

April 2022 Newsletter



Power MS Research With Your Data!

There have been many advances in MS research in recent years, but there is still so much to learn about the disease, such as its underlying causes, why some MS treatments work in certain individuals but not others, and why the disease progresses at different rates in different people. [iConquerMS™](#) (iCMS) is a research initiative that empowers everyone living with MS to participate in research to help answer these important questions. People with MS and their caregivers can easily and privately take surveys about their daily experiences and symptoms. This information is pooled with similar information from thousands of others living with MS, giving researchers an accurate, holistic picture of the disease. Researchers can use the collected data to detect patterns that would not be visible otherwise and use these patterns and insights they gain from them in the design and conduct of their studies. The initiative also serves as a bridge, connecting the MS and research communities. Network members can help steer the future direction of MS



research by [suggesting research topics and questions](#) in areas that matter to them. Participants also receive updates on what researchers are learning from their data.

In 2016, iCMS launched [REAL MS™](#) (Research Engagement About Life with Multiple Sclerosis), an ongoing longitudinal study of MS. Its purpose is to shed light on the experience of MS across the population of people living with the disease and to identify ways to personalize clinical care by identifying factors that affect progression and treatment outcomes. iConquerMS currently has over 7,800 participants from 58 countries and all 50 states, DC and Puerto Rico. Members participate by periodically



answering online questionnaires about their disease experience and, eventually, will be able to provide biosamples for molecular analysis. Participation of a diverse population of individuals living with MS is key to providing the most

comprehensive resource for MS research. Qualified investigators are able to access the REAL MS dataset for their ongoing or new studies about causes and progression of MS. They also have the opportunity to conduct special data collection activities via iCMS, seek individuals with certain characteristics for their research studies and potentially collect biosamples for genomic and other biochemical analyses.

The data collected through REAL MS are a growing and powerful resource for MS research, providing investigators and clinicians with real-life information on what living with MS is like. Participants are asked to complete online questionnaires twice each year on a wide range of subjects, including demographics, their MS history, overall health, quality of life, physical activity, wellness and diet, and other medical conditions they may have. These surveys primarily contain multiple choice questions that are intended to be straightforward, however some participants find that their circumstances don't align with the options provided. All are encouraged to [contact us](#) with questions or comments about participating in the study. Below is some of the input we've received.

Common themes and feedback from REAL MS™ participants

How do I answer a question about health or quality of life when the impact isn't due to MS? Do you assume it's due to MS?

- No, we don't assume this. We know that MS isn't the only thing people are dealing with. Unless the question specifically asks about the effects of MS, your answer should take your overall health and circumstances into account.

It can be hard for me to rate how I'm doing because my answer would change depending on which day it is, the time of day, etc.

- This is a common situation for people with MS. Sometimes a question will have a lead-in like "in the past 7 days..." In which case you should think of how you felt on average over that time period. For questions without a clear lead-in, you could answer based on how you are at that moment, or how you've generally been lately. Keep in mind that your individual answer will be added to those of many other people, so any variability in your answers won't throw off the overall analyses.

My information hasn't changed since the last time I completed these surveys so you're probably not interested in my data.

- Not true! Stability is just as important to us as change. We're interested in hearing from you regardless of whether anything has changed.

Some of these questions aren't meaningful to me, can there be an N/A option?

- We've tried to add "not applicable" options where we could in the surveys that we created. Unfortunately, some of these surveys were created by others and are standardized, so we're not able to modify them. We appreciate your doing the best you can to choose a response.

These questions make me feel bad (for example, because you're asking about family/friends that I don't have) or bring up other emotions.

- This is certainly not our intention and we apologize if this is the case. Most surveys end with a field for comments. Please use this field to let us know what, if any, emotions the surveys stir up. This is important information for us to know.

Can I see how my answers have changed over time in a graph? Can I compare my answers to those of others?

- Yes! You can explore the many options for viewing and comparing the data that you and others have contributed by logging in and clicking on "My Data."



REAL MS is modeled after the Framingham Heart Study, a longitudinal community-based research study which has had a profound impact on the understanding of the causes of heart disease and how to treat and prevent it. Our impact on MS research through REAL MS has the potential to be equally far reaching. By studying the patterns of thousands of individuals living with the disease, researchers may be able to discern factors that slow progression or improve day-to-day

functioning. The study may provide new information on an individual's likely response to particular treatment strategies and facilitate interventions early to optimize outcomes. This groundbreaking initiative may accelerate personalized approaches to MS by making it possible to identify new [types of MS](#) based on the personal characteristics and laboratory data from participants and enable the prediction of a likely disease course based on these subtypes. Similarly, by identifying genomic and other biochemical factors, REAL MS might reveal biological pathways for new treatments that will arrest, cure or prevent the disease longer-term, including a new understanding of biological mechanisms of progressive MS.

REAL MS data have been instrumental in deepening our understanding of many aspects of MS to date. Participants were asked to complete a Diet and Wellness Survey which included questions about diet, vitamins/supplements, exercise/wellness activities and if they found them helpful in managing their MS and improving other aspects of daily life. Data revealed some interesting differences between the most popular and the most helpful options. For example, the most popular diet choices among study participants were eating organic and gluten-free foods. While it was one of the least popular, the Swank diet was reported by participants who had tried it as the most helpful, followed by eating gluten-free. The most frequently used supplement overall was Vitamin D, with 59% of respondents indicating they found it helpful. The second most popular supplement was a multivitamin, which participants reported provided an almost equal benefit. The supplement reported as most helpful, however, was iron, benefiting 61% of respondents, followed by magnesium and vitamin C. With regards to herbal supplements, the most commonly used was turmeric, and the one reported to be most helpful was marijuana, followed by cranberry.



Dr. Nina Bozinov is a neurology specialist at Kootenai Clinic in Coeur d'Alene, ID. She has done extensive analyses of REAL MS data, looking at how MS symptoms affect quality of life in people with MS. She found that anxiety, depression, fatigue, emotional and behavioral [dyscontrol](#), cognitive function and sleep disturbance affect people with all types of MS similarly. However, there are differences between relapsing and progressive MS in terms of physical functioning, social health, stigma, positive affect and wellbeing. Over time, there was a trend towards improving fatigue, emotional and behavioral dyscontrol and anxiety across all subtypes. Those with secondary progressive MS trended towards worsening ability to participate in and satisfaction with social roles, positive affect and wellbeing, and depression. Moderate or severe disability was associated with a number of factors, including fatigue, sleep disturbance, depression, cognitive function, and communication. Medicaid/having no insurance was linked with increased fatigue, sleep disturbance, depression and cognitive function, to name a few. Living alone was associated with worse positive affect and wellbeing. Male sex was associated with better participation and satisfaction with social roles and activities. Anyone interested in hearing the details of Dr. Bozinov's research can tune in to the [October 2021 episode](#) of our Chat with Chat webinar.

Unlike other data-gathering programs, iConquerMS™ is governed and driven by people living with MS. The initiative is in tune with the interests and needs of the MS community and working with MS researchers to shape and guide their projects in directions that matter most to people living with the disease. It is constantly evolving to respond to changing interests and new discoveries. The next round of REAL MS surveys is available now through the [iConquerMS portal](#).

Completing these surveys is one of the simplest ways you can accelerate MS research. These data will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS!

