

Accelerated Cure Project for MS

June 2017



Accelerating research towards a cure for multiple sclerosis

iConquerMS™ -- Research Driven by You!

Have you ever wanted to tell MS researchers what topics you thought they should study? Or wished you had more opportunities to participate in MS research? Or felt that your knowledge as a person with MS could help in designing clinical trials or new products for MS?

If you have, we have an online community for people like you who want to engage in, learn about, and influence MS research. This community is called [iConquerMS™](http://iConquerMS.org), and its members participate in many kinds of activities, from joining research studies, to helping design studies and products, to sending in suggestions about the research they'd like to see performed.

We wanted to share a few of the many research activities that have happened recently in iConquerMS. If you're an iConquerMS member, you may have been involved in some of these activities. And if you're not already a member, we hope you'll sign up to contribute your ideas, information and experience going forward! Just go to iConquerMS.org to learn more and enroll.

Suggest a Research Question

As someone living with MS, you know the disease better than anyone — and your ideas about what researchers should explore are very valuable.

We encourage you to submit questions on topics that you care about, and that you think need to be addressed by the research community.

Please include your contact information; we may follow up to help further develop your question. If you prefer to submit an anonymous question, you may omit your name and contact information and delete your email address.

Once submitted, your question will be shared with the Accelerated Cure Project and the iConquerMS™ Research Committee.

Your Name:

Your Email:

Your Phone Number

Your Question: *

My Research Surveys

○ New | ● In Progress | ● Completed

- REAL MS - Demographics >
- REAL MS - MS History >
- REAL MS - Overall Health >
- REAL MS - Quality of Life >
- REAL MS - Other Conditions >
- REAL MS - Physical Activity >
- REAL MS - Demographics - Summer 2016 >
- REAL MS - MS History - Summer 2016 >
- REAL MS - Overall Health - Summer 2016 >

REAL MS: REAL MS™, aka Research Engagement about Life with MS, is the flagship research project of iConquerMS. REAL MS is what is called a prospective survey: we collect information from our members when they join iConquerMS, and then ask for updated information every 6 months thereafter.

We've conducted two updates so far and are starting to build a detailed picture of our members' health and quality of life over time. With data from over 2,200 iConquerMS members in hand, we've begun analyzing the responses to learn about life with MS and are sharing our findings at conferences:

- For the American Committee on Treatment and Research in MS (ACTRIMS) meeting in February, we showed the general characteristics of our members and highlighted the effects of MS that appear to affect people the most, such as fatigue and sleep disturbance. (Download this poster [here.](#))

Initial Characterization of Participants in the iConquerMS™ Network
 Robert N. McBurney, PhD¹, Yibai Zhao, MS¹, Sara Loud, MSE, MBA¹, Raj Balasubramanian, ScD¹, Hollie Schmidt, MS¹, Laura Kolarickowski, BA¹
¹Accelerated Cure Project for MS, Waltham, MA; ²University of Massachusetts, Amherst, MA; ³iConquerMS™ PPRN, Waltham, MA

Background
 iConquerMS™ is a patient-reported research network (PPRN) dedicated to engaging people affected by MS and researchers to study in ways that matter to the community. See [www.iConquerMS.com](#)

Objectives
 To determine the quality of life characteristics for all the iConquerMS™ participants who had completed the Neuro-QoL, Health Status Survey (HSS), and the PROMIS™ Global Health Survey (PROMIS-GHS) in the first 6 months of enrollment.

Methods
 The data were used to provide a general presentation of the distribution of all scores reported for each measure in terms of quality of life, demographic, and clinical characteristics of the network members. The data were also used to provide a general presentation of the proportion of people who reported being affected by a particular domain in each question in each quality of life domain.

Results
 Figure 1: Demographic and MS Subtype Characteristics of the Participants
 Figure 2: Standardized Differences Between MS Subtypes Average Scores for Neuro-QoL Domain Scores

Conclusions
 The quality of life characteristics of the iConquerMS™ participants are similar to those of the general population of people with MS. The network members were the best performing Neuro-QoL domain in terms of the degree to which they affect people with MS. This is consistent with the characteristics of the iConquerMS™ network and suggests that the network is a good source of data for research on quality of life in MS.

For More Information
[www.iConquerMS.com](#)

- In May for the Consortium of MS Centers (CMSC) meeting, we presented insights about our members' perception of stigma and their satisfaction with their social roles and activities. (Download this poster [here.](#))

Factors Correlating with Patient-Reported Measurements of Stigma and Satisfaction with Social Roles and Activities Reported by the iConquerMS™ Network
 Robert N. McBurney, PhD¹, Yibai Zhao, MS¹, Sara Loud, MSE, MBA¹, Raj Balasubramanian, ScD¹, Hollie Schmidt, MS¹, Laura Kolarickowski, BA¹
¹Accelerated Cure Project for MS, Waltham, MA; ²University of Massachusetts, Amherst, MA; ³iConquerMS™ PPRN, Waltham, MA

Background
 iConquerMS™ is a patient-reported research network (PPRN) dedicated to engaging people affected by multiple sclerosis (MS) and researchers to study in ways that matter to the community. See [www.iConquerMS.com](#)

Objectives
 To determine the relationship between the Neuro-QoL, Health Status Survey (HSS), and the PROMIS™ Global Health Survey (PROMIS-GHS) and the iConquerMS™ network members' perception of stigma and satisfaction with their social roles and activities.

Methods
 The data were used to provide a general presentation of the distribution of all scores reported for each measure in terms of quality of life, demographic, and clinical characteristics of the network members. The data were also used to provide a general presentation of the proportion of people who reported being affected by a particular domain in each question in each quality of life domain.

