Real-world insights from people living with myasthenia gravis: Analysis of user characteristics and adherence patterns from the HumaMG app

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Introduction

- MG is a chronic autoimmune disorder characterized by fluctuating muscle weakness
- The HumaMG app (**Figure 1**) enables remote real-world data collection directly from patients, deployed in the US via a direct-to-patient (D2P) model and in the UK through remote patient monitoring (RPM) prescribed by an HCP at St. George's Hospital
- This analysis aimed to describe patient characteristics and assess data completeness and retention patterns across deployment models, to evaluate the feasibility of generating real-world data

Methods

- A cross-sectional analysis was conducted on app data from 321 out of 386 patients (83.1%) who consented to data sharing
- Demographics, clinical characteristics, treatment data, PROs and retention were analyzed descriptively
- Dynamic retention was defined as the percentage of patients who remained active on the app at each week following onboarding. At each timepoint, only patients who had been enrolled for at least the corresponding number of weeks were included in the denominator. Patients were considered actively retained if they logged at least one clinically meaningful PRO score in that week

Results

- Among the 321 patients who consented to data sharing, 264 (82.2%) were enrolled via D2P (US) and 57 (17.7%) via RPM (UK)
- 88% of patients completed the demographics and MG profile questionnaire and 73.5% of patients entered medication data at baseline
- Most patients were female (73.7%) and 33.8% of patients were aged >55 years. Early-onset MG patients accounted for 75.5% of the patients, with double vision (17.8%) and eyelid droop (17.5%) being the most common initial symptoms (**Table 1**)
- Approximately half of patients had undergone thymectomy
- Initial PROs indicated moderate disease burden (RPM n=48, median MG-ADL: 5.0 [IQR: 5.25]; median EQ-5D-5L: 62.5 [IQR: 28.0] and D2P n=254, median MG-ADL: 8.0 [IQR: 6.0]; median EQ-5D-5L: 64.0 [IQR: 25.0]) (**Figure 2**)
- Retention after onboarding was higher in the RPM group compared with the D2P group. At Week 12, 84.4% of RPM patients remained active vs 32.3% of D2P patients; at Week 26, active retention was 76.5% and 12.3%, respectively
- These results suggest deeper engagement when use of the app is embedded in clinical care (**Figure 3** and **Table 2**)

Summary and conclusions

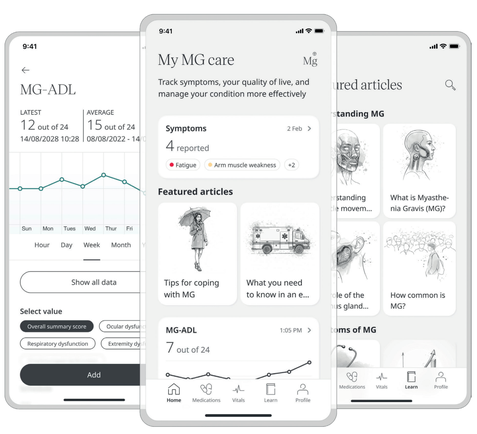
HumaMG collects high frequency MG disease burden metrics which can generate unique insights into the MG patient population

Despite the large difference in patient numbers at baseline between D2P and RPM, data from the latter group suggested stronger engagement and retention

These findings demonstrate the feasibility and potential of the HumaMG app for generating high-quality real-world data, particularly when integrated into clinical care pathways

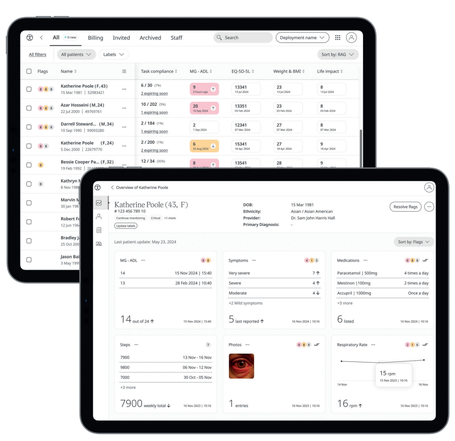
Figure 1 HumaMG app description

(a) HumaMG phone-based patient interface for MG patients



The app provides tools for symptom tracking, medication management and communication with healthcare.

(b) Web-based HumaMG portal for HCPs



The portal offers a comprehensive dashboard for monitoring patient progress, managing treatment plans and facilitating patient-provider interactions.

