Solutions to address the unmet needs of the gMG patient journey in the US: A multistakeholder Delphi consensus study

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Introduction

- Our prior research with patients, caregivers, and patient advocates identified substantial unmet needs for the gMG community, which persist despite advances in treatment; these include delays in diagnosis, lack of recognition of the disease by HCPs, and barriers to accessing support networks and care[1,2]
- The research identified 13 potential solutions to these unmet needs related to improving the diagnostic journey, disseminating education and educational materials, and broadening access to care, resources, and support[3,4]
- This Delphi study aimed to build consensus around the most impactful and implementable solutions from a diverse HCP audience involved in the management of patients with gMG
- The objective was to build a list of consensus-driven, implementable solutions or interventions for addressing unmet needs, as validated by HCP stakeholders, to improve the lives of patients with gMG and the caregiver community in the US
  − To understand potential challenges to the implementation of solutions
  − To understand the complexities of proposed solutions and the reasons why they may not be deemed impactful
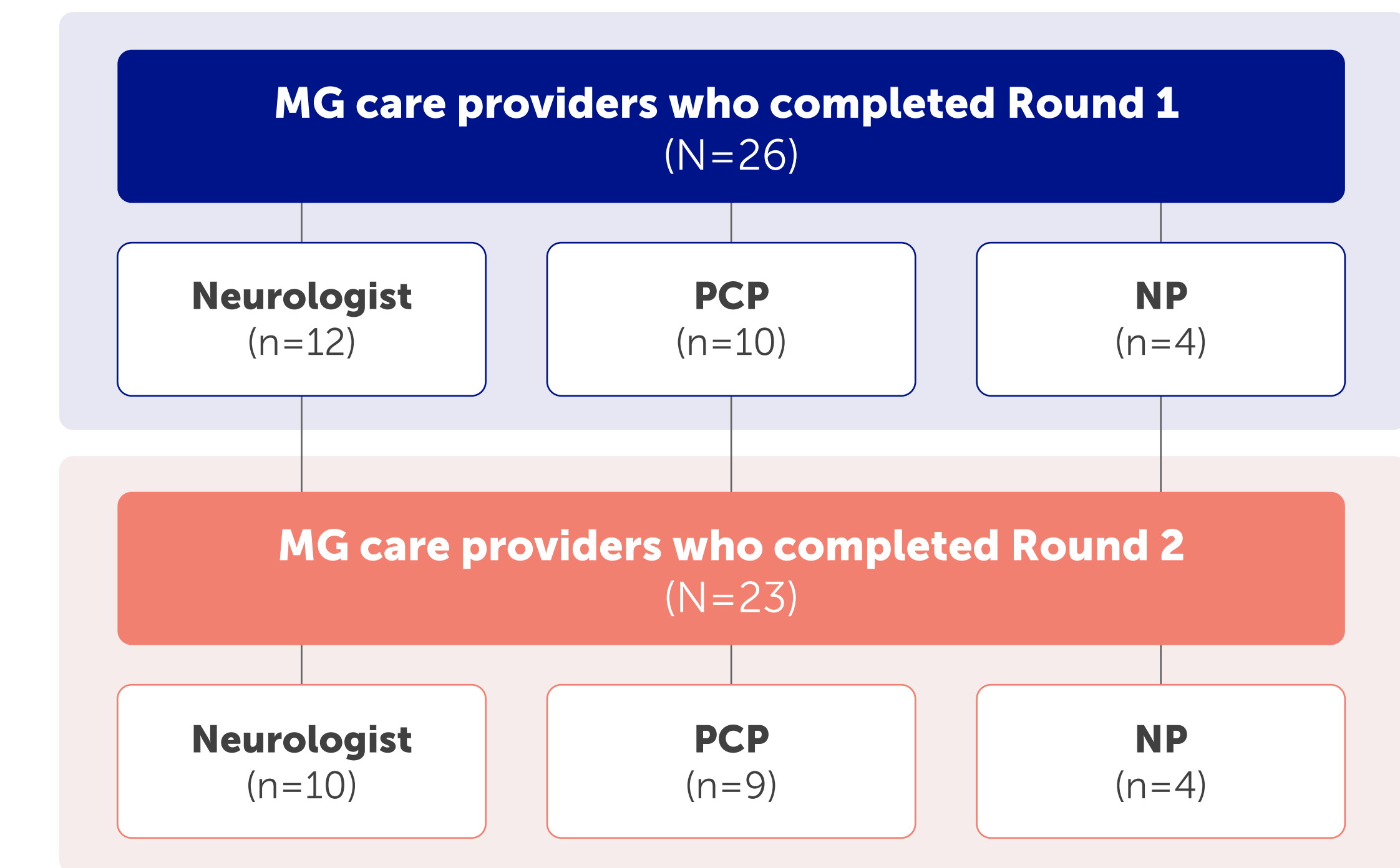
Methods

