Factors Correlating with Patient-Reported Measurements of *Stigma* and *Satisfaction with Social Roles and Activities* Reported by the iConquerMS™ Network

Robert N. McBurney, PhD[1], Yibai Zhao, MS[2], Sara Loud, MSEE, MBA[1], Raji Balasubramanian, ScD[2], Hollie Schmidt, MS[1], Laura Kolaczkowski, BA[3].

[1]Accelerated Cure Project for MS, Waltham, MA; [2]University of Massachusetts, Amherst, MA; [3]iConquerMS™ PPRN, Waltham, MA

iConquerMS™

QL21

Background

iConquerMS™ is a people-powered research network (PPRN), dedicated to engaging people affected by multiple sclerosis (MS) and researchers in studies on topics that matter to the community. To date, ~4,000 people affected by MS have joined iConquerMS™ and consented to contribute data on the iConquerMS.org portal.

At the time they join the network (baseline) and at 6-monthly intervals, participants complete a number of surveys, including Demographics, MS Characteristics, the PROMIS® Global Health Survey (GHS), and the Neuro-QoL Adult Short Forms (ASF).

In May 2017, a dataset comprising the baseline data provided by approximately 1,800 iConquerMS™ participants was downloaded in order to determine the characteristics of the network members.

Here, we present characteristics of the iConquerMS™ network related to *Stigma* and *Satisfaction with Social Roles and Activities*.

Objectives

- To characterize responses to the Neuro-QoL ASF domains of *Stigma* and *Satisfaction with Social Roles and Activities*.
- To identify factors strongly ($r^2 \geq 0.7$) or moderately strongly ($r^2 \geq 0.5$) correlating with scores in these two domains.

Methods

Standard Symptom, Function and Quality of Life (QoL) Surveys
Domains of the Neuro-QoL ASF used in the analyses:
[The indicated domain has (M) 5-point Likert-scale questions]
Stigma (8) and Satisfaction with Social Roles and Activities (8).

PROMIS® GHS Items used in the analyses:
Pain scale plus nine 5-point Likert-scale questions. See Table 2.

Graphical Presentation
We generated bar charts of the proportion of respondents that gave a particular answer to each question in the *Stigma* or *Satisfaction with Social Roles and Activities* domains for each MS subtype (CIS: Clinically-Isolated Syndrome, RRMS: Relapsing-Remitting MS, SPMS: Secondary Progressive MS, PPMS: Primary Progressive MS). (Ns for each subtype are shown.)

