

# Partnering with Patients and Caregivers to Guide the Development of Impactful Study Engagement Tools in a Generalized Myasthenia Gravis Real-world Study

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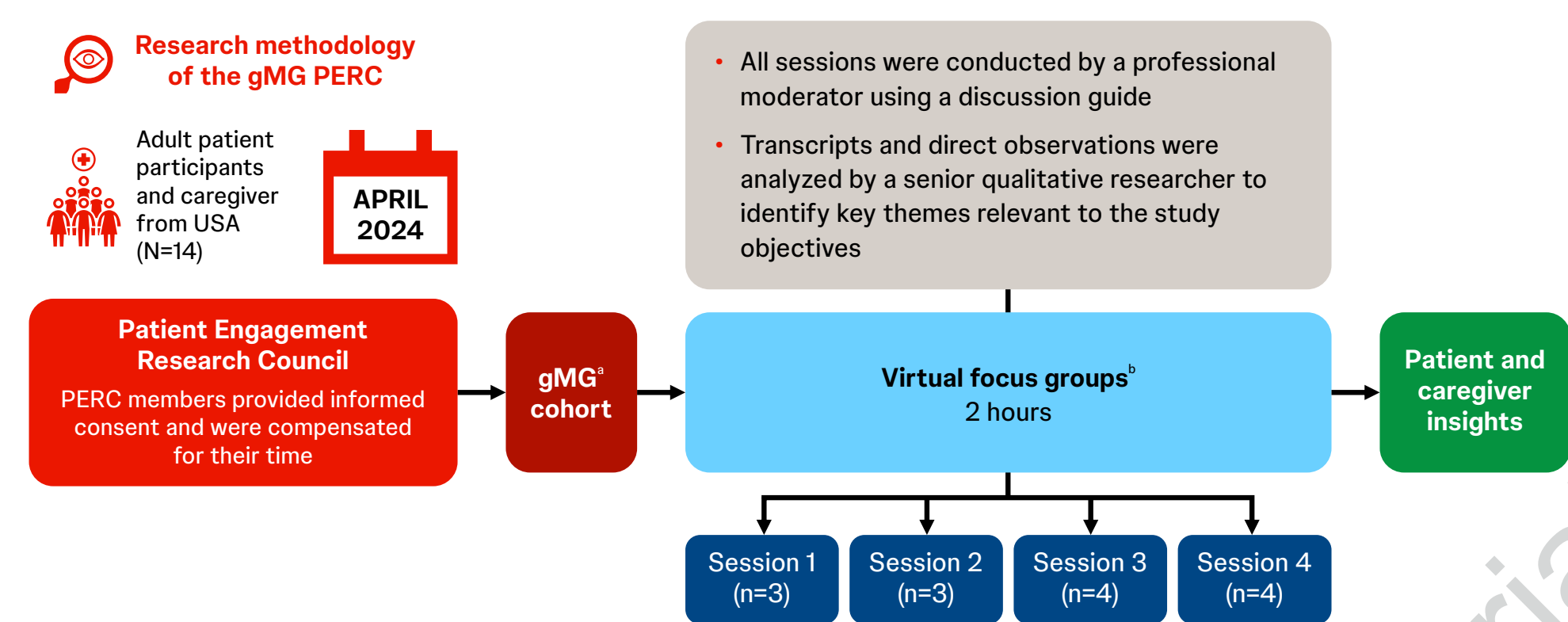
## Introduction

- Significant advances in generalized myasthenia gravis (gMG) research have been made in recent years, with clinical trials advancing new therapies and real-world studies identifying the unmet patient needs<sup>1</sup>
- In rare diseases such as gMG, successful study completion relies on patient recruitment and retention, which can be improved by integrating insights from patient and caregiver into study planning<sup>2</sup>
- Unique, actionable insights from patients with gMG and their caregivers can help guide study design, develop comprehensible recruitment materials, and devise patient-centric retention strategies that enhance accessibility and participant engagement<sup>3,4</sup>
- Patient Engagement Research Council (PERC), including gMG patients and caregivers, was formed to provide feedback on recruitment and retention strategies<sup>5,6</sup>
  - Initiatives like the PERC demonstrate the feasibility of consistently integrating patient and caregiver input into real-world studies to enhance participant engagement