Figure 2 MG-ADL and EQ-5D-5L visual analog scores (ranging from 0 to 100) at onboarding in the two deployments

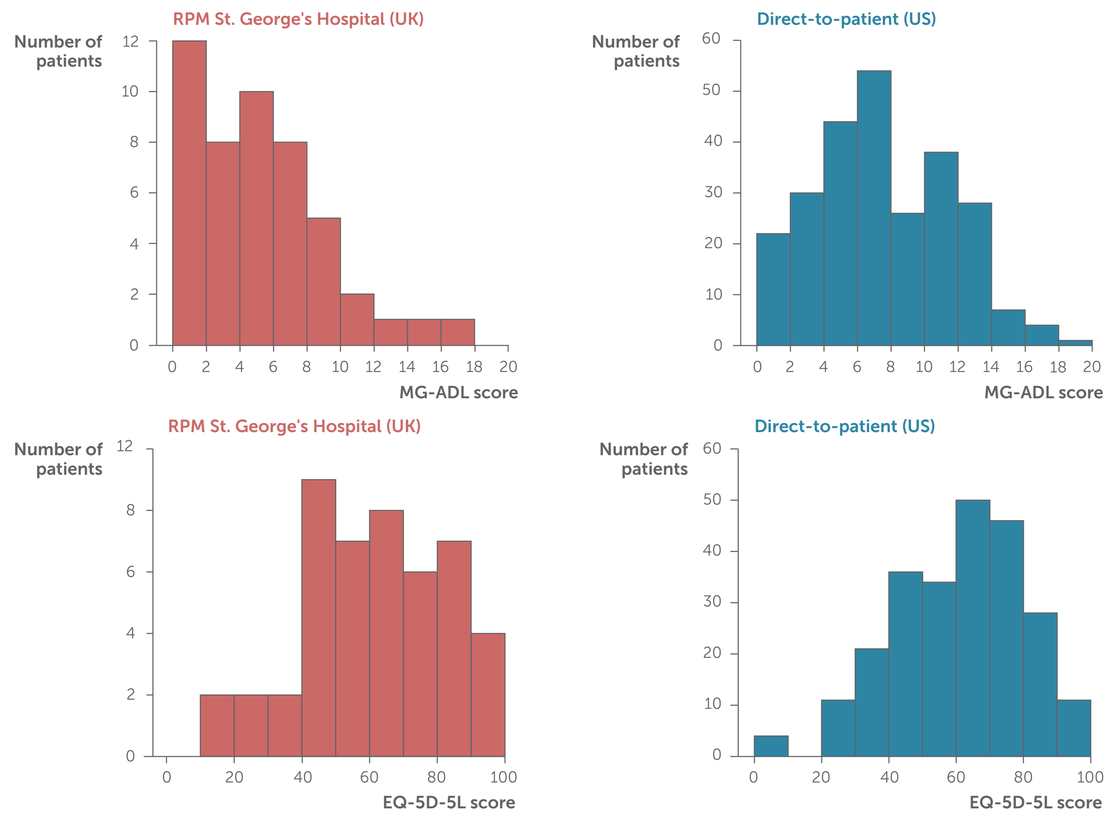


Table 1 Demographics of users at enrollment & MG onset description

Category	Subcategory	All	RPM St. George's Hospital (UK)	Direct-to-patient (US)
Responders (n)		**281**	**37**	**244**
Age at onboarding, n (%)	16–25	**6** (2.1%)	**5** (13.5%)	**1** (0.4%)
	26–55	**180** (64.7%)	**19** (51.4%)	**161** (66.0%)
	56–65	**50** (17.8%)	**3** (8.1%)	**47** (19.3%)
	≥66	**45** (16.0%)	**10** (27.0%)	**35** (14.3%)
Sex, n (%)	Female	**207** (73.7%)	**20** (54.1%)	**187** (76.6%)
	Male	**73** (26.0%)	**17** (45.9%)	**56** (23.0%)
	Not answered	**1** (0.4%)	**0** (0.0%)	**1** (0.4%)
Age at diagnosis, n (%)	Early onset (<50 years old)	**212** (75.5%)	**24** (64.9%)	**188** (77.0%)
	Late onset (≥50–<65 years old)	**50** (17.8%)	**5** (13.5%)	**45** (18.4%)
	Very late onset (≥65 years old)	**19** (6.8%)	**8** (21.6%)	**11** (4.5%)
First symptoms, n (%)	Pain	**20** (2.9%)	**4** (4.0%)	**16** (2.7%)
	Fatigue	**69** (10.0%)	**8** (8.0%)	**61** (10.3%)
	Sleep problems	**21** (3.0%)	**3** (3.0%)	**18** (3.0%)
	Unknown	**2** (0.3%)	**0** (0.0%)	**2** (0.3%)
	Not listed	**11** (1.6%)	**1** (1.0%)	**10** (1.7%)
	Drooping of one or both eyelids	**121** (17.5%)	**20** (20.0%)	**101** (17.1%)
	Blurred or double vision	**123** (17.8%)	**16** (16.0%)	**107** (18.1%)
	Change in voice/speech	**66** (9.5%)	**11** (11.0%)	**55** (9.3%)
	Difficulty swallowing	**59** (8.5%)	**11** (11.0%)	**48** (8.1%)
	Shortness of breath	**57** (8.2%)	**6** (6.0%)	**51** (8.6%)
	Weakness in the arms/legs	**108** (15.6%)	**14** (14.0%)	**94** (15.9%)
	Head droop	**35** (5.1%)	**6** (6.0%)	**29** (4.9%)

