

# Supplementary Material

## **People diagnosed with Myasthenia Gravis have lower HRQoL and need more medical and caregiver help in comparison to the General Population: analysis of two observational studies**

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**Table S1 Frequency of co-morbidities in MRW versus POPUP**

Type of co-morbidity (self-reported)	POPUP	MRW
Thyroid problems	9.5%	22.5%
Anxiety	14.4%	16.4%
Depression	11.4%	14.5%
Respiratory disease (e.g. asthma, COPD)	8.7%	12.6%
Osteoporosis	3.2%	10.1%
Diabetes	10.3%	8.0%
Cardiovascular disease	4.5%	4.8%
Cancer	2.0%	3.8%
Rheumatoid arthritis	4.7%	3.1%
Psoriasis	3.0%	2.3%
Psoriatic arthritis	0.8%	1.1%
<i>None of the above</i>	<i>41.0%</i>	<i>32.2%</i>

Abbreviations: MRW: MyRealWorld-MG dataset, POPUP: General Population Norms Study Dataset, COPD: chronic obstructive pulmonary disease.

**Table S2 Distribution of respondents from MRW vs POPUP across the 8 MG-ADL domains**

	<b>MRW</b>	<b>POPUP</b>
<b>Talking</b>		
Normal	55.5%	94.4%
Intermittent slurry or nasal speech	38.5%	3.9%
Constant slurring or nasal, but can be understood	3.6%	1.1%
Difficult to understand speech	2.4 %	0.6 %
<b>Chewing</b>		
Normal	54.6%	93.3%
Fatigue with solid food	39.8%	5.0%
Fatigue with soft food	4.9%	1.4%
Gastric tube	54.6 %	93.3 %
<b>Swallowing</b>		
Normal	52.1%	93.0%
Rare episode of choking	41.4%	5.1%
Frequent choking necessitating changes in diet	5.8%	1.5%
Gastric tube	0.7 %	0.4 %
<b>Breathing</b>		
Normal	37.5%	76.5%
Shortness of breath with exertion	51.0%	19.9%
Shortness of breath at rest	10.7%	2.8%
Ventilator dependence	0.9 %	0.8 %
<b>Impairment of ability to brush teeth or comb hair</b>		
None	51.5%	93.3%
Extra effort but no rest periods needed	29.6%	3.7%
Rest periods needed	18.0%	2.4%
Cannot do one of these functions	1.0 %	0.6 %
<b>Impairment of ability to rise from a chair</b>		
None	45.4%	82.4%
Mild, sometimes uses arms	33.4%	11.8%
Moderate, always use arms	20.1%	4.9%
Severe, requires assistance	1.1 %	0.9 %
<b>Double vision</b>		
None	39.6%	89.7%
Occurs, but not daily	30.6%	7.3%
Daily, but not constant	20.1%	2.1%
Constant	9.8 %	0.9 %

<b>Eyelid droop</b>		
None	37.7%	91.2%
Occurs, but not daily	33.7%	5.1%
Daily, but not constant	20.1%	2.0%
Constant	8.5%	1.6%

MG-ADL permission to use: Mapi Research Trust, Lyon, France, <https://eprovide.mapi-trust.org>