Statistical Analyses
Significant differences in QoL characteristics between pairs of MS subtypes, RRMS, SPMS and PPMS, were calculated by converting each Likert-scale answer to an integer value (1=worst status to 5=best status) followed by a Chi-squared test with: a) the integer values for each of the M questions in each domain; and, b) the average value for each respondent for all questions in a domain.
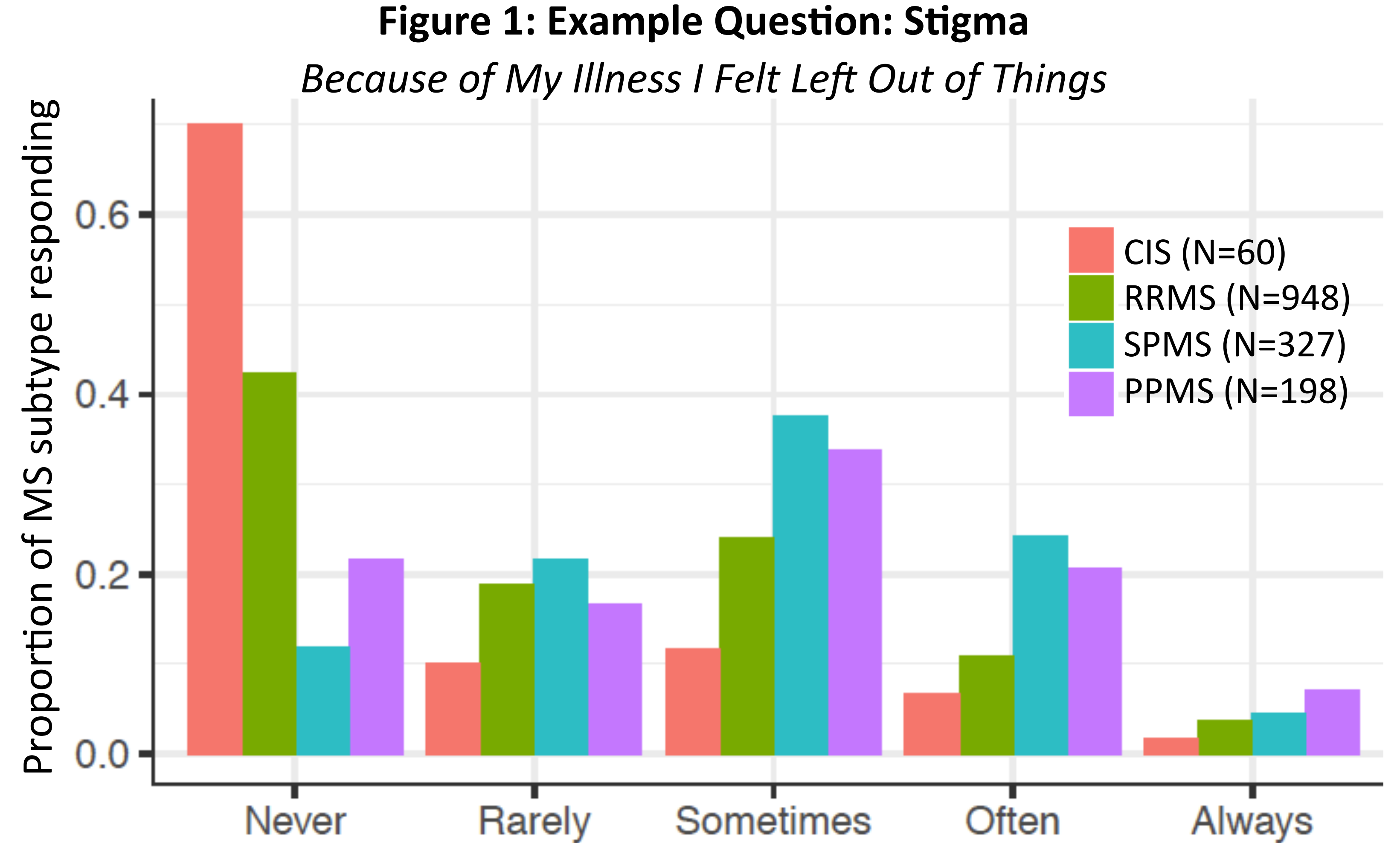
Results

Figure 1: Example Question: Stigma
Because of My Illness I Felt Left Out of Things

Table 1: Statistical Differences between MS Subtypes Average Scores for Neuro-QoL Domain *Stigma*

Comparison (N[1]) vs (N[2])	Ave Score 1	Ave Score 2	p-value	# Sig. Diff. Items
RRMS[1] (948) vs SPMS[2] (327)	4.33	3.93	7.3E-19	7
RRMS[1] (948) vs PPMS[2] (198)	4.33	4.02	2.2E-05	7
SPMS[1] (327) vs PPMS[2] (198)	3.93	4.02	1.2E-03	3