- A comprehensive two-round Delphi survey was conducted with a multidisciplinary HCP group to garner consensus (**Figure 1** and **Table 1**)
- In Round 1, participants rated their level of agreement on each solution's suitability to address its associated unmet needs, provided the rationale for their assessment, and listed potential implementation challenges
- In Round 2, participants re-evaluated those solutions, considering the synthesized insights from Round 1

Results

- A total of 23 HCPs (neurologists, NPs in a neurology setting, and PCPs) with experience of treating and managing patients with gMG in the US completed both Rounds 1 and 2
- Consensus (>70% agreement) was achieved for all 13 proposed solutions (**Table 2**)
- The solutions spanned areas such as improving diagnostic accuracy, enhancing patient support systems, and fostering multidisciplinary care approaches
- The solutions with the highest consensus focused on addressing barriers to support networks and care, including increasing access and reducing wait times for neuromuscular specialists along with caregiver-focused support (**Figure 2**)
- The solutions with the lowest consensus focused on providing more holistic resources and support for patients' daily lives, including materials for special populations and employer conversation resources (**Figure 2**)

Figure 1   Survey rounds' participants

Final results reflect feedback from MG care providers in the US who completed both Round 1 (April 25−June 6, 2024) and Round 2 (June 13−28, 2024) surveys

MG care providers who completed Round 1
(N=26)

| Neurologist (n=12) | PCP (n=10) | NP (n=4) |

MG care providers who completed Round 2
(N=23)

| Neurologist (n=10) | PCP (n=9) | NP (n=4) |

Data from participants who completed only Round 1 were excluded to ensure accurate longitudinal comparisons. The reduced sample for Round 2 is a result of the expected participant drop-off in multiround Delphi studies.[5]
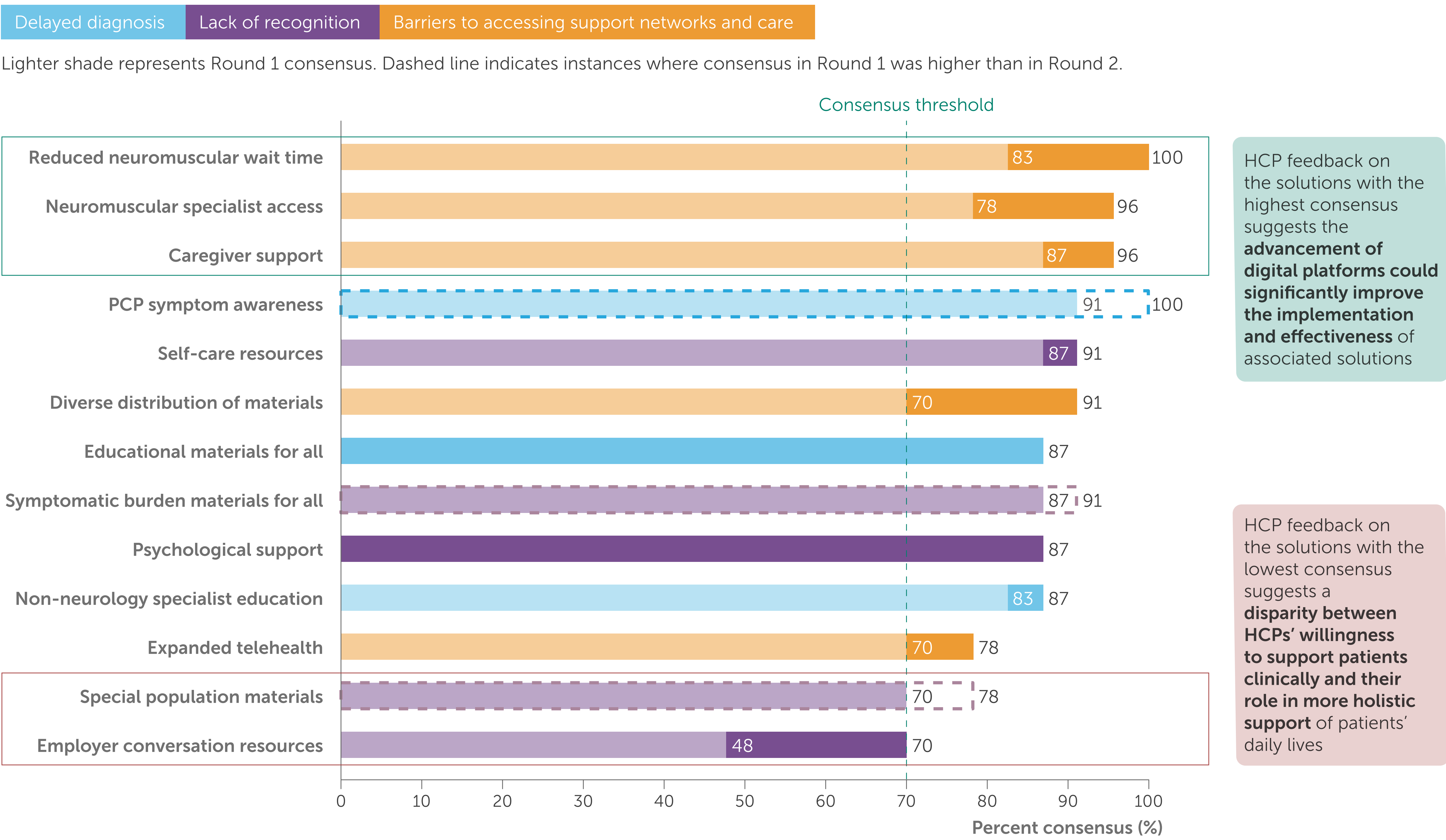
Table 1   Participant screening criteria

