Design of a digital solution to improve myasthenia gravis patient symptom tracking in routine clinical care

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Background

- Myasthenia gravis (MG) is a chronic, debilitating, antibody-mediated autoimmune neuromuscular disease characterized by fluctuating, fatigable muscle weakness^{1–3}
- The fluctuating nature of MG symptoms creates challenges for disease management¹
- Validated patient-reported outcomes (PROs) are utilized in clinical research to assess symptom changes over time, but symptom monitoring in clinical practice could be improved¹
- Limitations of MG PROs include infrequent collection of data and the inability to gather a holistic picture of patients' disease burden³
- The objective of this study was to determine design requirements for a digital tool that utilizes validated PROs to improve symptom tracking and communication between patients with MG and healthcare providers (HCPs) in routine clinical practice

Methods

- A literature review was carried out and preliminary interviews with US-based patients with MG (n=3) and HCPs (n=4 neurologists) were conducted to assess the current state of MG symptom tracking and identify opportunities for improvement (Figure 1)
- Structured workshops with HCPs (n=5 neuromuscular neurologists) and validation interviews with patients with MG (n=10) and HCPs (n=9 neurologists, academic- and community-based) were held to design a novel digital tool and understand factors influencing adoption (**Figure 1**)
- Transcripts were analyzed for themes regarding challenges, preferred solutions, and benefits and applications of the proposed digital tool

FIGURE 1: Study design

Literature

Review Analyzed validated MC measures as well as a competitive landscape POV on MG mobile tools to better understand current offerings and needs for a ne MG tracking offering.

Recruitment for HCP

Workshops Five HCPs specializing in neuromuscular medicine were selected to represent physician interests in a series of 3 workshops aimed at understanding physician needs for MG tracking and testing application features.

Patient Validation Interviews

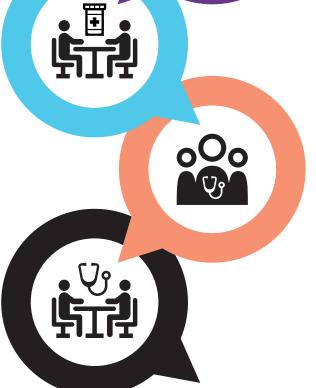
In-depth interviews with 10 patients with MG collected feedback on **design** mock-ups of the digital tool The primary aim was to understand what features would provide the most and least **benefit** to patients and understand how patients would use the tool in conversations with their physician.

HCP Validation

Interviews In-depth interviews with 9 neurologists from a variety of practice types were conducted to understand how they would use the tool in a clinical setting both in regard to **patients** communication and treatment decisions

Participating patients and HCPs were US-based. HCP, healthcare provider; MG, myasthenia gravis; POV, point of view.

4 neurologists to ŝŝ nOn



Preliminary HCP Patient Interviews

Preliminary interviews with 3 patients with MG and

better understand iews on MG tracking and openness o a new tracking tool.

HCP Workshops 1&2

Held the first 2 of 3 structured workshops with HCPs. HCP Workshop⁻ was centered around defining the challenges neurologists face in nanaging and tracking MG symptoms, while HCP Workshop 2 synthesized these challenges into desired solutions.

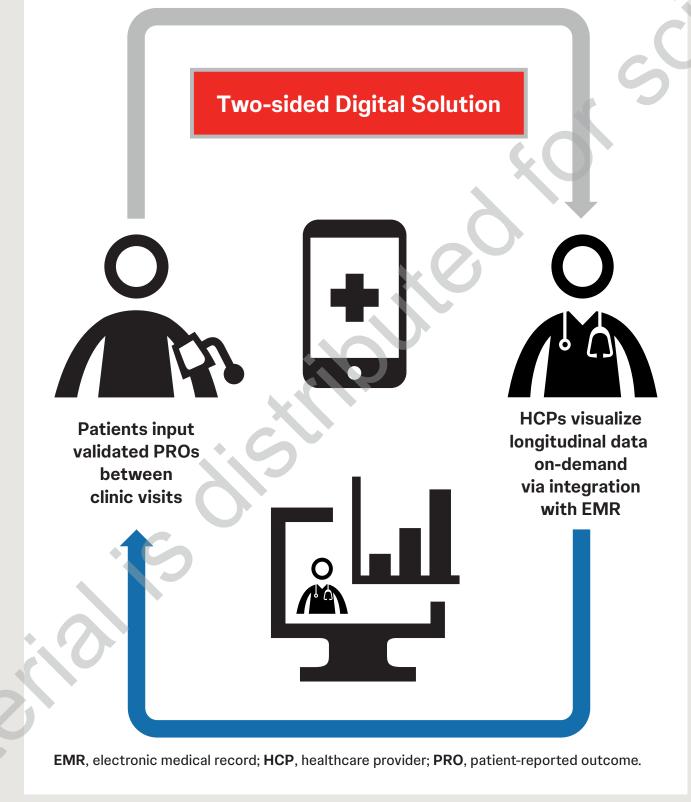
HCP

Workshop 3 HCP Workshop 3 liscussed **utilization of** the digital tool in clinical decision making for various types of patients to understand the **applicability** of the tool in different settings and scenarios.