Figure 2: Example Question: Satisfaction with Social Roles and Activities
I am Bothered by Limitations in My Regular Activities with Friends
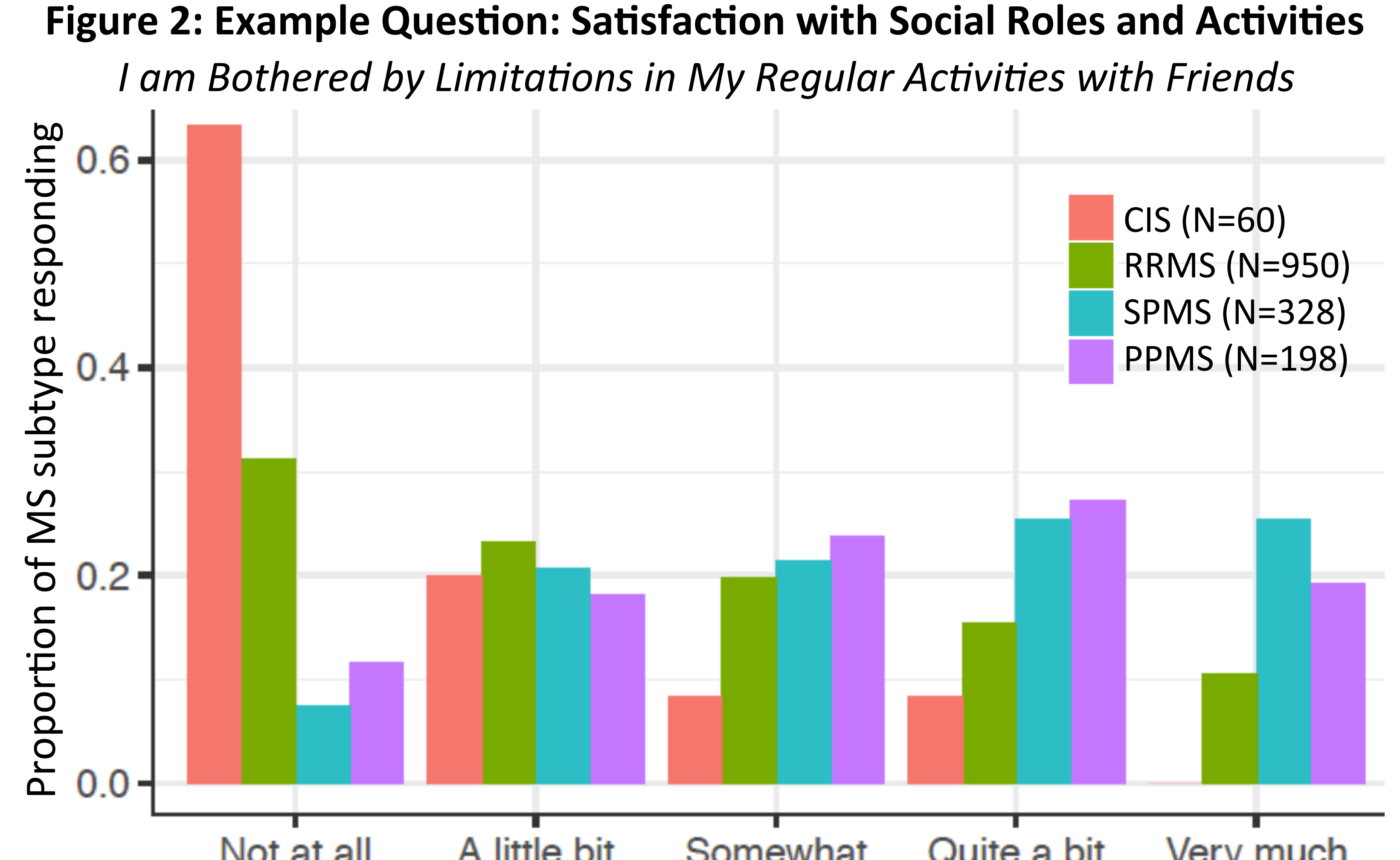

Table 2: Statistical Differences between MS Subtypes Average Scores for Neuro-QoL Domain *Satisfaction with Social Roles and Activities*