Results
 Figure 1: Standardized Differences Between MS Subtypes Average Scores for Neuro-QoL Domain Scores
 Figure 2: Standardized Differences Between MS Subtypes Average Scores for Neuro-QoL Domain Scores
 Figure 3: Standardized Differences Between MS Subtypes Average Scores for Neuro-QoL Domain Scores

Conclusions
 People with MS experienced an increase in stigma and a decrease in their satisfaction with social roles and activities as their disability increased. The experience was 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.

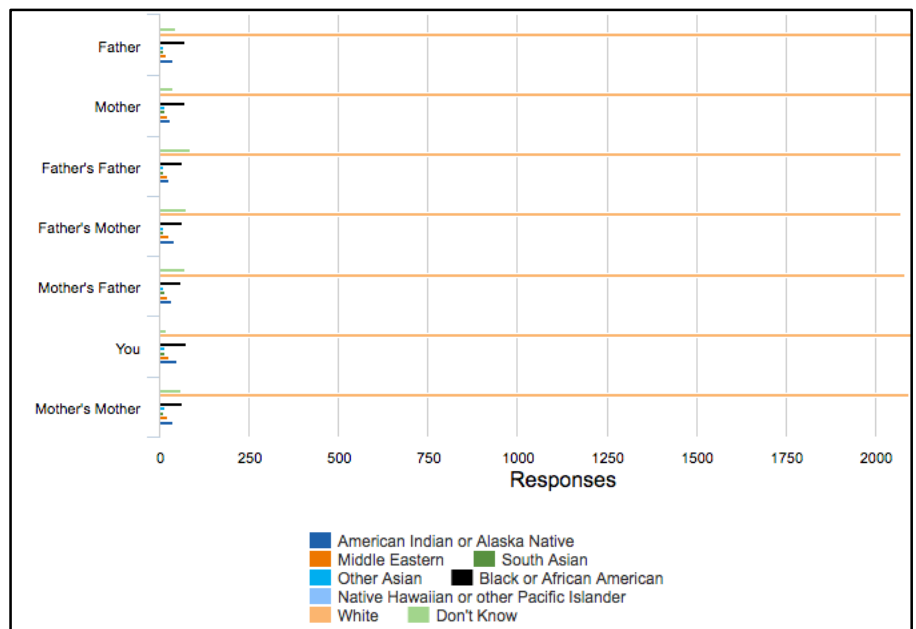
For More Information
[www.iConquerMS.com](#)

Later this summer we'll be releasing the 3rd round of surveys, which will include improvements and new topics and questions suggested by our members. We look forward to a great response and the ability to answer many more questions about life with MS, thanks to the help of the iConquerMS community!

Other Studies: Last year, iConquerMS members were invited to be part of a study led by Dr. Deborah Miller of the Cleveland Clinic on the topic of **insurance coverage and concerns**. This May, Dr. Miller and her colleagues presented two posters at the CMSC meeting with a variety of findings. For instance, most of the study participants reporting having health insurance, but over half of them were concerned about losing this insurance if their employment situation changed. Also, fewer than half of the participants had disability or long-term care insurance that would provide support if they became disabled. You can see the abstracts for these posters [here](#) and [here](#).

The study team is now working on additional analyses and publications, and the National MS Society will be using the results in its public policy and educational efforts.

In May, ACP invited iConquerMS members and others to take a survey on **research participation and perceptions** among people with MS. We noticed that racial and ethnic minority groups were not fully represented in iConquerMS or the ACP Repository, or in clinical trials and studies performed elsewhere.



So we applied for funding from the Patient-Centered Outcomes Research Institute to study the reasons behind this imbalance. This survey will help us understand which factors are most important to focus on in research-related outreach efforts. We'll share the findings of the survey and will ask for ideas for follow-up activities that might help encourage research participation in a wider group of people.

Coming up next: a study to learn about the most valuable characteristics of **MS medicines** for people with MS. Lots of conversations are taking place among health care leaders, politicians, and organizations about the price and value of drugs. But the voice of people living with MS hasn't been included as much as it should be. Working with Dr. Surachat Ngorsuraches from South Dakota State University, we'll be sending a group of iConquerMS members a survey that asks them to compare and choose between pairs of hypothetical MS therapies. The results of this study will contribute to efforts to ensure that people can get access to their therapy of choice.

Research Input Opportunities: People with MS are experts about living with and managing the disease, and each individual with MS has a unique and valuable set of insights. Researchers are increasingly recognizing how useful those insights could be when planning their studies, and are coming to iConquerMS for help connecting with this expertise.

Recently we helped a biotech company invite people with MS to a one-day **patient advisory board**. They were designing a clinical trial for a new MS drug and wanted to make sure it was designed and communicated as effectively as possible. The input from our members will help ensure that the trial can be completed successfully.

We also helped a team of engineering students from Arizona State University who were developing an **auto-injector support device** and needed input on their design. Many iConquerMS members viewed the team's video online and provided constructive feedback. The students have all graduated, but one of them is pursuing further development of the device and hopes to bring it to market!

Over the next few weeks, we'll be inviting iConquerMS members to talk with the founders of a start-up company. They're developing products to support people with MS and their doctors in making healthcare decisions, and want to know more about the **experience of being an MS patient**. One-on-one interviews will help them create products that meet the needs of people with MS.

Do you want to share your expertise as a person with MS? Join [iConquerMS](#), and be sure to complete your REAL MS surveys so we can match you up with the right opportunities!