## Methods

- Johnson & Johnson's PERC program represents diverse groups of disease-aware adults with chronic health conditions living in the United States who provide insights and feedback around specific, structured or semi-structured series of activities<sup>7,8</sup>
- The group of patients and caregivers in gMG PERC are diverse with respect to time since diagnosis, disease severity, serostatus, treatment experience, age, gender, education level, and race/ethnicity
- Inclusion criteria included patients of ≥18 years, US residents, and with self-reported diagnosis of MG. Caregiver providing support to patients meeting the same criteria were included in the study<sup>9</sup>
- In April 2024, patients with gMG and caregivers from the gMG PERC participated in 4 virtual, 2-hour, semi-structured focus groups (Figure 1)
  - This study was qualitative and descriptive; thus, no formal statistical analysis was performed
  - Sessions were moderated by a Patient Insights Research Specialist using a semi-structured discussion guide to elicit open and honest patient feedback and opinions
  - All focus group discussions were audio-recorded and transcribed, then coded, analyzed, and distilled into key insights
- Sessions focused on reviewing recruitment materials, accessibility, engagement, and retention strategies designed for a real-world study

Figure 1. Research methodology of the gMG PERC



\*Self-reported diagnosis. \*Also attended by at least one scientific Johnson & Johnson employee. gMG=Generalized myasthenia gravis; PERC=Patient Engagement Research Council; USA=United States of America.

## Results

- A total of nine people with gMG and five caregivers participated in the virtual focus groups. Key participant demographics are summarized in (Figure 2)
- Insights gathered on recruitment materials provided actionable changes such as enlarging and standardizing text fonts to support patients with ocular MG symptoms while creating concise materials with easy-to-understand language for the end-user
- Additional suggestions were also collected to better understand motivation and retention of patients in an ongoing 2-year study

