April 2022 Newsletter

Accelerated Cure project for multiple sclerosis

iConquerMS™

ACP Repository™

MS Minority Research Engagement PARTNERSHIP NETWORK

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.

Australian researchers analyzed the data from the Diet and Wellness survey further and concluded that the benefit of certain lifestyle behaviors on quality of life differs among MS subtypes. Data showed that anti-inflammatory and low-carbohydrate diets improved stigma in people with relapsing remitting MS. In progressive MS, anti-inflammatory diets were associated with higher mobility and positive affect. Low-carbohydrate diets were also associated with higher positive affect in participants with progressive MS and diets low in saturated fat diet were associated with improved communication. Results showed that physical activity improved quality of life across the board. Participation in wellness activities such as meditation, mindfulness or Tai Chi had mixed associations with quality of life in relapsing MS and had no effect on quality of life in progressive MS. These findings suggest a role for modifiable lifestyle behaviors as a potential intervention for improving quality of life in people with MS. Investigators conclude that further research is required to make specific recommendations.

Several **posters** based on analysis of REAL MS data have been presented at professional conferences over the past few years:

CMSC
THE CONSORTIUM OF MULTIPLE SCLEROSIS CENTERS

People with MS experience higher stigma and less satisfaction with social roles/activities as their disability worsens. These experiences are correlated with their overall physical/mental health and quality of life (QOL).

actrims
2018 FORUM
February 1-3
San Diego, California

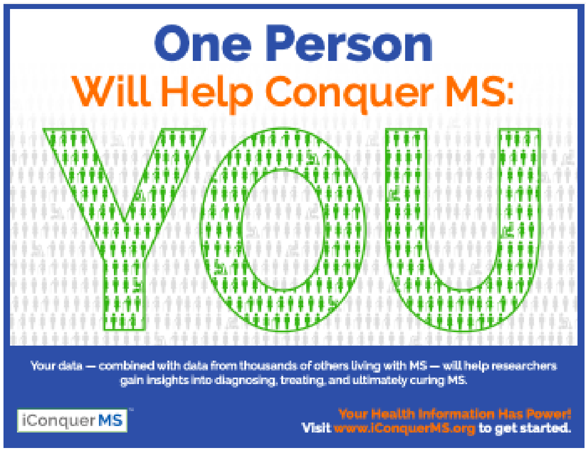
Symptoms, functioning and QOL in relapsing and progressive MS were compared. The most significant differences were between relapsing and secondary progressive MS. Fatigue and sleep disturbance were the worst symptoms for all.

actrims
2020 FORUM
February 27-29
West Palm Beach, Florida

Better tools are needed to assess MS disability. Patient reported outcomes (PROs) provide key details in the assessment of physical abilities associated with activities of daily living that matter to people with MS.

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!



Dizziness, Vertigo and MS

Dizziness is a common MS symptom, affecting over half of people living with the disease. Some (approximately 20 percent) also have episodes of vertigo, which is an intense spinning sensation that can last anywhere from a few seconds to a few days. Vertigo may be accompanied by nausea, vomiting, ringing in the ears (tinnitus), abnormal or jerking eye movements (nystagmus), sweating or headaches. Balance problems in MS are due to nerve damage (lesions) along the pathways to the brain that coordinate the input that is needed to maintain balance. Ongoing dizziness and vertigo can interfere with daily tasks, increase the risk of falls, and can even become disabling. Anyone struggling with these symptoms should take heart, however, as there are a number of ways to ease them.

Many body systems must work together to maintain the body's equilibrium. When any of these systems aren't functioning well, instability can occur. Sensory information from the eyes, muscles, tendons, joints, and balance organs in the inner ear (the vestibular system) are all sent to the brain stem. The vestibular system is composed of three canals and two sacs filled with fluid. The fluid shifts when the head changes position and stimulates hair cell receptors in the inner ear to tell the brain what's happening. The brain stem also gets information from other parts of the brain (the cerebellum and cerebral cortex), mostly about previous experiences that have affected balance. Once the brain stem sorts out all of this information, it sends messages to the eyes and other parts of the body to move in a way that will help maintain balance and have clear vision while moving. The brain can control balance by using the information that is most important for a particular situation. For example, in the dark, when the information from the eyes is reduced or might not be accurate, the brain will use more information from the legs and inner ear. If an individual is walking on a sandy beach during the day, the information coming from their legs and feet will be less reliable and their brain will use information from their visual and vestibular systems more.