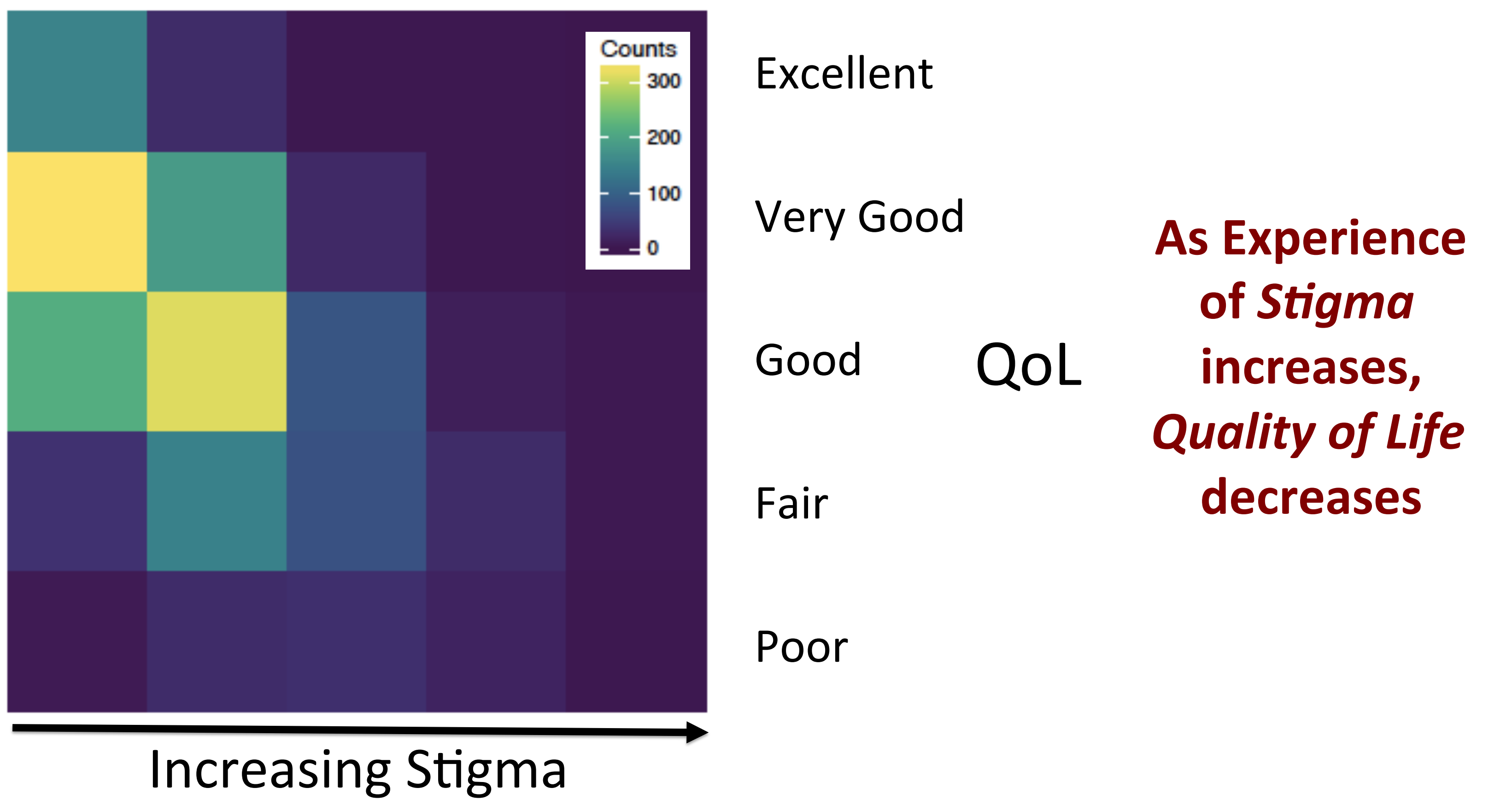| Comparison (N[1]) vs (N[2])	Ave Score 1	Ave Score 2	p-value	# Sig. Diff. Items
RRMS[1] (950) vs SPMS[2] (328)	3.33	2.60	6.5E-20	8
RRMS[1] (950) vs PPMS[2] (198)	3.33	2.70	6.3E-10	8
SPMS[1] (328) vs PPMS[2] (198)	2.60	2.70	4.6E-01	0

Table 3: Correlation of PROMIS® GHS Item Scores with Average Scores for *Stigma* or *Satisfaction with Social Roles and Activities* (Pearson r^2 values)

Cell shading: Orange = strong correlation; Green = moderately-strong correlation

PROMIS® GHS Item	Stigma	Satisfaction w/ Social Roles and Activities
Overall Health	0.42	0.54
Quality of Life	0.51	0.66
Overall Physical Health	0.41	0.57
Overall Mental Health	0.36	0.50
Carry Out Everyday Physical Activities	0.49	0.64
Carry Out Social Activities and Roles	0.52	0.73
Satisfaction with Social Roles and Relationships	0.49	0.65
Frequency of Emotional Problems (e.g., Anxiety or Depression)	0.35	0.44
Fatigue	0.40	0.60
Pain	0.42	0.45

Figure 3: Example Correlation "HeatMap": Correlation between *Stigma* and *Quality of Life*

As Experience of *Stigma* increases, *Quality of Life* decreases

Increasing Stigma

Conclusions

People with MS experience an increase in Stigma and a decrease in their *Satisfaction with Social Roles and* Activities as their disability worsens. These experiences are moderately strongly to strongly correlated with the overall physical and mental health of people with MS, and with their overall quality of life. Further research is needed to explore, in detail, the factors associated with these quality of life features.