

May 2021 Newsletter

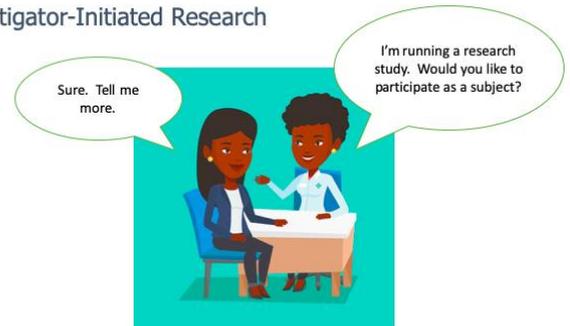


Are You in the Driver's Seat?

There is a growing recognition of the importance of incorporating the patient and caregiver perspectives into clinical research and decision making. People living with conditions like MS are the experts on what it's like to live with chronic illness and the impact of treatments on quality of life. These points of view can be used to deepen the understanding of living with such conditions. They can also inform research priorities and guide the way medical products are developed and brought to the marketplace, aligning them with the priorities of the populations they are intended to serve.

In general terms, research is defined as “the detailed study of a subject in order to discover information or achieve a new understanding of it.” Clinical research helps find new and better ways to detect, diagnose, treat and prevent disease. Most research today is “**investigator-driven**” where the idea for the research topic to be studied comes from a researcher or scientist. Recently, “**participant-powered**” or “**participant-centered**” research has become more common. This type of research still relies on a researcher to come up with the initial idea for study but people living with the disease are

Investigator-Initiated Research

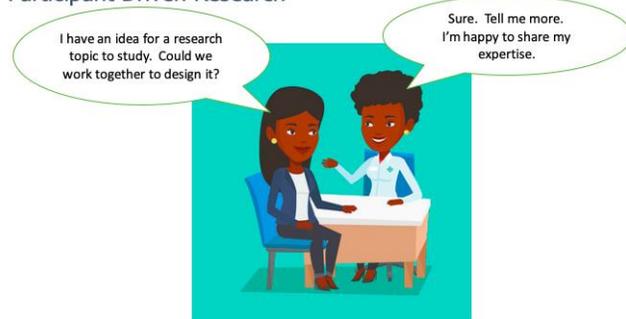


more involved in designing the study in collaboration with the researcher. Going a step further, “**participant-driven**” research (PDR) is where the question to be answered comes not from a researcher but from a person affected by the disease of interest who then works with a researcher to co-design the study. Participant-powered and participant-driven research represent a fundamental shift in how healthcare research questions are identified and prioritized, and research is designed, implemented and disseminated. Engaging patients and caregivers as true partners in research has the potential to improve research, answering the questions that matter most to people living with health conditions like MS. The end result is better, safer treatments, including non-pharmacological ones, that target what patients really need and want.

Participant-Powered Research (People-Powered Research)



Participant-Driven Research



[iConquerMS](#) is a great example of participant-powered research. iConquerMS was co-designed with people affected by MS and research conducted through the network is done in close collaboration with its members. iConquerMS participants have contributed to the design of [multiple studies](#), providing their insights and experiences to researchers in order to ensure the investigation not only addresses a topic of interest to those affected by MS, but also the study design itself fits into the lives and lifestyles of people who will participate.