Results

- MG-ADL had strong advantages in ease of
- would fill this gap
- medications; **Figure 3**)
- MG management tool (Figure 6)

FIGURE 2: Key design requirements



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• The result of the study was the conceptual design of a two-sided digital solution that enables patients to input validated PROs between clinic visits and helps HCPs visualize longitudinal data on demand via integration with electronic medical records (Figure 2)

Findings from the literature review and preliminary patient and HCP interviews confirmed that opportunities exist to improve the current state of MG symptom tracking Patients noted that they felt neglected in their MG journey, mostly regarding their experiences outside of the clinic; HCPs who manage a high volume of patients with MG saw the greatest value in a new digital tool

• The Myasthenia Gravis Activities of Daily Living (MG-ADL) scale, Patient Acceptable Symptom State (PASS), and Quality of Life in Neurological Disorders (Neuro-QOL) -Fatigue subscore were measures identified for inclusion

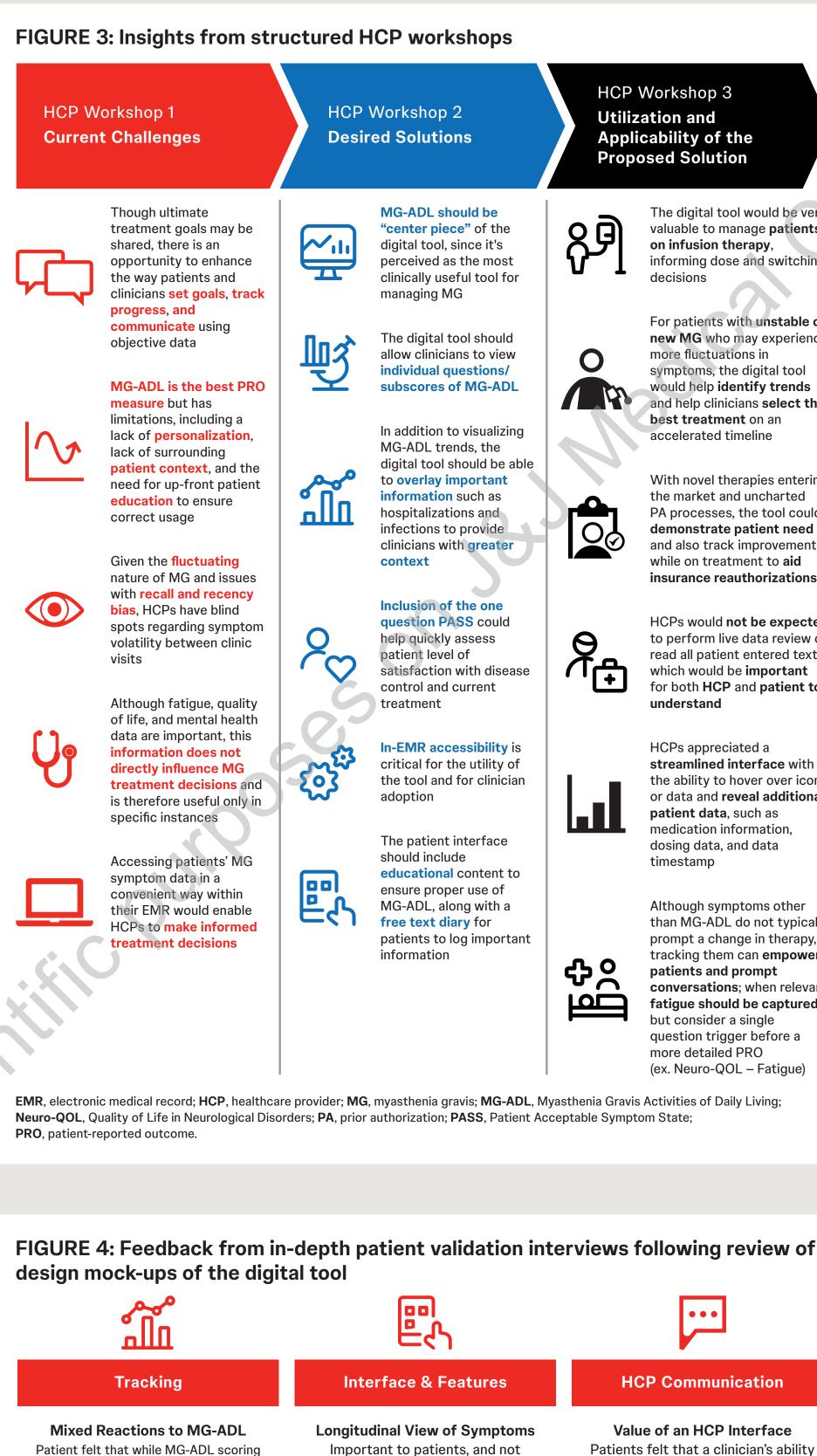
administration and utilization/validation in clinical trials, but lack of fatigue assessment was identified as a weakness; inclusion of Neuro-QOL – Fatigue and PASS