Figure 2. Key demographic information of the gMG PERC participants

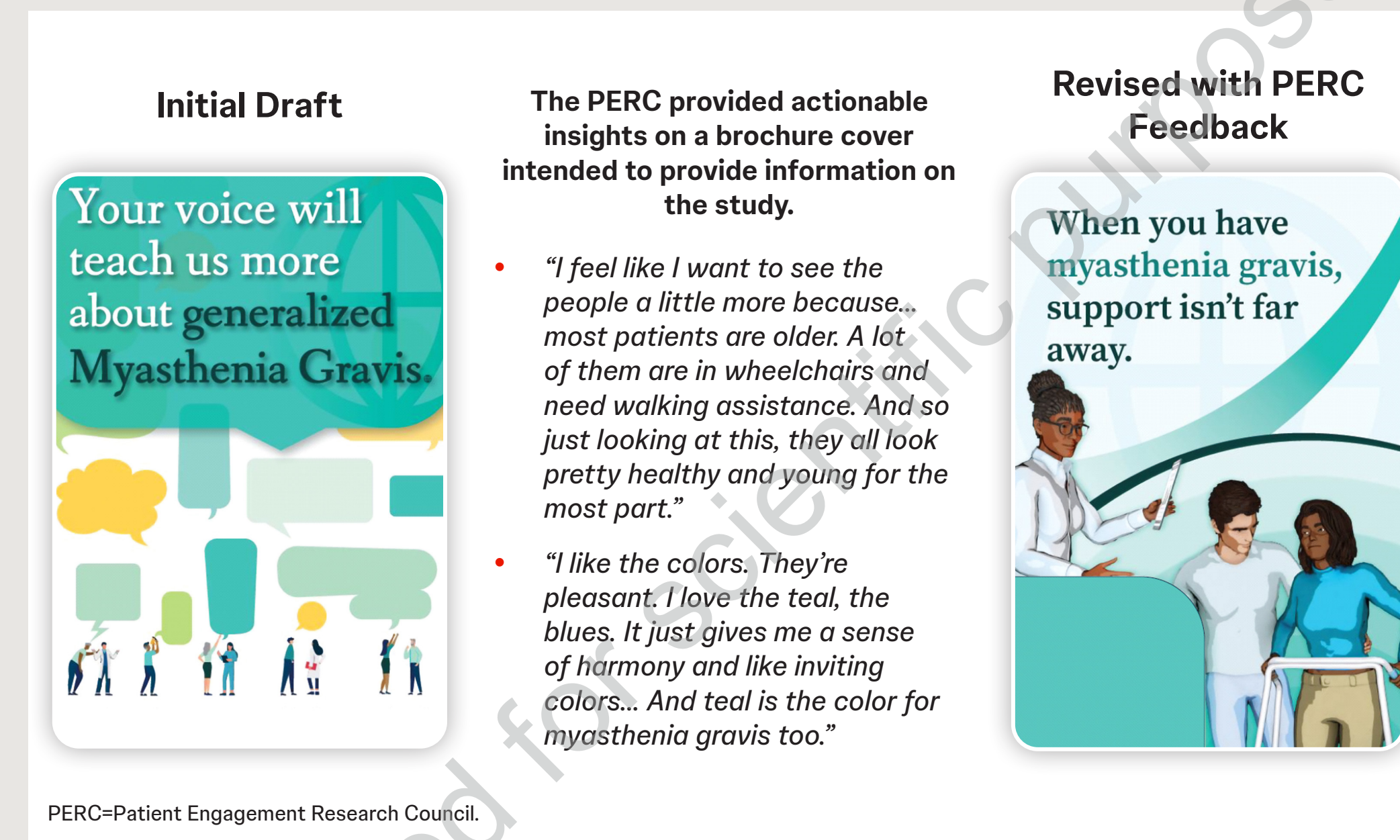
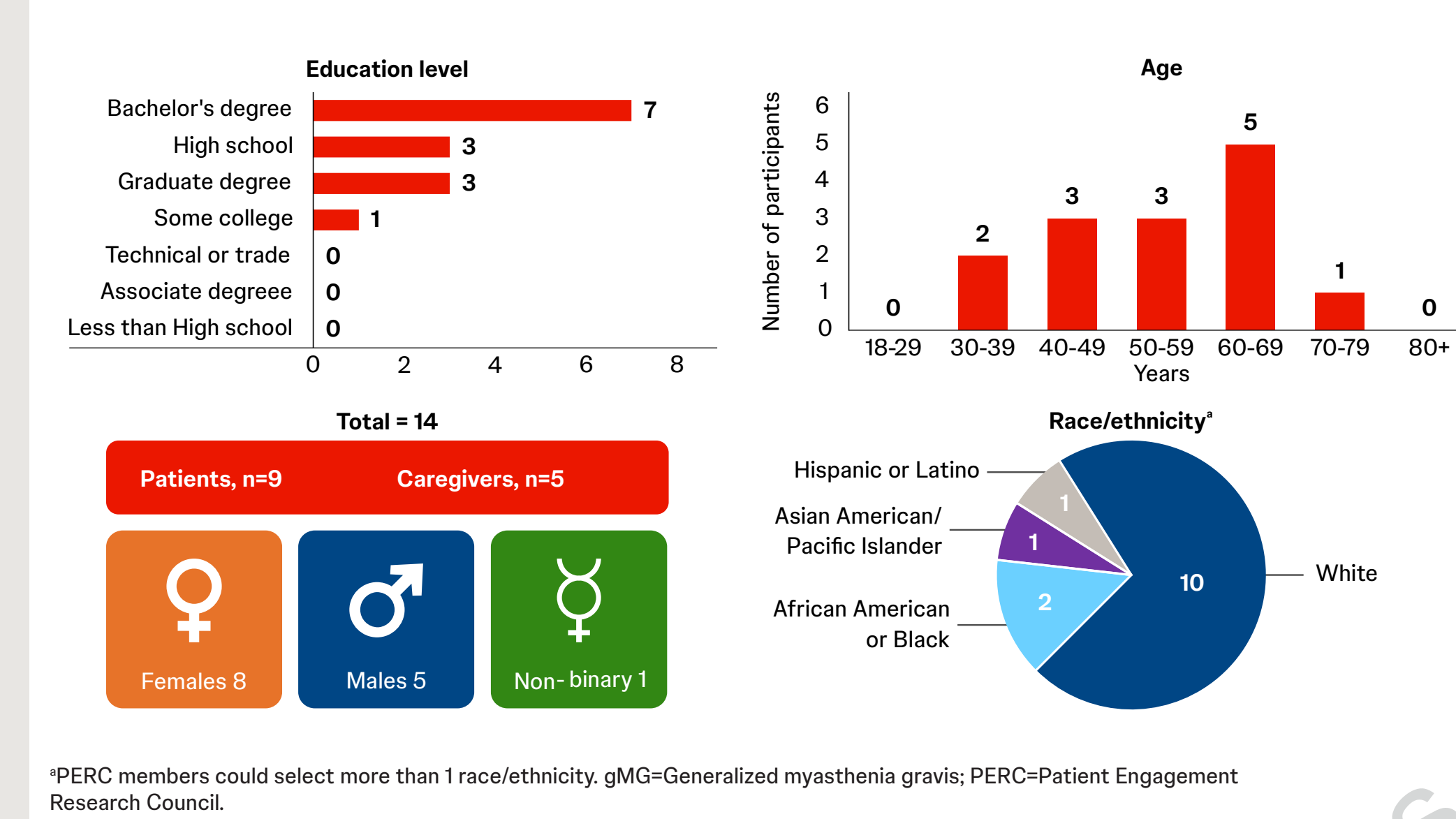


