# 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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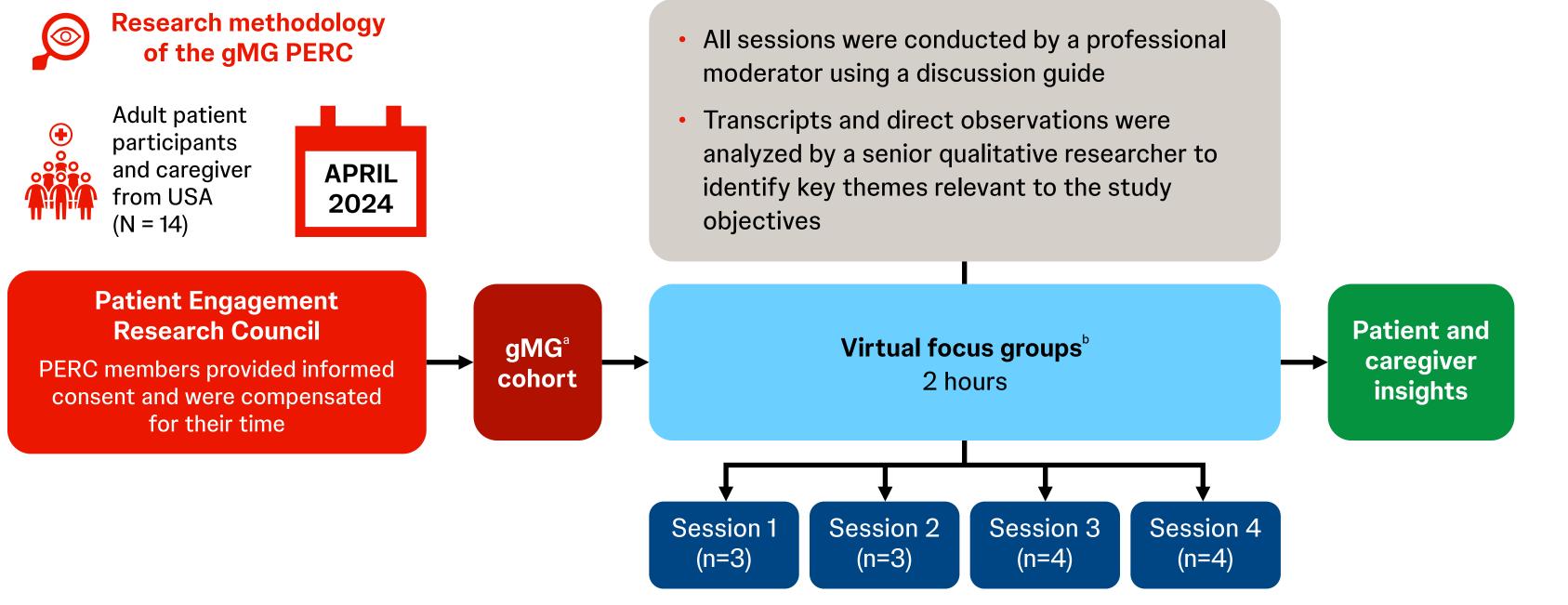
# Introduction

- 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 Patient Engagement and Research Council (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  $\geq$  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>8</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