General neurologists	PCPs	NPs
• Be board-certified/licensed, or board-eligible in neurology • Be a general neurologist with either no sub-specialty or additional training in neuro-immunology, neuro-oncology, or behavioral neurology • Have treated or managed between 5 and 20 patients with MG within the past 12 months with >5 patients in MGFA classifications II (mild), III (moderate), or IV (severe)	• Be board-certified/licensed, or board-eligible in family medicine, internal medicine, or geriatric medicine • Have encountered >2 patients with MG over the previous 10 years • Have been involved with the ongoing care within the past 12 months of >1 patient with MG in MGFA classifications II (mild), III (moderate), or IV (severe)	• Primarily manage patients in a neurology practice setting • Have managed >5 patients with MG in MGFA classifications II (mild), III (moderate), or IV (severe) • Uphold three or more relevant responsibilities related to the management of patients with MG to ensure understanding of patient management

Neurologists and PCPs must:
- Have clinical practice experience ranging from 3 to 30 years
- Devote at least 50% of their professional time to direct patient care

All respondents must:
Work in an academic/teaching hospital or center of excellence; community hospital; private, solo, or group practice or clinic; federally-qualified health center; or department of public health

Note: Respondents were initially asked about MG during screening and were only introduced to gMG during the main survey.

Table 2   gMG community-derived solutions

Delayed diagnosis

PCP symptom awareness:
Enhancing awareness for PCPs on diverse gMG symptoms

Non-neurology specialist education:
Investing more in educating non-neurology specialists like rheumatologists, ophthalmologists, and psychologists to increase gMG awareness

Educational materials for all:
Creating easy-to-understand educational materials (videos, Q&As, support groups) for patients, caregivers, and HCPs

Lack of recognition

Employer conversation resources:
Training/resources to manage conversations between employers and patients with gMG/caregivers

Special population materials:
Targeted materials to support women of childbearing age and other special gMG patient populations

Symptomatic burden materials for all:
Materials for patients, caregivers, and healthcare providers on the full symptomatic burden of gMG

Self-care resources:
Resources for patients with gMG/caregivers to support self-care

Psychological support:
Psychological support for patients with gMG/caregivers

Barriers to accessing support networks and care

Expanded telehealth:
Expanded use of telehealth and other healthcare provider-based resources

Neuromuscular specialist access:
Improved access to neuromuscular specialists

Reduced neuromuscular wait time:
Reduced wait time to see neuromuscular specialists

Caregiver support:
Caregiver-focused support

Diverse distribution of materials:
The distribution of materials through a wider range of channels, such as websites and social media

Figure 2   Results of HCP validation research

Delayed diagnosis | Lack of recognition | Barriers to accessing support networks and care

Lighter shade represents Round 1 consensus. Dashed line indicates instances where consensus in Round 1 was higher than in Round 2.

Solution	Round 1	Round 2
Reduced neuromuscular wait time	83	100
Neuromuscular specialist access	78	96
Caregiver support	87	96
PCP symptom awareness	91	100
Self-care resources	87	91
Diverse distribution of materials	70	91
Educational materials for all		87
Symptomatic burden materials for all	87	91
Psychological support		87
Non-neurology specialist education	83	87
Expanded telehealth	70	78
Special population materials	70	78
Employer conversation resources	48	70

Consensus threshold

Percent consensus (%)

HCP feedback on the solutions with the highest consensus suggests the **advancement of digital platforms could significantly improve the implementation and effectiveness** of associated solutions

HCP feedback on the solutions with the lowest consensus suggests a **disparity between HCPs' willingness to support patients clinically and their role in more holistic support** of patients' daily lives

Summary and conclusions

- Consensus (>70% agreement) was achieved for all 13 proposed solutions spanning areas like improving diagnostic accuracy and timelines, raising MG awareness, enhancing patient support systems, and fostering multidisciplinary care approaches

- Solutions with the highest consensus focused on addressing barriers to support networks and care, including increasing access and reducing wait times for neuromuscular specialists along with caregiver-focused support

- The consensus indicates the importance and priority of implementation of the gMG community-derived solutions

- These findings highlight critical areas for intervention and underscore the feasibility of implementing these solutions to improve the journey for patients with gMG and their caregivers

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