

The impact of remaining and fluctuating gMG symptoms

Following established Delphi panel methodology, this survey has been designed to elicit consensus regarding how remaining symptoms and changes in the intensity and unpredictability of symptoms, despite treatment, may affect a person's day to-day activities while living with generalised myasthenia gravis (gMG).

You may leave the survey and resume where you left off at any point, but you must ensure to save the survey using the "save and continue" function and inform the fieldwork team so they can share an updated link.

This survey is the second part of a two-phase study including two survey rounds (both are designed to take no more than 40 minutes to complete), which all participants will complete.

Please ensure you answer each question presented in this survey to the best of your ability.

Please contact the fieldwork agency SHG: natalia.borrell@surveyhealthcareglobal.com if you would like to review or amend your consent that you have previously provided for this study.

- * 1. You were previously provided with a unique ID number via email from the fieldwork agency (SHG). Please enter the unique ID number you have been assigned for this survey below

The impact of remaining and fluctuating gMG symptoms

The first-round survey responses were collated and analysed to inform the development of this second-round survey. Due to variability in patients' experiences with symptoms of gMG, there were minimal areas that reached consensus in the first round. Consensus is defined as more than 80% of participants agreeing (rating 7-9 using a 9-point scale) or disagreeing (rating 1-3 using a 9-point scale) on a statement.

Therefore, the questions included in this second-round survey are based on the free-text responses received in the first round. With these free-text responses, participants provided their thoughts on open questions in their own words. Analysis of these responses enabled the further exploration of participants' experiences of their remaining gMG symptoms.

This survey is designed to take no more than 40 minutes to complete. When prompted to enter a free-text response, please feel free to provide key words, where applicable, if this simplifies the task.

For further information, please refer to the study brief that has been shared with you by the fieldwork agency.

The impact of remaining and fluctuating gMG symptoms

While the burden of living with myasthenia gravis (MG) is relatively well-characterized, very little is known from the scientific literature on the specific burden of remaining symptoms and changes in the intensity and unpredictability of symptoms on the day-to-day lives of those living with generalised myasthenia gravis (gMG).

Therefore, the aim of this project is:

- To describe, from a qualitative perspective, how remaining symptoms and changes in the intensity and unpredictability of symptoms, despite treatment, may affect a person's day-to-day activities while living with gMG.

For the purpose of this survey, "remaining gMG symptoms" refers to symptoms that occur despite treatment for gMG.

"Fluctuating symptoms" are defined by a "sudden onset/worsening of symptoms" and refers to variations in the intensity and/or predictability of symptoms.

You will be able to refer back to this definition throughout the survey by clicking on the (?) symbol in relevant questions.

Please note that questions regarding "remaining" symptoms of gMG have been colour coded in blue and questions regarding the "intensity/unpredictability" of symptoms of gMG have been colour coded in purple for clarity.

[illegible]

Social life and relationships

Committing to social plans/ maintaining a social circle

6. Please rank your agreement with the following statements regarding your **ability to commit to and attend social events**, on a scale of 1-9 with 1 being completely disagree and 9 being completely agree.

* 20. 6. a) "My social life has been limited due to my **remaining** gMG symptoms."

(Select one option)

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG. Impacts on your social life may refer to your capacity to attend social events and plan your social gatherings. Remaining symptoms that have an impact may include, but are not limited to: muscle weakness and fatigue. For the purpose of this survey, fatigue is defined as a lack/ loss of mental and physical energy. Please note that this is different to fatigability, which refers to muscle weakness/ tiredness.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

* 21. 6. b) "Due to my **remaining** gMG symptoms, I find it difficult to attend long social event or social events taking place in the evening."

(Select one option)

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

* 22. 6. c) "I sometimes have to cancel my social plans and feel that I let my friends or family down, as my symptoms can **suddenly worsen**."

(Select one option)

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

* 23. 6. d) "I find it necessary to rest so that I am able to attend a social event to mitigate the fatigue I may experience due to the **sudden worsening of my gMG symptom**." (Select one option)

Tip: For the purpose of this survey, fatigue is defined as a lack/ loss of mental and physical energy.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

* 24. 6. e) "I worry I may not be invited to social plans in the future, as I cannot commit to social plans ahead of time due to the **unpredictability of my gMG symptoms**." (Select one option)

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

25. 6. f) [Optional question] Please provide any additional information regarding the challenges you experience with committing to social plans/ maintaining a social circle due to your **remaining** symptoms of gMG and their **variations in intensity and/or unpredictability**. [Please consider providing a response. This information will be helpful for survey administrators.]
Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

[illegible]

Romantic/ sexual relationships

7. Please rank your agreement with the following statements regarding **romantic and sexual relationships** on a scale of 1-9, with 1 being completely disagree and 9 being completely agree.
These questions are optional but please answer if you feel comfortable to do so.

