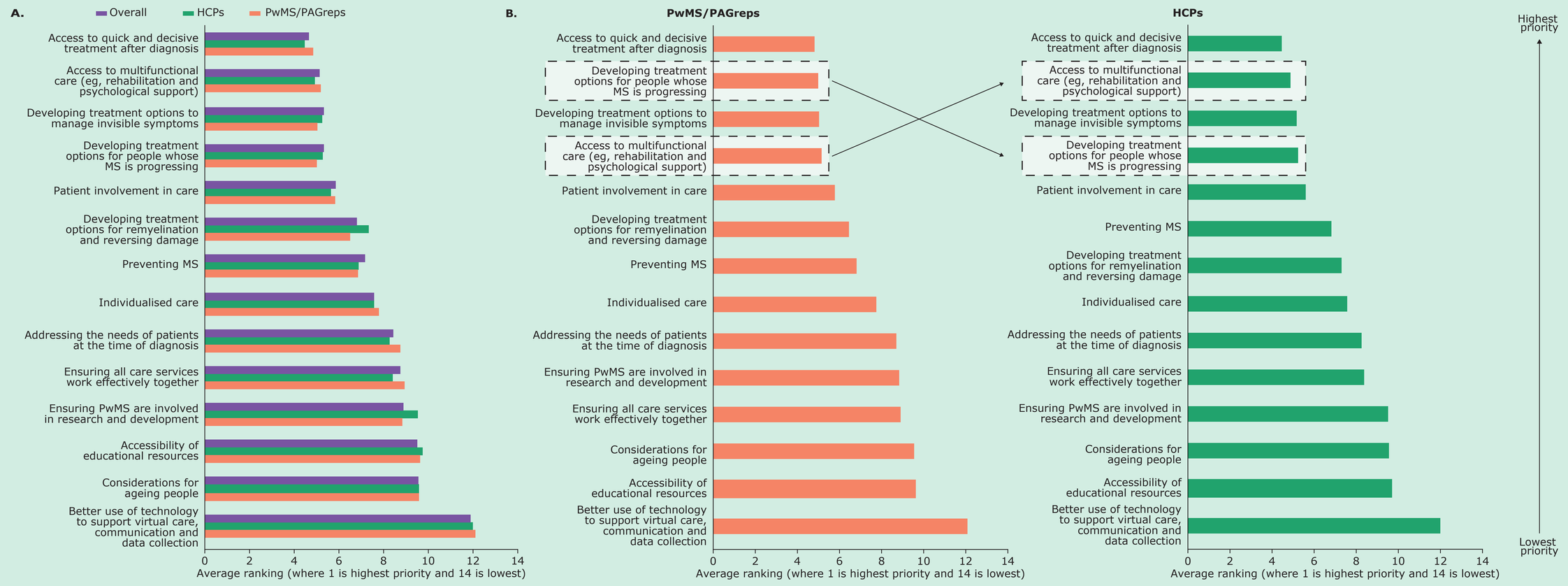
HCP, health care professional; PAG, patient advocacy group; PwMS, people living with multiple sclerosis

Results

- The 2013 definition of "freedom from disease" was further defined as "living symptom-free without treatment burden, with no or limited impact on quality of life and wellbeing, and no evidence of disease activity, progression, relapses or damage accrued over time".
- There was a 70% response rate at each round of voting, with respondents representing 13 countries (**Table 1**).
- The 7 original principles constructed in 2013 were expanded to 14 (shown in **Figure 2**).
- At the second round of voting, participants were asked to rank the 14 principles in order of importance for improving outcomes for PwMS (**Figure 2A**).
  - Prioritisation of key themes revealed close alignment among HCPs and PwMS/PAG representatives, with the same top 4 priorities (**Figure 2B**).
  - HCPs ranked "access to multifunctional care" higher than "development of treatments for progressive MS," while the opposite was true for PwMS/PAG representatives (**Figure 2B**).
- A final set of 40 consensus statements were developed to support these principles. Statements relating to the top 5 principles are shown in **Table 2**.

Final consensus statements

Figure 2. Prioritisation of MS care principles overall (A) and by PwMS/PAG representatives and HCPs (B)



HCP, health care professional; MS, multiple sclerosis; PAGrep, patient advocacy group representative; PwMS, people living with multiple sclerosis

Table 2. Final consensus statements relating to the top five priority principles

Theme 01 Optimising current MS care provision

1.1	**Access to quick and decisive treatment after diagnosis**
1.1.1	HCPs are advised to treat PwMS as soon as possible, in the context of clinical profile and personal preferences.
1.1.2[a]	HCPs are advised to work with PwMS to agree on an effective personalised treatment plan that addresses relapse, relapse-associated worsening of disease and PIRA, as appropriate.
1.1.3[a]	HCPs are advised to provide PwMS with a general overview of how MS can develop, balancing the positive and negative aspects, and signposting PwMS to lay-friendly material through patient advocacy groups, for example, to support their understanding of MS.
1.1.4	HCPs are advised to prioritise listening to PwMS in order to understand their individual needs (eg, personal/social life and employment status) and personalise their treatment. Consultation framework tools can help structure appointments to address all aspects.
1.2	**Access to multifunctional care**
1.2.1[a]	Health organisations, payers and associated stakeholders are advised to provide PwMS with early and ongoing access to rehabilitation services (physiotherapy/occupational therapy) and psychological services.

Theme 02 Facilitating shared decision making and patient education

2.1	**Patient involvement in care**
2.1.1	Health care organisations and associated stakeholders are advised to provide PwMS with the educational resources that can equip them to use MS vocabulary and discuss MS-related decisions with confidence.
2.1.2[a]	Patient advocacy groups and HCPs are advised to encourage PwMS to be more engaged with their care and treatment. Providing PwMS with balanced information and support can empower them to take part in shared decision making.
2.1.3[a]	HCPs are advised to offer appropriate-level information about MS to caregivers and/or parents if the patient desires their input into their care.
2.1.4[a]	Patients are advised to discuss symptoms they may be experiencing with their HCP, even in the absence of relapses or MRI activity.

Theme 03 Continuing MS research and development

3.1	**Developing treatment options to manage invisible symptoms**
3.1.1	HCPs are advised to implement and evaluate evidence-based management plans to minimise the impact of invisible symptoms.
3.1.2	HCPs are advised to tailor management specifically to the symptoms experienced by the PwMS, prioritising QOL.
3.2	**Preventing MS and developing treatment options for MS that is progressing**
3.2.1	All stakeholders, including pharmaceutical organisations, are advised to prioritise research into the factors that are preventative in MS (eg, the potential role of Epstein-Barr virus in causing MS) and the development of treatments for unmet needs, such as progressive MS and PIRA.

HCP, health care professional; MRI, magnetic resonance imaging; MS, multiple sclerosis; PIRA, progression independent of relapse activity; PwMS, people living with multiple sclerosis; QOL, quality of life
[a]Achieved 100% consensus

Conclusions

- **For PwMS to be unburdened by symptoms, the updated vision for MS care in the 21st century lays out 14 principles to be addressed by HCPs and decision makers in MS, the most important of which include access to quick and decisive treatment after diagnosis, access to multifunctional care, and developing treatment options for managing invisible symptoms and for people whose MS is progressing.**
- **The MS community must keep working together to meet the updated MS21 vision and ensure that all PwMS have access to appropriate care, are involved in decisions relating to their care, and that research and development continues to address their unmet clinical needs.**

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Reference: 1. Rieckmann P, et al. *J Neurol*. 2013;260:462–469.

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