 HCPs preferred the MG-ADL scale as their primary visual, with ability to overlay subscores and other contextual data (i.e., PASS, Neuro-QOL – Fatigue, hospitalizations, and

Free text patient diary entries with artificial intelligencegenerated summaries for HCPs were desired for additional contextualization and personalization (**Figures 4** and **5**)

Factors influencing patient adoption of the digital solution included HCP use and the potential to have a single central

HCPs noted adoption of the tool would be facilitated by electronic medical record integration and streamlined visualizations enabling quick data synthesis to support treatment decisions and features to simplify insurance prior authorization/reauthorization (**Figures 3** and **6**)



Value of Free Text Diary Patients viewed the free text diary and photo/video upload functionality as critical for personalizing tracking and sharing context behind symptoms

works for some (e.g., patients who have

ocular/bulbar symptoms), it is **not**

personalized and specific for others

(i.e., those who have issues related

to fatigue)

Fatigue Tracking Brought up unaided across multiple interviews as a key pain point for patients

HCP, healthcare provider; MG-ADL, Myasthenia Gravis Activities of Daily Living

commonly offered by existing solutions.

Patients particularly resonated with

subscore-level views

Consolidation of

Multiple Functionalities

Patients currently use a fragmented mix

of applications to track information.

A single digital resource that

consolidates these functions was seen

as valuable

Medication Reminders

Brought up by patients as high value

especially in the context of the rest

of the application

HCP Workshop 3 Utilization and Applicability of the **Proposed Solution**

> valuable to manage **patients** on infusion therapy, informing dose and switching

For patients with unstable or new MG who may experience e fluctuations in symptoms, the digital too would help identify trends and help clinicians select the **best treatment** on an accelerated timeline

With novel therapies entering the market and uncharted PA processes, the tool could lemonstrate patient need and also track improvements while on treatment to **aid** insurance reauthorizations

HCPs would not be expected to perform live data review or read all patient entered text, which would be **important** for both HCP and patient to understand

HCPs appreciated a streamlined interface with the ability to hover over icons or data and **reveal additional** patient data, such as nedication information

dosing data, and data

timestamp

Although symptoms other than MG-ADL do not typically prompt a change in therapy, tracking them can **empower** patients and prompt conversations; when relevant fatigue should be captured, ut consider a single question trigger before a more detailed PRO

(ex. Neuro-QOL – Fatigue)



HCP Communication

Value of an HCP Interface Patients felt that a clinician's ability to easily view all this information would significantly improve current communication and

decision-making models

Conversational Tool Many users talked about the utility of this tool to guide conversations with HCPs. Many patients called out their own inability to remember or bring up symptoms (i.e., brain fog)

FIGURE 5: Themes that emerged from in-depth HCP validation interviews on applicability of the digital tool in a clinical setting

Patient Benefits

- Provides comfort to patients to be in control of tracking symptoms
- Helps validate gualitative symptom tracking and provides objective data showing that symptoms in fact are worsening
- Helpful for patients with **poor recall of symptoms** at the time of visit by allowing them to both track symptoms accurately and time of onset
- Particularly useful for new or newly diagnosed patients who may have less controlled symptoms or change treatments more frequently
- I have been wanting an application like this for about 10 years. I think many more patients would track this information and benefit from tracking if there was an easy way of doing it. 😱

Clinical Decision-Making

- Allows both patient and HCP to be alerted early & make quicker decisions about changes in symptoms
- Makes HCPs aware of non-MG causes of symptom exacerbation, such as other illnesses or medications, resulting in the avoidance of unnecessary treatment escalation
- When patients call about symptoms, the digital tool can help validate if symptoms are MG related and reduce unnecessary patient visits
- For patients with vague complaints like fatigue the digital tool provides objective data and Al summaries to better differentiate MG related vs non-MG related symptoms
- Things like fatigue are 'squishy' complaints that are hard to find on an exam. Now we have an app to validate this and show objective evidence of symptoms that are not well controlled, allowing us to change treatments more quickly.

