Characterizing patient care before and after a myasthenia gravis diagnosis

Sara Snell Taylor[1], PhD; Joy Chen[1], MPH; Meghan Tierney[1], PhD, RN; Emily Cibelli[1], PhD
[1]PicnicHealth, San Francisco CA

Background + Objective

- Myasthenia gravis (MG), is a rare, neuromuscular disorder that affects muscle strength and movement
- Patients typically require more frequent and specialized care post-diagnosis

Our objective is to characterize changes in frequency and types of care visits before and after patients receive an MG diagnosis

Methods

Data Source
- Patients with MG enrolled in the PicnicHealth Research Platform, consenting to collection of their medical records across U.S. health systems
- Data were abstracted from structured and unstructured medical records using human-validated machine learning
- MG cohort recruitment began in August 2021 and is ongoing, with the most recent enrollment in this study in March 2023

Methodology
- Inclusion criteria:
  - MG diagnosis on or after January 1, 2010
  - At least 1 visit within the 4-year study period, defined as MG diagnosis date +/- 2 years
- Summary statistics were calculated for patients pre- and post-diagnosis (diagnosis date was included in post-diagnosis group), and paired t-tests were conducted on continuous outcomes

Table 1. Demographics and clinical characteristics of patients with MG included in this study, stratified by sex.
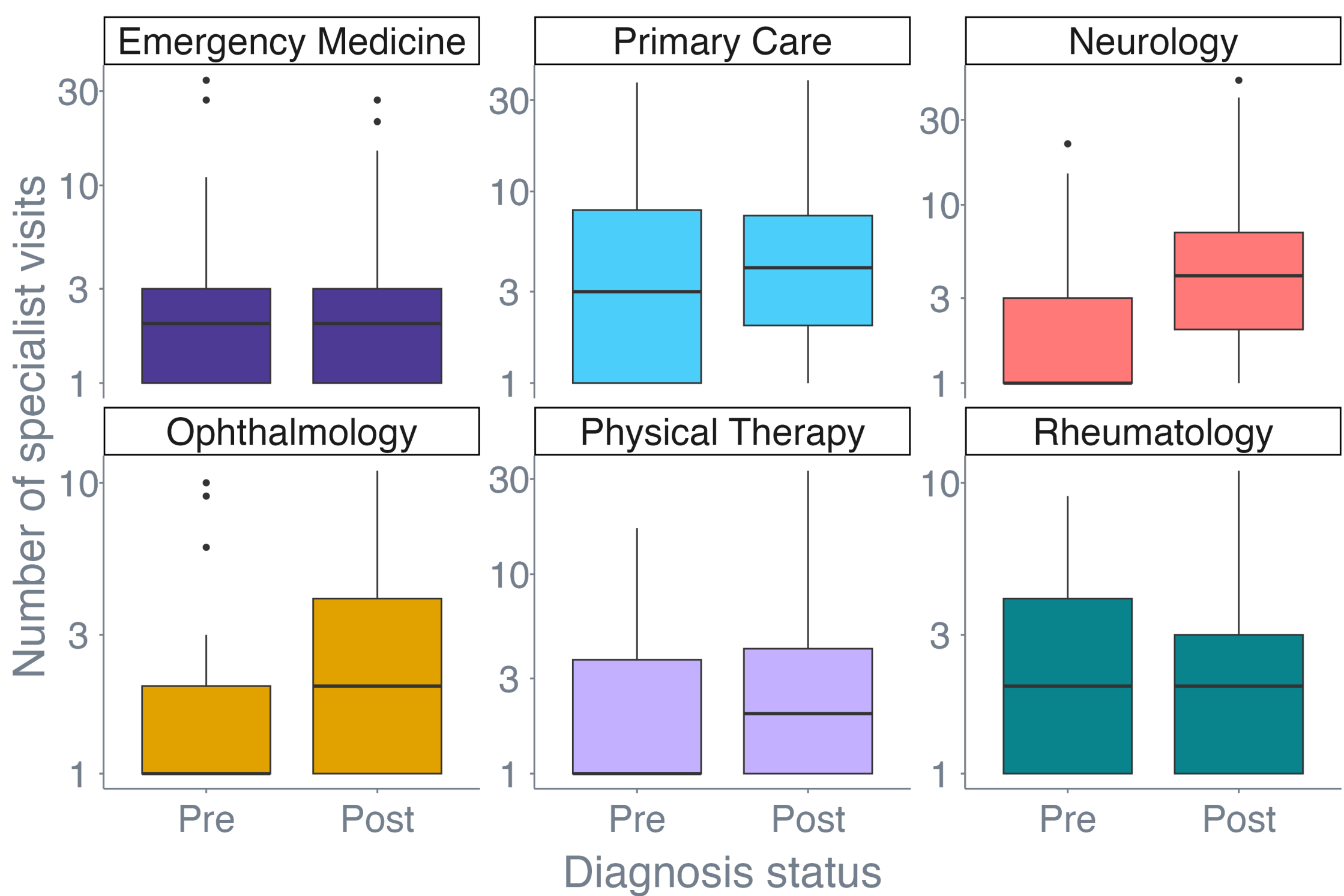
	Female N = 443	Male N = 214	Overall N = 657
Race			
White	327 (73.8%)	181 (84.6%)	508 (77.3%)
Black or African American	66 (14.9%)	18 (8.4%)	84 (12.8%)
Asian	8 (1.8%)	4 (1.9%)	12 (1.8%)
American Indian or Alaska Native	2 (0.5%)	1 (0.5%)	3 (0.5%)
More than one race	18 (4.1%)	3 (1.4%)	21 (3.2%)
Unknown*	22 (4.9%)	7 (3.2%)	29 (4.4%)
Ethnicity			
Hispanic or Latino	43 (9.7%)	18 (8.4%)	61 (9.3%)
Not Hispanic or Latino	388 (87.6%)	182 (85%)	570 (86.8%)
Prefer not to say	12 (2.7%)	14 (6.5%)	26 (4.0%)
Age at diagnosis			
Mean (SD)	44.9 (15.8%)	56.8 (16.2%)	48.8 (16.9%)
Median [min, max]	44.0 [14.7, 83.2]	60.8 [4.54, 89.0]	49.5 [4.54, 89.0]

