Initial Characterization of Participants in the iConquerMS™ Network

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Background

iConquerMS™ is a novel MS participant-powered research network (PPRN), dedicated to engaging people affected by MS and researchers in studies on topics that matter to the MS community. See www.iConquerMS.org.

This MS PPRN is funded by the Patient-Centered Outcomes Research Institute (PCORI) as part of PCORnet, the National Patient-Centered Research Network which currently encompasses data from over 100 million people in the USA. iConquerMS™ is managed by Accelerated Cure Project for MS in partnership with Arizona State University and Feinstein Kean Healthcare. The network is governed by a Governing Board, Research Committee and Engagement Committee, the majority of whose members are people living with MS.

iConquerMS™ participants contribute baseline and 6-monthly data about their demographics, MS characteristics, including medications, symptoms and quality of life by answering a number of well-validated questionnaires.

In May 2016, about 18 months following the launch of the PPRN, we downloaded a dataset comprising the initial (baseline) data provided by approximately 1,400 iConquerMS™ participants in order to determine the characteristics of the network members. Here, we present some of the characteristics of the iConquerMS™ PPRN at the time of the data download.

Objectives

- To determine the quality of life characteristics for all the iConquerMS™ participants who had completed the Neuro-QoL Adult Short Form (Neuro-QoL ASF, Table 1) and the PROMIS® Global Health Survey (PROMIS® GHS) by the time of the dataset download.
- To create graphical presentations of the characteristics of the Neuro-QoL ASF and PROMIS® GHS in order to understand the distributions of responses for subgroups of the respondents based on self-reported MS subtypes - Relapsing Remitting MS (RRMS), Secondary Progressive MS (SPMS) and Primary Progressive MS (PPMS).
- To determine the statistically-significant differences in the quality of life characteristics between pairs of 3 MS subtype populations (RRMS vs SPMS, RRMS vs PPMS, and SPMS vs PPMS).
- To determine the quality of life aspects that affect iConquerMS™ respondents the most by ranking the average scores for each quality of life domain in the Neuro-QoL ASF.

Methods

Pie charts were used to provide a graphical presentation of the distribution of Likert Scale responses for each question in each quality of life domain across the entire population of respondents. Bar charts were used to provide a graphical presentation of the proportion of people with each MS subtype that gave a particular answer to each question in each quality of life domain.

For statistical analyses to determine the significant differences in the quality of life characteristics between pairs of the 3 MS subtypes examined, the Likert scale answers were converted to integer values. We used the Chi-squared test for most of the questions in each domain and Fisher's Exact Test for the questions with very sparse responses.

Table 1: Neuro-QoL ASF Domains

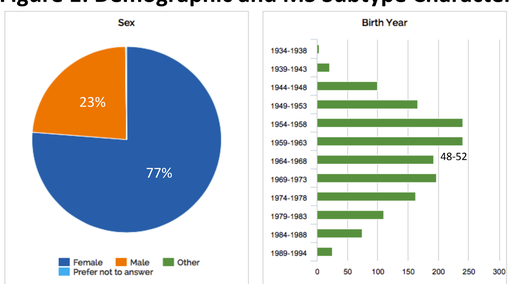
(# = number of 5-point Likert scale questions/domain)

Physical Health	#	Mental Health	#	Social Health	#
Upper Extremity Function	8	Positive Effect & Well-Being	8	Ability to Participate in Social Roles/Activities	8
Lower Extremity Function	8	Emotional & Behavioral Dyscontrol	8	Satisfaction with Social Roles/Activities	8
Fatigue	8	Depression	8		
Sleep Disturbance	8	Anxiety	8		
		Cognitive Function	8		
		Communication	5		
		Stigma	8		

The PROMIS® GHS consists of a 10-point pain scale plus nine quality of life domains with one 5-point Likert scale question for each of the following domains: General Health; Overall Quality of Life; Overall Physical Health; Mental Health including Mood and Ability to Think; Satisfaction with Social Roles and Relationships; Carrying out Everyday Physical Activities; and, Emotional Problems, such as Anxiety, Depression or Irritability.

