



Power MS Research With Your Participation

We've recently published articles related to the Accelerated Cure Project (ACP) Repository and the research being done with its biosamples and data. In this issue, we focus on another of ACP's initiatives, [iConquerMS™](#), the people-powered research network that ACP launched in 2015.

Developed in collaboration with a major university and a communications firm, iConquerMS takes the original Repository concept of a centralized and open-access resource for researchers, and shape-shifts it in a variety of directions. Instead of being conducted in the MS clinic, anyone with access to a computer can join iConquerMS and participate from their home, office, or other location. And instead of having a limited "research subject" role, the members of iConquerMS are included in driving and shaping both the resource and the research being conducted with it, in unique and powerful ways.

Many other initiatives exist to collect health information from people with MS. They range from classic clinical research studies (which may have stringent rules about who is eligible to participate), to online and paper surveys, to social networks that compile the information shared by their members and then repurpose that information for research. iConquerMS is different from them in many ways. First, participation is open to all affected by and with an interest in MS. And while members do contribute health information via surveys, there are many other ways for them to engage with and impact MS research.



So what do we mean by "engage with MS research"? It can start with completing surveys about yourself (age, gender, race, geographic location), your experience of the disease (age at diagnosis, type of MS, symptoms and how they affect you), your treatment history, and other aspects of your quality of life. ACP removes any identifying characteristics from your data, combines it with data contributed by others and makes it available to researchers for the purpose of developing a better understanding of MS and its impact.

Through iConquerMS, to date more than 2,000 people have chosen to participate in this way. Their data may help uncover the causes of MS, inform us about who will respond best to various treatments, and help us understand better what complementary activities people could be doing to manage or improve their symptoms and well-being. As we say in iConquerMS, “Your information has power!” The act of sharing it is another way to fight MS.

Engaging in research through iConquerMS can include suggesting research topics of importance to you, and providing your feedback on topics and research studies being proposed by others. Members of iConquerMS receive updates on the initiative’s activities, such as what researchers are learning, and they can also learn about opportunities to participate in focus groups or clinical studies.

Perhaps most notably, iConquerMS is governed by a majority of people with MS. Through a Governing Board and two committees -- Engagement and Research -- some iConquerMS members contribute their professional and life experiences in order to design, grow, and manage the initiative. These individuals work closely with ACP and its founding partners to ensure that iConquerMS accelerates MS research in the ways and avenues that matter most to people with MS. We hope that you will consider becoming an iConquerMS Champion and work to engage and educate others on the initiative. Or alternatively, join the Board or one of the committees and become a leader in this global movement of people-powered research.

Your level of engagement with iConquerMS is up to you.

Today, over 3,600 people with MS have enrolled to be part of the iConquerMS network. All 3,600 have formally consented to participate in research. A majority of them also contribute baseline and 6 month data about their demographics and MS characteristics, including medications, symptoms and quality of life, by answering questions posed in online surveys. Many of the surveys take less than 5 minutes to complete and while a small number of them take longer, the answers that participants have contributed make up a trove of data that is enormously valuable to researchers.

The value of building a network committed to working with researchers is underscored by iConquerMS’s activity over the past year. At present, there are 6 scientific studies that have been funded and are underway, and another 10 that are awaiting grant funding from various sources to proceed. They include:

- A study being conducted by researchers at the famed Cleveland Clinic, to understand issues related to access to insurance for people living with MS. The scientists want to know what kind of insurance people with MS have (health, life, disability, long term care, none?) and want to understand how having different types of insurance impacts people’s lives. For example, if you have insurance through your own or a spouse’s employer, do you fear losing it in the event the employment ends and, if so, how does that impact your mental and physical health?

- A study being conducted by scientists at Harvard Medical School and the Massachusetts General Hospital, whose collaboration is named [The Mood Network](#). The study is testing an online approach to treating stress in people with medical conditions and their caregivers. They are experimenting with an online mindfulness treatment model, seeking to understand its effectiveness in reducing stress and its acceptability across a varied population.
- A large scale study proposed by ACP that will follow people on all the available Disease Modifying Therapies for a period of 4 years, in an effort to understand what factors influence how each individual does on a particular treatment. Knowledge gleaned through the study could translate into guidance for patients and health care providers considering treatment choices.
- A study proposed by researchers at Brigham and Women's Hospital in Boston to understand the extent to which people with MS use complementary and alternative medicine (things like yoga, meditation, acupuncture) and to what extent they combine it with more mainstream medical interventions.

People enrolled in iConquerMS have already contributed meaningfully to some of these studies, by participating in ad hoc surveys that the researchers developed in collaboration with the Research Committee of iConquerMS and the staff of ACP. For example, in preparation for seeking funding of ACP's study related to treatments, ACP asked people enrolled in iConquerMS to identify the functions and capabilities, e.g., mobility, mood, or energy level, that matter most to them when selecting a disease modifying therapy. More than 800 iConquerMS members responded, and their input profoundly influenced the design of the study.

Thirty years ago, the most common images associated with medical research were a slide under a microscope or a line of test tubes in a rack. But today, the image might just as likely be letters and numbers flitting across a computer screen. We have come a long way, baby, and the present and future of medical research depends on grouping, comparing, sorting and analyzing large amounts of data about people affected by disease. Your information, combined with the data of thousands of others, helps researchers uncover critical patterns and insights.

Joining iConquerMS is straightforward. Just click [here](#) on your computer or mobile device. After you click the "Join Now" button, you'll need to provide your email address and complete your personal profile. Once you've provided informed consent, you'll be ready to contribute data, ideas, and insights, and to shape and drive research as never before. For those of you who haven't yet enrolled, we look forward to welcoming you at www.iconquerMS.org very soon.