Continuous variables are reported as mean (standard deviation); categorical variables are reported as N (%)
*Unknown includes missing data and prefer not to say

Results
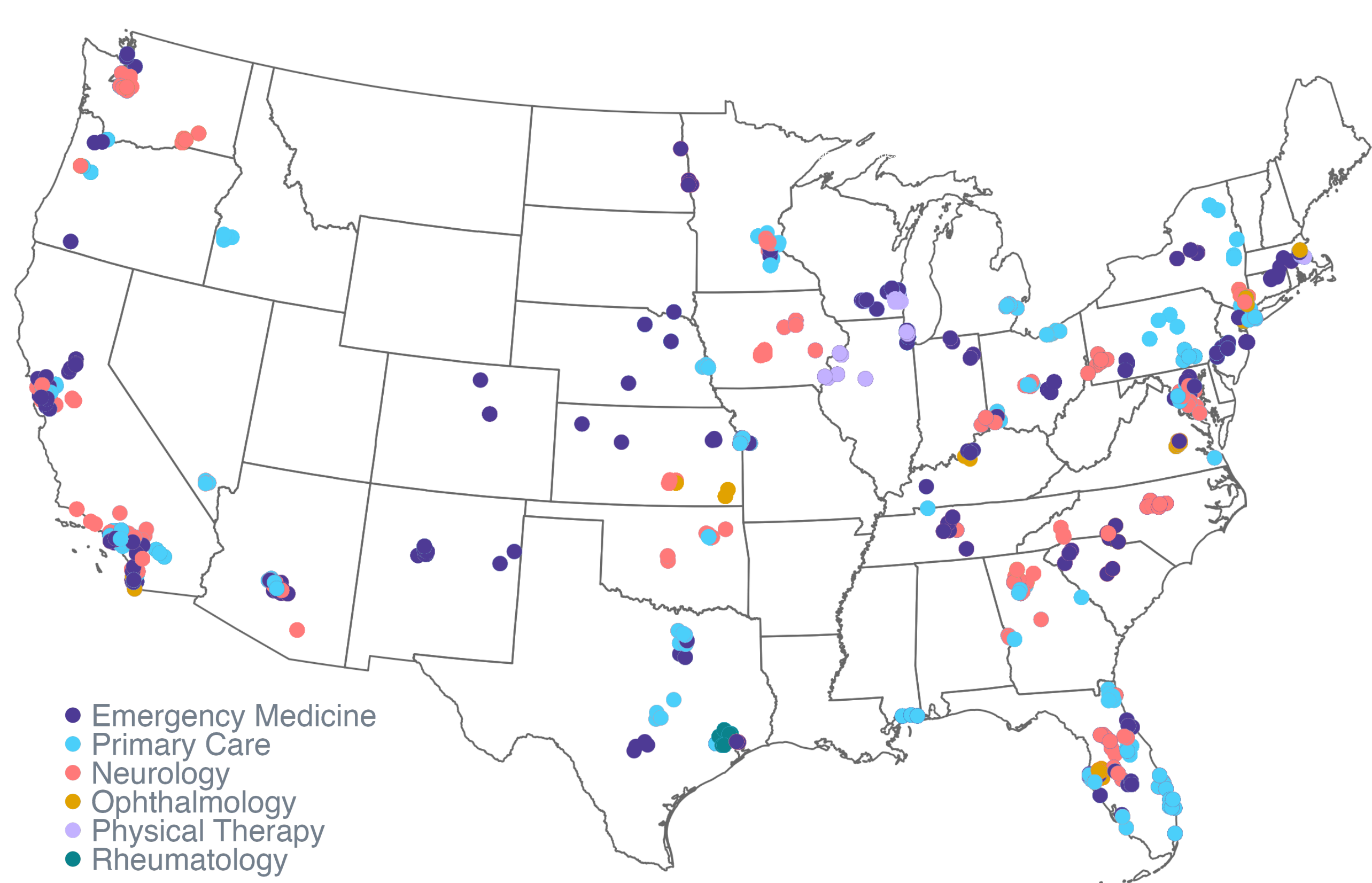
Figure 1. Distribution of care sites patients visited during the study period, colored by specialty.

Legend:
- Emergency Medicine
- Primary Care
- Neurology
- Ophthalmology
- Physical Therapy
- Rheumatology