While dizziness and vertigo in MS are usually due to the growth of an existing lesion or the appearance of a new lesion in the brain stem or cerebellum (making it difficult to send messages to the rest of the body), they can also be caused by other factors. Some people with MS experience dizziness and vertigo as a side effect of medications they are taking, whether for MS or for another condition. Other conditions may also cause these troubling symptoms, such as bacterial/viral infections, dehydration, stress, anxiety, high and low blood pressure, blood vessel disease, stroke, migraines or inner-ear problems. A specific type of vertigo called benign paroxysmal positioning vertigo (BPPV) often occurs when crystals of calcium carbonate collect in parts of the ear canal that affect the vestibular system. These crystals can dislodge from the tiny hairs in the ear when an individual moves their head, causing the hairs to move and sending false signals to the brain that result in vertigo.

In order to effectively treat dizziness or vertigo, it's important to know the cause. These symptoms should be assessed by a health care professional before starting treatment. Medications used to treat motion sickness are often helpful. This includes antihistamines, such as Antivert (meclizine), Dramamine (dimenhydrinate) and Benadryl (diphenhydramine). In cases of severe vertigo, a physician may prescribe a short course of high-dose corticosteroids to reduce any inflammation in the nervous system that may be contributing. BPPV is treated with a procedure called the Epley maneuver that involves manipulating the head in a series of distinct movements in order to reposition the above-mentioned crystals that are causing the problem. A number of rehabilitation specialists can also provide advice and teach techniques to improve balance and coordination. Vestibular rehabilitation therapy is a specialized form of physical therapy that is used to improve balance. Research shows these exercises are effective at reducing dizziness in MS. An occupational therapist may also be able to recommend methods to stay safe during an episode of dizziness/vertigo, such as removing rugs to reduce the risk of falls and installing handrails.

A number of preventive measures can be taken that may make living with dizziness or vertigo a bit easier. It's important to clear any tripping hazards around the house (especially throw rugs). Staying active is not only a good idea in general, but exercise can also help with balance issues. Keeping a journal and noting the times when these symptoms are most likely may be a helpful strategy so that activities can be planned at optimum times.

When vertigo occurs, the following steps can help you stay safe and feel more comfortable:


Sit until it passes. Lean your head on a wall or the back of a chair.

Avoid moving your head or body position.


Keep a support device nearby in case you must move around.


Dim bright lights and don't try to read or watch TV.

Avoid stairs.

Don't drive.


Move slowly once you feel better.

If vertigo strikes during the night, sit up straight, turn on soft lighting, and remain still until you feel better. If vertigo returns when you lie down, try sleeping in a comfortable recliner.

Dizziness and vertigo in people with MS are not usually permanent, they typically come and go. Nonetheless, these sensations can be very unsettling. In addition, balance issues increase the risk of injury due to falls, especially for people whose MS symptoms already include trouble walking, weakness, and fatigue. It's important for people with MS to work with their physician to determine the cause of any dizziness or vertigo they may be experiencing. Once the cause is known, he or she can offer advice on an effective treatment plan to minimize their impact on daily life.

Don’t miss our Chat with Chat webinar series!

The Next Steps Committee of iConquerMS has launched a webinar series called “Chat with Chat” and you’re invited! Hosted by our research collaborator Chat Ngorsuraches, these conversations provide a glimpse at the researchers working with iConquerMS, what they study, and how their work will benefit people with MS.

In Episode 1, Chat spoke about his own research into the aspects of MS drugs that people value the most.

In Episode 2, Chat spoke with Nina Bozinov, MD MS, about "Measuring the Quality of Life of People With MS: Findings From the REAL MS Study."

In Episode 3, Chat spoke with Farrah Mateen, MD PhD, about what we've learned from iConquerMS about COVID-19 and MS.

In Episode 4, Chat spoke with Farren Briggs, PhD ScM, about “COVID-19 vaccine safety: A study from iConquerMS data.”

A heartfelt thank you to Chat and his colleagues for making this educational resource possible. Stay tuned for future episodes!

April 2022 Research Spotlight

RESEARCH OPPORTUNITIES

Complete your REAL MS surveys!

New REAL MS surveys have landed on your iConquerMS dashboard! Please log in today and fuel MS research by completing your open surveys. The information you provide will not only accelerate MS research, but also help us tailor upcoming research opportunities for you. Knowing information about your demographics and MS history means that when the right opportunity comes along, we can reach out to YOU!

How to accelerate MS research (and ensure we can contact you with additional research opportunities!):

Visit your dashboard (you'll be prompted to log in).

Click on the "View and Complete My Research Surveys" button.

Complete your first open survey.

Repeat until you have no more open surveys!

Thank you for your continued participation! Your health information is important even if you think things haven't changed much in the last few months. Your data, especially your REAL MS data, has power! If you are not already a member, please consider joining iConquerMS, the only people-powered research network for MS!

UNIVERSITY of WASHINGTON

A study looking at language usage among people with disabilities – all adults with disabilities are welcome to participate!