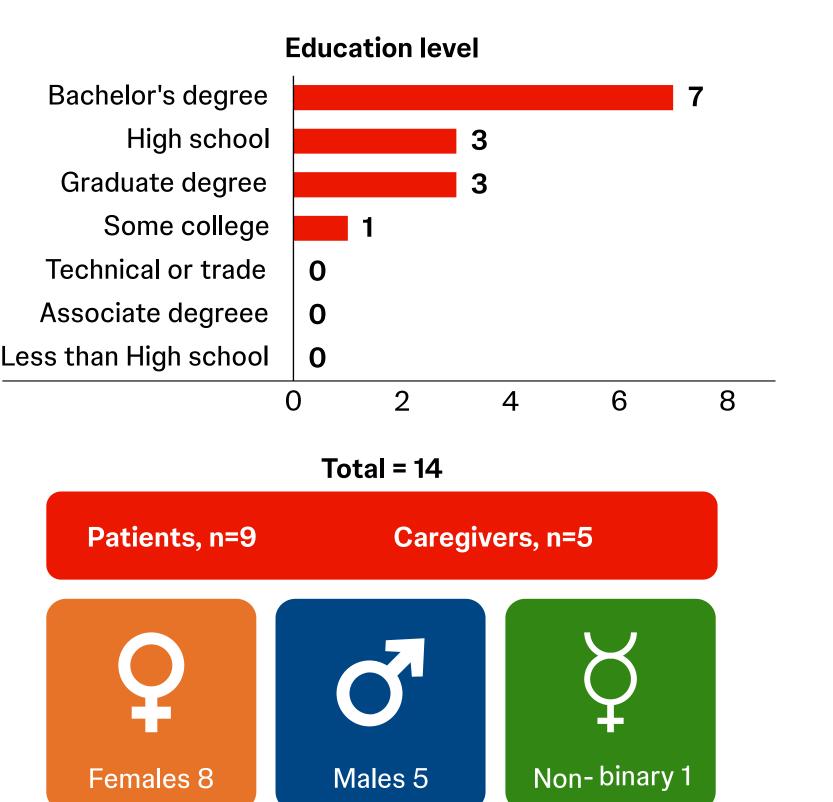


<sup>a</sup>Self reported diagnosis. <sup>b</sup>Also attended by at least one scientific Janssen employee. gMG=Generalized myasthenia gravis; PERC=Patient Engagement Research

Presented at the Myasthenia Gravis Foundation of America (MGFA) Scientific Session of the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM) Annual Meeting, Savanah, Georgia, October 15-18, 2024.

# Results

- ongoing 2-year study



<sup>a</sup>PERC members could select more than 1 race/ethnicity. gMG=Generalized myasthenia gravis; PERC=Patient Engagement Research Counc

#### **Initial Draft**

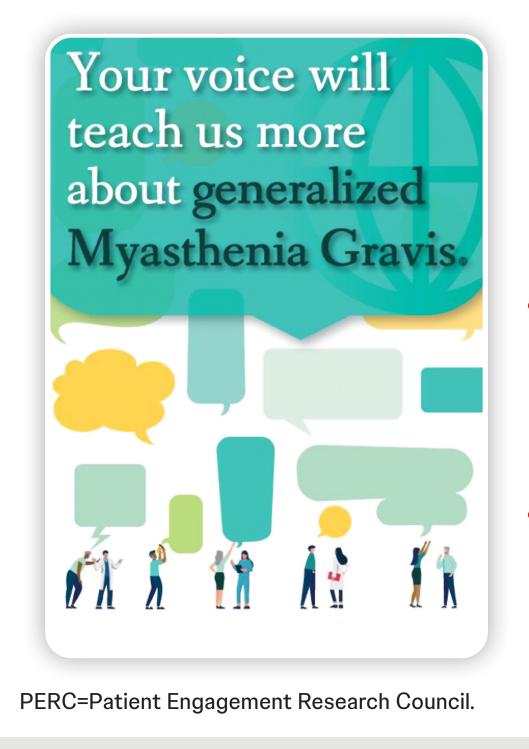


Table 1. Summa		
	Participan brochure v informatic	
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gMG=Ge	gMG=Generalized myasthe	

## **References:**

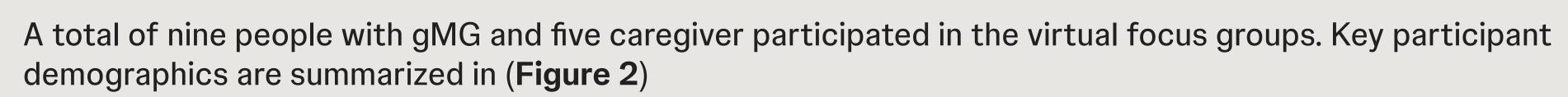
1. Saccà F et al. Eur J Neurol. 2024 Jun; 31(6):e16180; 2. Faulkner SD et al. Pharmaceut Med. 2023; 37(2):129-138; 3. Arumugam A et al. Arum **7.** Chakravarty SD, et al. Rheumatol Ther. 2021;8:609–20; **8.** Yung M et al. Health Sci Rep. 2024;7(9):e70081.