Figure 3. Distribution of the number of visits pre- and post-diagnosis by specialty. Total number of visits by specialty include 318 emergency medicine, 548 primary care, 694 neurology, 116 ophthalmology, 90 physical therapy, and 89 rheumatology visits. Y-axis is log-transformed.
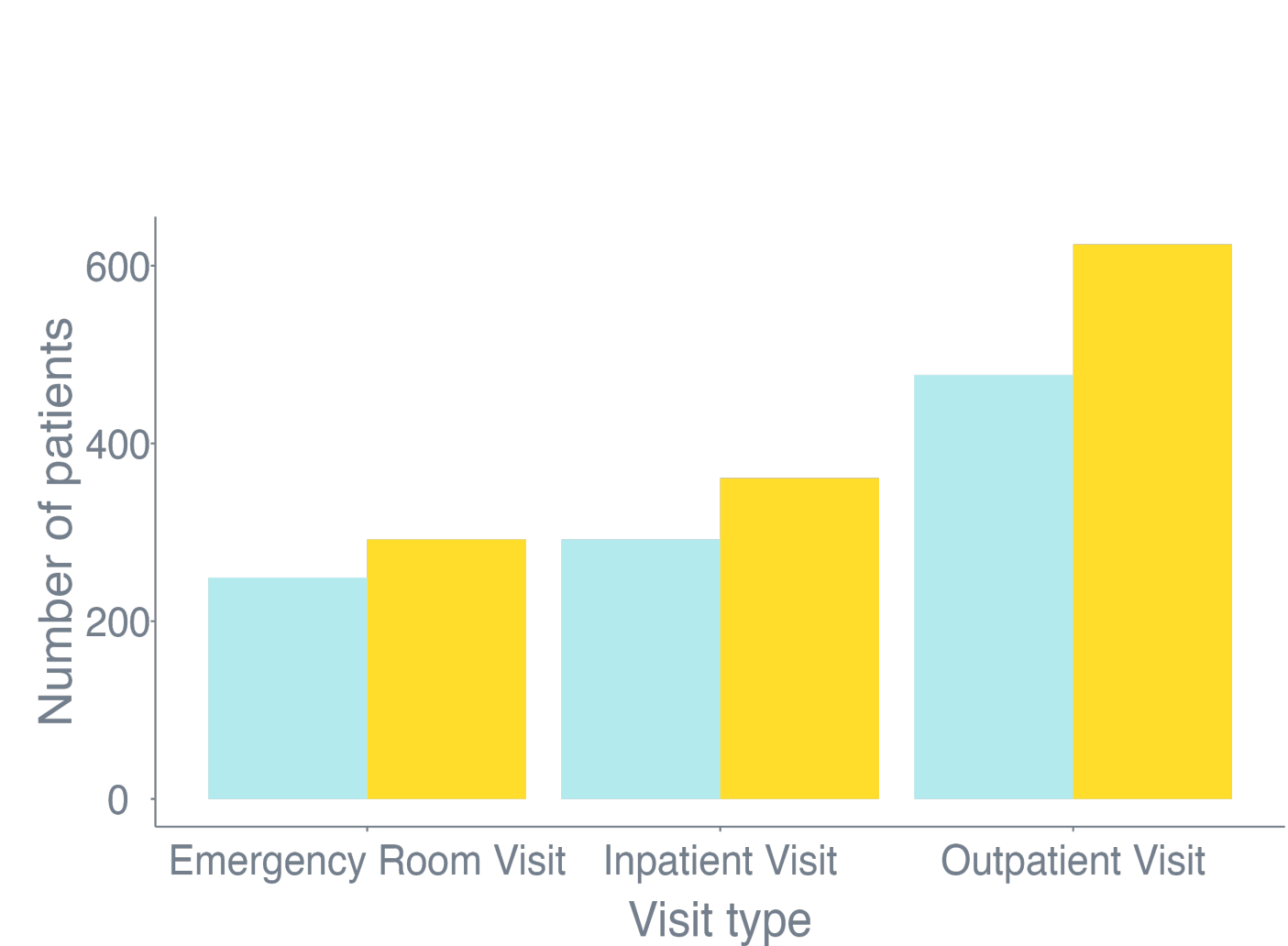
Figure 4. The number of patients with each visit type pre- and post-diagnosis. Emergency visits that become inpatient visits were classified as inpatient visits.
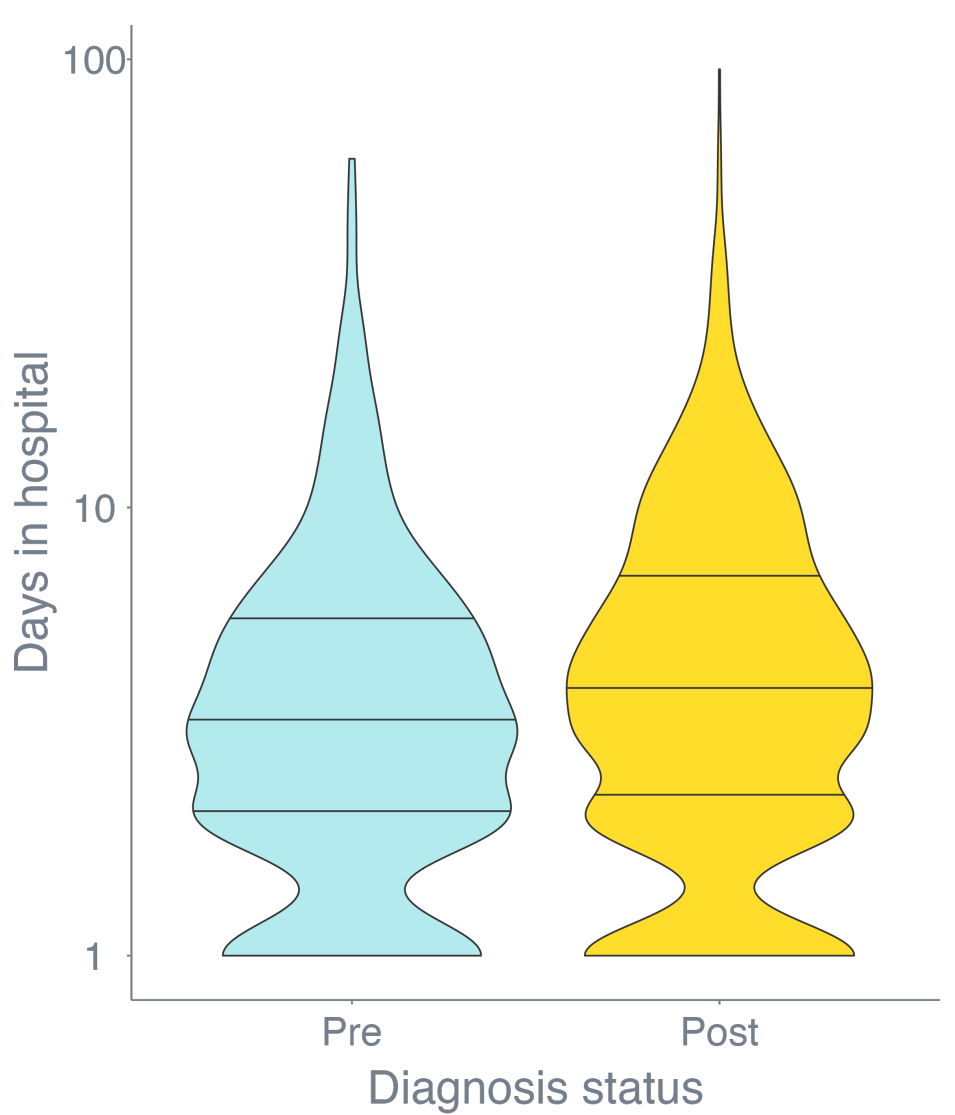
Figure 5. Number of days patients spent in the hospital stratified by diagnosis status, including emergency visits that become inpatient visits. Y-axis is log-transformed.