What is the study about?

This research attempts to gather evidence on the preference between identity-first and person-first language by and for people with disabilities. The lead researcher is a graduate student in the University of Washington’s department of Computer Science and Engineering as a member of multiple labs focused on accessibility in computing.

Why participate?

The topic of language preference has been discussed often, but often while excluding community and individual perspectives. The research data gathered will help to work towards more consistent respectful language usage in future projects. Participants will contribute to a public website that features a visualization that explores the ways different backgrounds (age, country, gender) may or may not affect language preference.

Who can participate?

All people with disabilities over the age of 18 who have access to and can use a computer and access to the internet are welcome to participate.

How to participate:

Follow this link: https://bit.ly/disability-language-survey to access our participant survey. It should take around 5 minutes to complete.

DELIVER-MS

Early Intensive versus Escalation Approaches for the Treatment of Relapsing Remitting MS – Which is More Effective?

A study based at the Cleveland Clinic and the University of Nottingham (United Kingdom) is comparing two treatment strategies in 800 people with relapsing-remitting MS who have never taken a disease-modifying therapy. The study is recruiting at 30 centers in the United States and United Kingdom. One strategy is an "escalation" approach, in which individuals start taking a less-powerful therapy with the option of switching to a more potent one if disease activity continues. The other strategy involves starting with a strong therapy that is potentially more effective, but also carries greater risk for significant adverse effects. The DELIVER-MS Trial (Determining the Effectiveness of Early Intensive versus Escalation Approaches for the Treatment of Relapsing-Remitting Multiple Sclerosis) is funded by the Patient-Centered Outcomes Research Institute (PCORI).

Eligibility and Details

Investigators are seeking participants diagnosed with relapsing-remitting MS who are between the ages of 18 and 60 years. Participants are eligible if they have had MS for five years or less and have never been treated with an MS disease-modifying therapy. Further enrollment criteria are available from the contact section below.

Eligible participants will be randomly assigned into one of two groups and will choose along with their neurology provider among options in either a first-line or higher-efficacy therapy group. Participants and their neurology specialist will choose the therapy within the category that is most appropriate for them.

During the three years that they are enrolled in the study, participants will have regular check-ups and MRI scans with their MS team, to look at the effects of treatment. They will be free to change treatment, in discussion with their neurologist, for any reason at any time. The primary outcome being measured is the effect of treatment on brain tissue loss. Investigators will also monitor treatment effects on disability progression as measured by the EDSS scale, quality of life, other imaging measures, and safety.

Contact

To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please visit the study website and you will be connected with a participating site in your area.

Site Locations

Cleveland Clinic, Cleveland, OH
Cleveland Clinic-Las Vegas, NV
Ohio Health, Columbus, OH
University of Colorado, Anschutz Medical Campus, Aurora, CO
University of Rochester, Rochester, NY
University of Texas, Houston, TX
University of Virginia, Charlottesville, VA
Baylor College of Medicine, Houston, TX
University of Wisconsin, Madison, WI

University of Cincinnati, Cincinnati, OH
University of Minnesota, Minneapolis, MN
Mayo Clinic, Rochester, MN
University of Texas, Austin, TX
University of Buffalo, Buffalo, NY
Virginia Commonwealth University, Richmond, VA

The DELIVER-MS Trial is one of two studies funded by PCORI that will help inform treatment decisions around whether, and which, people with MS would most benefit from early, possibly more risky aggressive therapy. The other study is TREAT-MS (TRaditional versus Early Aggressive Therapy for Multiple Sclerosis). Both studies are recruiting participants.

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iConquerMS™

Your health data has power!

A new topic for the Our Questions Have Power program!

When it comes to MS symptoms and how to manage them, what questions are most important to you? What symptom-related topics do you wish researchers were studying? **Your questions are valuable** and we invite you to share them through the **Our Questions Have Power** program on the iConquerMS website.

The Our Questions Have Power program was launched in March 2021 with an initial focus on COVID-19. Questions submitted by iConquerMS members have helped shape the COVER-MS vaccination study and are being shared with the research community to guide other efforts.

We're now extending Our Questions Have Power to include a second topic: **MS symptoms and their management and treatment**. As before, you're invited to share questions on this topic that you think should be studied and to vote on questions submitted by other iConquerMS members. We'll share these questions with people affected by MS, researchers, healthcare professionals, advocates, and funders – and, together, we'll work to launch research studies to answer those questions.

It's easy to share your ideas and input in Our Questions Have Power!

Log in to iConquerMS to start (create an account first if you don't already have one).

Click **PROPOSE an MS Research Question** to submit a question you'd like to see studied.

Click **VOTE and COMMENT on MS Research Questions** to review, comment, and vote on questions submitted by other iConquerMS members.