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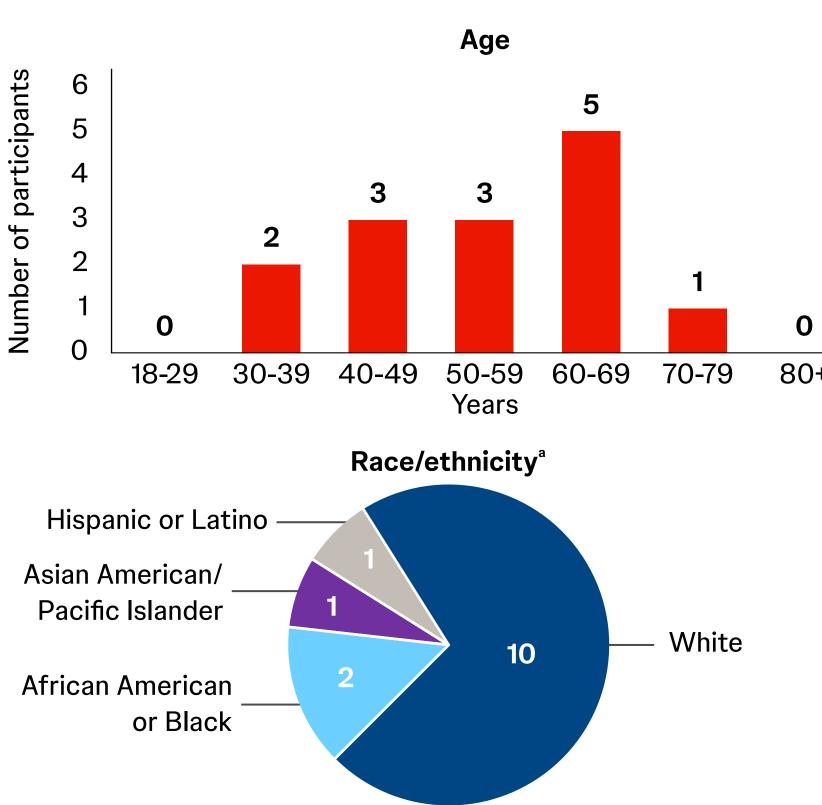
going on.



• 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-tounderstand language for the end-user

Additional suggestions were also collected to better understand motivation and retention of patients in an