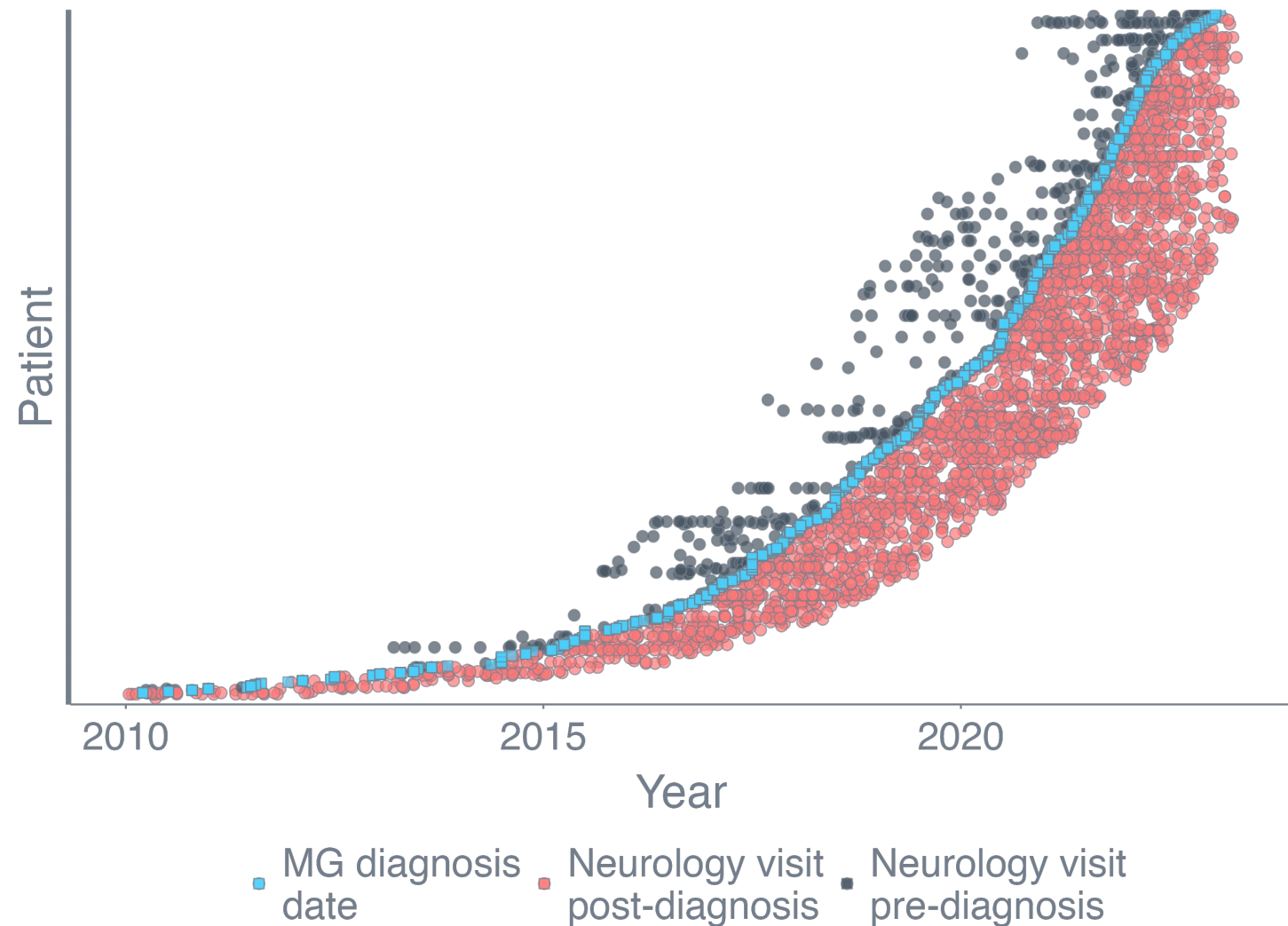
Figure 2. Distribution of neurology visits, colored by MG diagnosis date.

- 519 patients saw a neurologist during the study period; 198 patients saw a neurologist before diagnosis, 71 reported their first symptom at diagnosis (**Figure 2**)
- The mean increase in the number of visits from pre to post-diagnosis was 4 visits (95% CI: 3.8 - 4.7; **Figure 3**)
- Patients had 4 more neurology visits (95% CI: 3.8 - 4.2), 3 more internal medicine (95% CI: 2.0 - 3.1), 2 physical therapy (95% CI: 0.5 - 3.9), 1 emergency medicine (95% CI: 0.8 - 1.5), and 1 ophthalmology (95% CI: 0.2 - 1.3) visits after MG diagnosis (**Figure 3**)
- On average, patients had 7 outpatient, 1 inpatient and 1 emergency medicine visit/year (**Figure 4**)
- Median inpatient length of stay was 2 days pre-diagnosis and 3 days post-diagnosis (**Figure 5**)

Conclusions

- Patients diagnosed with MG seek care more frequently in the two years after their diagnosis compared to before, including
  - disease-specific specialists
  - physical rehabilitation
- More visits likely leads to a larger burden for patients traveling more frequently for care
- Future studies should be conducted to quantify these impacts on patients

Acknowledgements & disclosures