Results

Figure 1: Demographic and MS Subtype Characteristics of the Participants



Self-Reported MS Subtype	% of Participants
CIS	4.4
RRMS	59.7
SPMS	22.8
PPMS	13.0

Following are examples of the results of this preliminary quality of life characterization of the iConquerMS™ participants.

Figure 2: Selected Responses to Neuro-QoL Depression Domain Questions

(All MS Subtypes Combined)

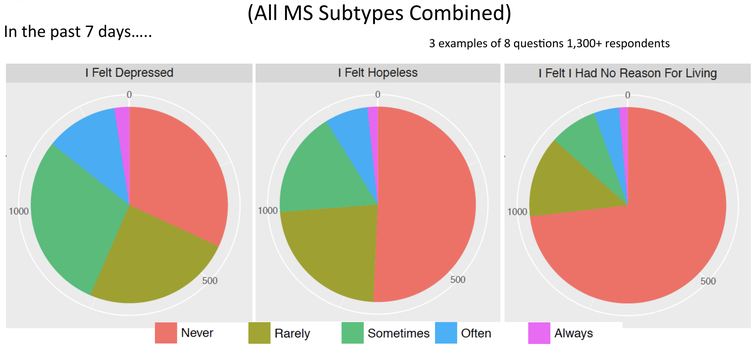
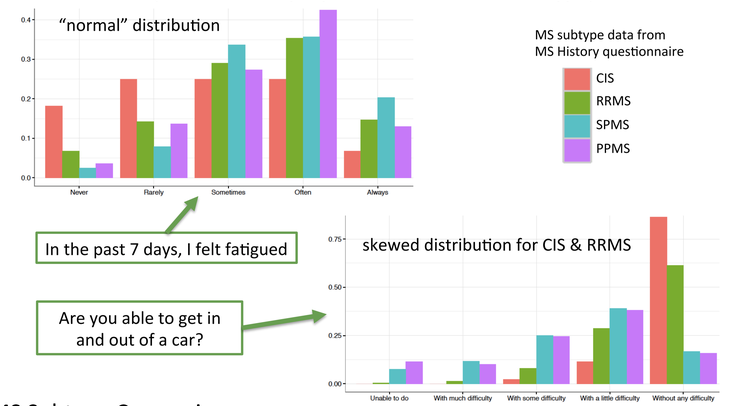


Figure 3: Different QoL Domains have Different Response Distributions

(ordinates are proportions of each MS subtype)



MS Subtype Comparisons

Statistical analyses of 111 Neuro-QoL ASF + PROMIS® GHS questions for 3 self-reported MS subtype comparisons yielded the following numbers of significant differences ($p \leq 0.05$) between subtypes: 66 for RRMS ($N \approx 635$) vs SPMS ($N \approx 240$); 61 for RRMS vs PPMS ($N \approx 140$); and, 12 for SPMS vs PPMS.

Table 3: Ranking of Neuro-QoL Domains (Combined Participants)

Rank Order	Neuro-QoL Domain (5-point Likert scale questions) Scored: 1[worst], 2, 3, 4 , 5[best]	Average Score (N = ~1,400)
1	Fatigue	1.89
2	Sleep Disturbance	2.59
3	Anxiety	2.68
4	Emotional and Behavioral Dyscontrol	2.92
5	Satisfaction with Social Roles and Activities	3.09
6	Depression	3.11
7	Stigma	3.17
8	Positive Affect and Well Being	3.59
9	Ability to Participate in Social Roles and Activities	3.60
10	Cognitive Function	3.71
11	Lower Extremity Functional Mobility	3.93
12	Communication	4.41
13	Upper Extremity Function Fine Motor ADL	4.54

Conclusions

The quality of life characteristics of the iConquerMS™ participants as of May 2016 were determined. The largest number of statistically-significant differences in answers to the QoL questions were between respondents with RRMS versus those with SPMS. Fatigue and sleep disturbance were the two top ranking Neuro-QoL domains in terms of the degree to which they affect people with MS. This initial characterization of the iConquerMS™ network provides a basis for future research studies.

For More Information

See www.iConquerMS.org. For general iConquerMS™ information: Sara Loud, sloud@acceleratedcure.org, 781-487-0032. For information about research collaborations: Hollie Schmidt, hollie@acceleratedcure.org, 781-487-0099