Table 1. Summary of gMG PERC feedback and how it has been addressed

Feedback	Action
Participants expressed that the informational brochure was text-heavy and there was a surplus of information on each page	Informational brochure was modified to reduce the amount of text on each page
Patients noted that varying text sizes and fonts on recruitment materials made reading the text more difficult	Written recruitment materials were edited to a standardized font size and text across materials to increase ease

gMG=Generalized myasthenia gravis; PERC=Patient Engagement Research Council.

Figure 3. Key insights from participants on a prospective RW study design

**Key insight: Recruitment Materials – Clarify Tasks**

Members wanted to see a clear, concise overview of what the study participants will be asked to do, such as:

- A callout box with a task list, and/or
- A timeline or other graphic summarizing their tasks, frequency and duration of tasks, and duration of study, and/or
- How tasks will be accomplished (via an app or website portal or visits), and/or
- Delineated patient tasks, caregiver tasks, and physician tasks

**Key insight: Recruitment Materials – Clarify Benefit**

Members wanted to see a clearer description of what participants might gain from the study, for example:

- Access to news about new treatments for gMG
- How this study would impact awareness of gMG and treatment development
- Compensation for participants
- Access to data, such as a personalized dashboard of their own data and/or rolling aggregated questionnaire results by all participants
- Opportunity to connect with other participants, such as a closed online community

**Key insight: Recruitment Materials – Clarify Purpose**

Members wanted the purpose of the study to be clarified, as it may motivate them to participate.

- Motivations for participating in such a study include contributing to the development of new treatments, supporting the gMG community, and/or raising awareness about the gMG patient experience amongst physicians.

**Key insight: Retention Strategies – Motivations**

**Access to Personal Data**

- Members would be motivated to participate for 24 months by having access to their own historical data, such as a dashboard of their past questionnaires and access to medical data submitted by their providers.

**Rolling Study Results**

- Members would be motivated to remain in the study by receiving timely updates on the progress of the study, such as aggregated questionnaire results, what researchers are learning from the data as the study progresses, and how the study might be informing other gMG research.

**Key insight: Recruitment Materials – Clarify Caregiver Eligibility and Roles**

- Members felt that the caregiver's perspective should be more prominent in the materials, if materials are intended to recruit caregivers.
- The eligibility criteria could be re-worded to include caregivers, or a separate eligibility criteria section for caregivers could be added.
- Additional information is needed regarding what caregivers will be asked in the questionnaires. The reference to questions around work impacts are off-putting to patients and caregivers as disruptions to work are only a small portion of the impacts to caregivers.

## Conclusions

- Patients and caregivers can contribute to scientific advancements and help better understand MG
- Including patient and caregiver perspectives in the development and review of study recruitment material is key to creating thoughtfully designed, impactful and easy to understand engagement tools
- The collected insights are of great value, informing how to best approach study recruitment efforts and design in the future. The outcomes of this collaboration drastically helped to make materials more easily comprehensible for patients and caregivers and which should be adopted as a best practice
- This practice should be applied beyond clinical research, particularly to any materials that will be patient or caregiver facing.
  - Patients and caregivers can be empowered and involved in shared decision making when it comes to the development of study design, recruitment tools, and beyond

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## Disclosures

Brindley Rospars, Brian Sawyer, Zia Choudhry and Lisa Shea are employees, consultants or contractors of Johnson & Johnson and may hold stock or stock options in Johnson & Johnson. Maria A-Tihyaty was an employee of Johnson & Johnson at the time of the study. Jessica Wright and Marcia Landen have nothing to disclose.

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Autoantibody: gMG



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