#### The PERC provided actionable insights on a brochure cover intended to provide information on the study.

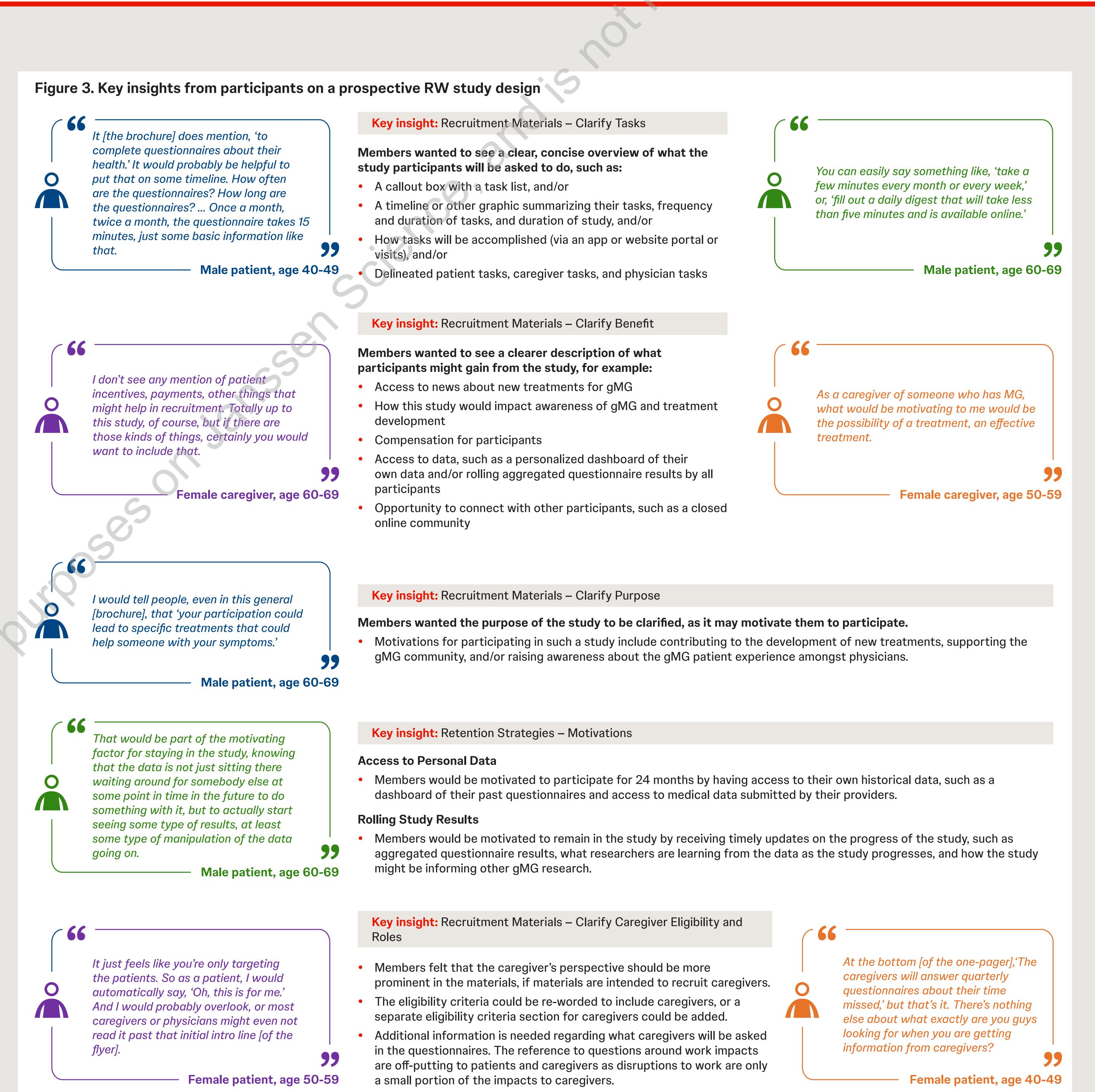
- "I feel like I want to see the people a little more because.. most patients are older. A lot of them are in wheelchairs and need walking assistance. And so just looking at this, they all look pretty healthy and young for the most part."
- "I like the colors. They're pleasant. I love the teal, the blues. It just gives me a sense of harmony and like inviting colors... And teal is the color for myasthenia gravis too."

**Revised with PERC** Feedback



#### nary of gMG PERC feedback and how it has been addressed

Feedback	Action	the patients. So as a patient, automatically say, 'Oh, this is
ants expressed that the informational e was text-heavy and there was a surplus of tion on each page	Informational brochure was modified to reduce the amount of text on each page	And I would probably overlook caregivers or physicians migh read it past that initial intro lin flyer]. Female pa
s noted that varying text sizes and fonts on nent materials made reading the text more	<ul> <li>Written recruitment materials were edited to a standardized font size and text across materials to increase ease</li> </ul>	
thenia gravis; PERC=Patient Engagement Research Council.		gMG=Generalized myasthenia gravis; RW=Real world.





\*Presenting Author

Patients and caregivers can contribute to scientific advancements and help better understand MG

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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



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

The collected insights are of great value,

informing how to best approach study

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

Maria A-Tihyaty, Brindley Rospars, Brian Sawyer, Zia Choudhry and Lisa Shea are or were employees, consultants or contractors of Janssen Pharmaceuticals and may hold stock or stock options in Johnson & Johnson. Jessica Wright and Marcia Landen have nothing to disclose

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Autoantibody: gMG