Figure 3 Weekly percentage of active patients over 6 months after onboarding to HumaMG

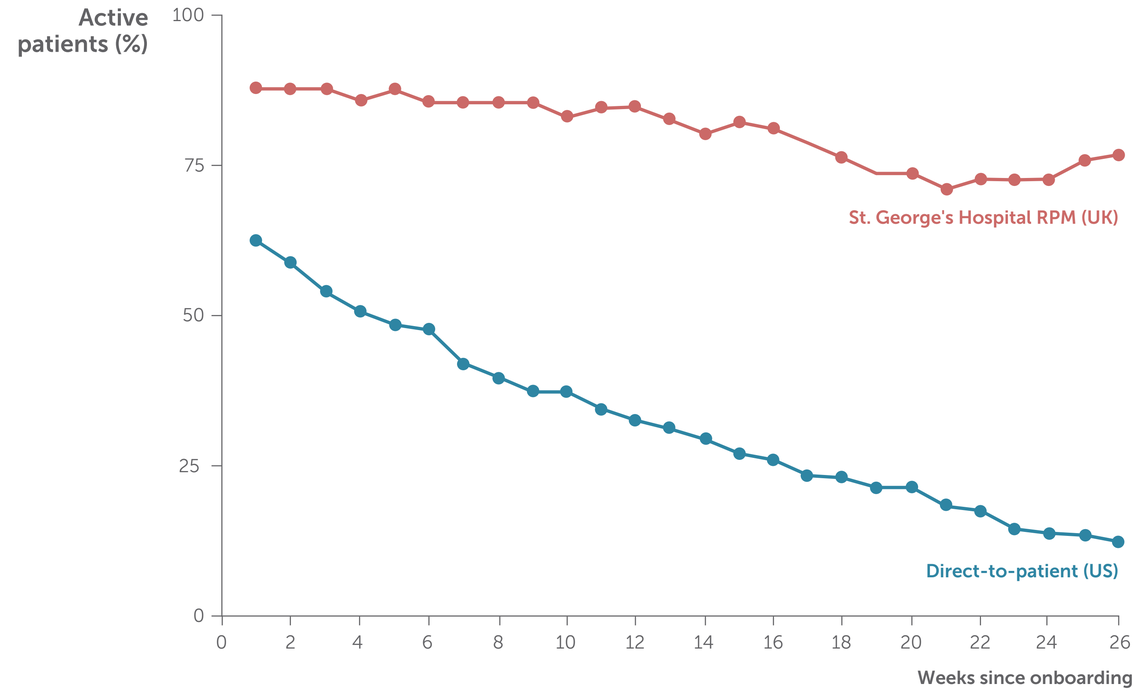


Table 2 Weekly dynamic retention: Number of eligible patients, number of active patients (logged at least one clinically meaningful PRO score) and corresponding retention percentage for RPM and D2P

	Week	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26
RPM	Eligible n	48	48	48	48	47	47	47	47	47	47	45	45	45	45	44	42	42	42	41	41	41	40	40	40	37	34
	Retained	42	42	42	41	41	40	40	40	40	39	38	38	37	36	36	34	33	32	30	30	29	29	29	29	28	26
	%	87.5	87.5	87.5	85.4	87.2	85.1	85.1	85.1	85.1	83.0	84.4	84.4	82.2	80.0	81.8	81.0	78.6	76.2	73.2	73.2	70.7	72.5	72.5	72.5	75.7	76.5
D2P	Eligible n	254	254	254	254	254	254	254	254	254	254	254	254	254	254	254	253	253	253	253	253	253	253	253	253	253	253
	Retained	158	149	136	128	123	120	106	100	94	94	87	82	79	74	68	65	59	58	54	54	46	44	37	35	34	31
	%	62.2	58.7	53.5	50.4	48.4	47.2	41.7	39.4	37.0	37.0	34.3	32.3	31.1	29.1	26.8	25.7	23.3	22.9	21.3	21.3	18.2	17.4	14.6	13.8	13.4	12.3

Disclaimer: The database has been updated since abstract submission. **Abbreviations:** D2P, direct-to-patient; EQ-5D-5L, EuroQoL 5-Dimension 5-Level; HCP, healthcare professional; IQR, interquartile range; MG, myasthenia gravis; MG-ADL, Myasthenia Gravis Activities of Daily Living; PRO, patient-reported outcome; RPM, remote patient monitoring.

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