- **Applicability for Infusion Patients**
- Provides baseline data before starting infusions to **understand effectiveness** of infusion once started
- Provides objective data particularly in advanced patients such as those who are running out of treatment options or are on infusions
- Helps clinicians make treatment decisions based on objective data indicating how patients are handling MG symptoms during and after infusion

This is particularly useful for infusion patients. Currently we have to wait until the patient calls us with concerns, but having access to this data helps us see trends and determine how often the infusions should be given.

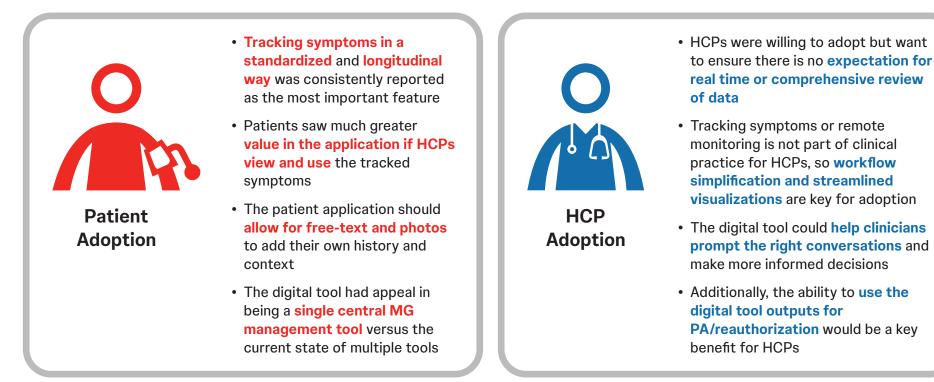
HCP Benefits

- Helps provide objective data to support the prior authorization process since MG-ADL baselines and any worsening of symptoms will be captured in the data and can be copied into a PA form
- Clinicians, ideally, want to be reimbursed for usage of the tool – if used during the clinic visit, the time should be reimbursable (RPM codes seem less likely)
- HCPs want to quickly read the graphic and text summary and not have to spend time manipulating HCP dashboard – the generative AI and a clear default graph were important

Sometimes apps like this are tricky because I don't get reimbursed for my effort using them. If I were able to get that reimbursement, I'd be more likely to use it.

AI, artificial intelligence; HCP, healthcare provider; MG, myasthenia gravis; MG-ADL, Myasthenia Gravis Activities of Daily Living; **PA**, prior authorization; **RPM**, remote patient monitoring

FIGURE 6: Key factors influencing patient and HCP adoption of the digital tool



HCP, healthcare provider; MG, myasthenia gravis; PA, prior authorization.

REFERENCES:



Key takeaway A two-sided

digital solution was designed that would support evidence-based care management of patients with MG

Conclusions



The designed solution would allow patients to input validated PROs between clinic visits, and HCPs to visualize longitudinal data on demand via integration with electronic medical records



Patients and HCPs agreed that the proposed digital solution would enhance clinical care by improving MG symptom tracking and, ultimately, treatment decisions



These results support continued development of the digital tool and studies investigating its clinical utility

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Disclosures

SM has served on advisory boards for Alexion, AstraZeneca Rare Disease, argenx, Horizon Therapeutics/Amgen, and Ra Pharmaceuticals (now UCB). **JA** has served as a paid consultant for Alexion Pharmaceuticals, argenx, and UCB; he has served on speakers' bureaus for Alexion Pharmaceuticals, argenx, and UCB. **AELA** has served on a speaker's bureau for Alexion Pharmaceuticals and has served on advisory boards and as a paid consultant for Johnson & Johnson. **N Silvestri** has served as a paid consultant for Alexion Pharmaceuticals, Amgen, Annexon, argenx, UCB, and Immunovant; he has served on speakers' bureaus for Alexion Pharmaceuticals, argenx, and UCB. N Streicher has served as a speaker for Alexion and AstraZeneca Rare Disease. AVP. HJ. and AG are employees of ZS Associates, a company paid by Johnson & Johnson to undertake the analyses for this study. **NC** and **ZC** are employees of and hold stock in Johnson & Johnson.