**Table S3. Distribution of respondents from MRW vs POPUP across the 8 HUI 3 domains<sup>a</sup>**

	<b>MRW</b>	<b>POPUP</b>
<b>Seeing</b>		
Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, without glasses or contact lenses.	18.9%	34.4%
Able to see well enough to read ordinary newsprint and recognize a friend on the other side of the street, but with glasses.	61.7%	60.7%
Able to read ordinary newsprint with or without glasses but unable to recognize a friend on the other side of the street, even with glasses.	3.7%	1.5%
Able to recognize a friend on the other side of the street with or without glasses but unable to read ordinary newsprint, even with glasses.	8.0%	1.6%
Unable to read ordinary newsprint and unable to recognize a friend on the other side of the street, even with glasses.	7.2%	1.2%
Unable to see at all.	0.6%	0.7%
<b>Hearing</b>		
Able to hear what is said in a group conversation with at least three other people, without a hearing aid.	86.5%	90.0%
Able to hear what is said in a conversation with one other person in a quiet room without a hearing aid, but requires a hearing aid to hear what is said in a group conversation with at least three other people.	0.4%	1.4%
Able to hear what is said in a conversation with one other person in a quiet room with a hearing aid and able to hear what is said in a group conversation with at least three other people with a hearing aid.	3.0%	3.8%
Able to hear what is said in a conversation with one other person in a quiet room without a hearing aid, but unable to hear what is said in a group conversation with at least three other people even with a hearing aid.	4.8%	1.8%
Able to hear what is said in a conversation with one other person in a quiet room with a hearing aid, but unable to hear what is said in a group conversation with at least three other people even with a hearing aid.	0.2%	0.8%
Unable to hear at all.	5.2%	2.2%
<b>Speech</b>		
Able to be understood completely when speaking with strangers or friends.	77.0%	91.8%
Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know me well.	6.7%	2.9%
Able to be understood partially when speaking with strangers or people who know me well.	13.9%	3.5%
Unable to be understood when speaking with strangers but able to be understood partially by people who know me well.	1.3%	0.7%
Unable to be understood when speaking to other people (or unable to speak at all).	1.1%	1.0%
<b>Ambulation</b>		
Able to walk around the neighborhood without difficulty, and without walking equipment.	48%	83%
Able to walk around the neighborhood with difficulty, but does not require walking equipment or the help of another person.	30.9%	10.9%

Able to walk around the neighborhood with walking equipment, but without the help of another person.	10.4%	3.5%
Able to walk only short distances with walking equipment, and requires a wheelchair to get around the neighborhood.	7.8%	1.7%
Unable to walk alone, even with walking equipment. Able to walk short distances with the help of another person, and requires a wheelchair to get around the neighborhood.	1.3%	0.7%
<b>Dexterity</b>		
Full use of two hands and ten fingers.	55.6%	88.6%
Limitations in the use of hands or fingers, but does not require special tools or help of another person.	31.1%	6.7%
Limitations in the use of hands or fingers, is independent with use of special tools (does not require the help of another person).	6.3%	2.4%
Limitations in the use of hands or fingers, requires the help of another person for some tasks (not independent even with the use of special tools).	5.9%	1.7%
Limitations in the use of hands or fingers, requires the help of another person for most tasks (not independent even with the use of special tools).	0.7%	0.4%
Limitations in the use of hands or fingers, requires the help of another person for all tasks (not independent even with the use of special tools).	0.4%	0.3%
<b>Emotion</b>		
Happy and interested in life.	25.0%	41.2%
Somewhat happy.	44.1%	39.1%
Somewhat unhappy.	21.7%	14.4%
Very unhappy.	6.7%	3.7%
So unhappy that life is not worthwhile.	2.6%	1.7%
<b>Cognition</b>		
Able to remember most things, think clearly and solve day to day problems.	43.2%	73.2%
Able to remember most things, but have a little difficulty when trying to think and solve day to day problems.	14.3%	5.3%
Somewhat forgetful, but able to think clearly and solve day to day problems.	11.5%	9.2%
Somewhat forgetful, and have a little difficulty when trying to think or solve day to day problems.	18.9%	8.3%
Very forgetful, and have great difficulty when trying to think or solve day to day problems.	11.9%	3.2%
Unable to remember anything at all, and unable to think or solve day to day problems.	0.4%	0.8%
<b>Pain</b>		
Free of pain and discomfort.	15.2%	45.0%
Mild to moderate pain that prevents no activities.	31.1%	38.2%
Moderate pain that prevents a few activities.	37.0%	11.1%
Moderate to severe pain that prevents some activities.	11.7%	4.1%
Severe pain that prevents most activities.	5.0%	1.7%

HUI 3 attribute levels are reproduced with permission from Table 1 in: Feeny D, Furlong W, Torrance GW, et al. Multiattribute and single-attribute utility functions for the health utilities index mark 3 system. *Med Care*. Feb 2002;40(2):113-28. doi:10.1097/00005650-200202000-00006