26. 7. a) [Optional question] "My **remaining symptoms** of gMG can sometimes have a negative impact on my romantic/ sexual relationships."

(Select one option)

[Please consider providing a response. This information will be helpful for survey administrators.]

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

Mental wellbeing

Experiencing stress or anxiety

8. Please rank your agreement with the following statements regarding your **experience of stress and/or anxiety**, on a scale of 1-9 with 1 being completely disagree and 9 being completely agree.

* 27. 8. a) "I sometimes feel anxious and/or stressed that I may have a **sudden worsening** of gMG symptoms, as they are **difficult to predict**." (Select one option)

Tip: gMG symptoms may include, but are not limited to: muscle weakness or brain fog, tiredness, slurred speech.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

* 28. 8. b) "I am afraid that I may appear unreliable at work as the **sudden worsening** of my gMG symptoms means that I am unable to always be present at work." (Select one option)

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

* 29. 8. c) "Despite my treatment being effective at mitigating symptoms, I sometimes feel stressed that my **remaining gMG symptoms** may worsen or return before my next dose." (Select one option)

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

Mental wellbeing

Self-esteem

9. Please rank your agreement with the following statements regarding your self-esteem, on a scale of 1-9 with 1 being completely disagree and 9 being completely agree.

* 30. 9. a) "I feel less independent and require more help when I am experiencing a **sudden onset and/or worsening of symptoms** of gMG, which impacts my **self-esteem**." (Select one option)

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

* 31. 9. b) "Changes to my appearance due to my **remaining gMG symptoms**, impact my self-confidence and esteem." (Select one option)

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG. Changes to appearance may include, but are not limited to: droopy eyelids, changes in facial expressivity.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

* 32. 9. c) "I sometimes feel worried about how I may be perceived by others due to my **remaining gMG symptoms**." (Select one option)

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG. Examples of this experience may include but are not limited to: feeling self-conscious about one's appearance, or the fear of being perceived as lazy or incapable of carrying out tasks.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

Mental wellbeing

Feelings of frustration

10. Please rank your agreement with the following statement regarding feelings of frustration, on a scale of 1-9 with 1 being completely disagree and 9 being completely agree.

* 33. 10. a) "The **unpredictability** of my symptoms makes activities in my daily life difficult to plan, which is frustrating, as I do not know how I will feel on a particular day and I am not able to do as much as I usually can." (Select one option)

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

Work and education

Learning new skills/ ability to learn

13. Please rank your agreement with the following statements regarding the impact of your gMG symptoms on your ability to learn new skills/ study, on a scale of 1–9 with 1 being completely disagree and 9 being completely agree.

* 37. 13. a) "The **unpredictability** of my gMG symptoms has hindered my ability and/or desire to learn new skills/ study." (Select one option)

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree
☐ N/A								

* 38. 13. b) "I learnt to make accommodations in my learning of new skills/studying, when my gMG symptoms are **particularly challenging**." (Select one option)

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree
☐ N/A								

14. Please rank your agreement with the following statements regarding the impact of your gMG symptoms on your work and finances, on a scale of 1-9 with 1 being completely disagree and 9 being completely agree.

☐ N/A☐ N/A

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Future plans

* 42. 15. a) "I find it difficult to be (more) ambitious in my career, as I worry that the impact of my **remaining symptoms** will prevent me from taking on additional responsibilities within my job role."
(Select one option)

1 2 3 4 5 6 7 8 9

○ ○ ○ ○ ○ ○ ○ ○ ○

Completely disagree Completely agree

* 43. 16. a) "My **remaining symptoms** have influenced my decision to have or continue having more children."

1 2 3 4 5 6 7 8 9

○ ○ ○ ○ ○ ○ ○ ○ ○

Completely disagree Completely agree

Symptom control

1 2 3 4 5 6 7 8 9

Completely disagree Completely agree

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