

# April 2022 Newsletter



## April 2022 Research Spotlight

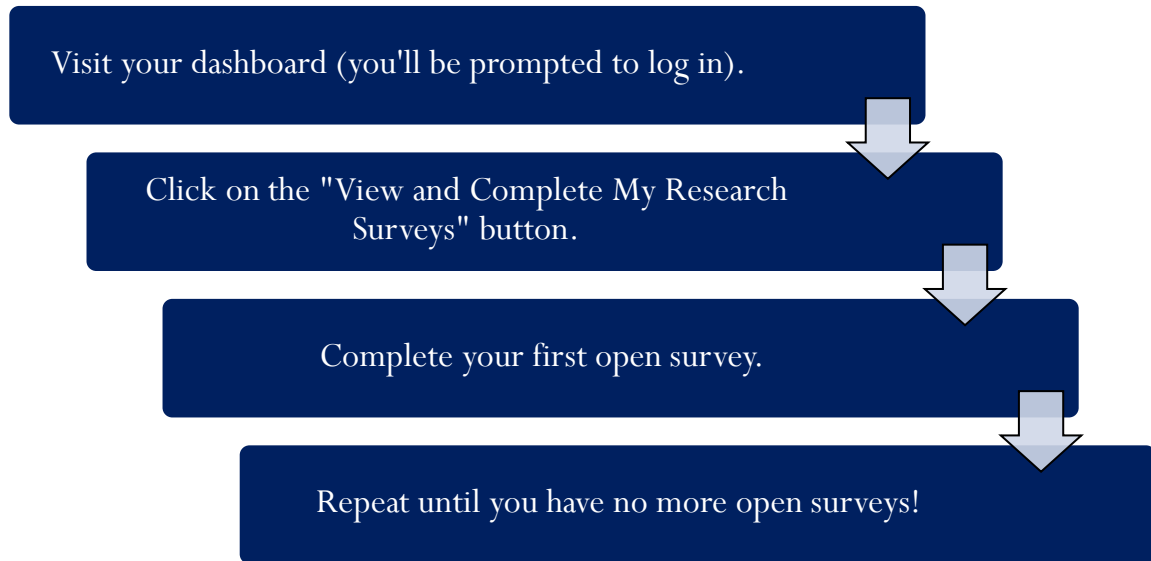
## RESEARCH OPPORTUNITIES



### 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!):**



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!

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**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.



**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!**