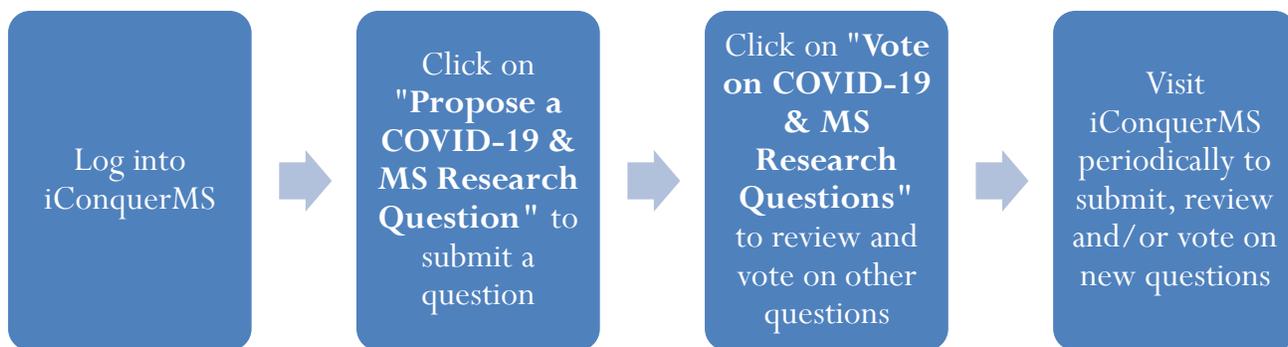


Now, it's possible for iConquerMS participants to play a larger role than ever in guiding MS research! The newly launched [Our Questions Have Power](#) program gives network members the opportunity to submit MS research questions on topics they deem important and would like answered, and also comment and vote on questions submitted by others. How do these questions become new MS knowledge? High priority questions will be shared with investigators, who will work in collaboration with the iConquerMS community to design and conduct the research. An iConquerMS proposal team is

available to help researchers with their research study plan and budget (which is submitted to organizations that fund research). Once a proposal is approved and funded, a study team (consisting of researchers and network members) will conduct the research and distribute the results to the iConquerMS and scientific communities, study participants and the general public.

Participation is easy!

If you have MS or care for someone who does, you probably have questions about the disease and its effects. Your questions and insights can help scientists shape research studies to advance knowledge about the disease and improve MS care. Take part in PDR through iConquerMS and help drive the direction of MS research by bringing these questions and priorities to the attention of researchers. Together, people affected by MS can weigh in on the importance of different questions or bring to light new questions.



If you are not already a member, please consider [joining](#) iConquerMS, the world's first and only people-powered MS research network. There are many ways for everyone affected by MS to get involved! Become a member and start learning about MS research and how you can play a role. Complete surveys to provide data about life with MS for researchers to use in their studies. Share your ideas for future research with the iConquerMS community. Comment and vote on questions you think are most important that have been shared by others. Join an iConquerMS team overseeing the research process or participate in a study. Tell others affected by MS about the initiative and encourage them to join! Spread the word to help ensure MS research reflects the needs and priorities of those living with the disease. Together we can improve MS care and bring us closer to a cure!



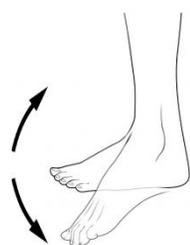
Managing Muscle Spasticity and Spasms

Spasticity and muscle spasms can have a big impact on quality of life and daily activities for many people with MS. A recent [survey](#) of over 10,000 participants in the



[North American Research Committee on Multiple Sclerosis \(NARCOMS\) registry](#) showed over 80 percent reported experiencing spasticity. More than 35 percent of respondents were moderately or greatly bothered by stiffness, spasms, or pain, predominantly in the legs. Data suggest the level of spasticity corresponded with an individual's level of disability, bladder dysfunction, and fatigue related to MS. Most reported receiving treatment for spasticity (mainly oral medications, stretching, home exercise, and physical therapy), yet fewer than half reported being satisfied with their current treatment.

Spasticity and spasms can occur in any muscle. Nerve pathways that connect the brain, spinal cord and muscles work together to coordinate smooth movement. When demyelination occurs along one of these nerves, signals are interrupted and the affected muscle can remain in its shortened state, making the limb it controls feel stiff or tight and often difficult to move (spasticity). When spasticity is severe it can be very difficult to bend a limb at all. If a limb becomes fixed in one position it is known as a **contracture**. Disrupted nerve messages can also cause over activity of muscles, leading to spasms. This is a sudden involuntary tightening or contraction of a muscle which may cause a limb to kick out or jerk towards the body. There are several different types of muscle spasm. **Flexor spasms**, as the name implies, cause a limb to bend and **extensor spasms** cause a limb to extend. A spasm that causes a limb to be pulled in towards the body (for example, making it difficult to separate the thighs) is called an **adductor spasm**. Spasms affecting the trunk can cause the back to arch off of a bed or away from the back of a chair.



It isn't unusual for individuals with tight or hyperactive muscles to also experience pain, weakness and [clonus](#) (involuntary muscle contractions). The intensity of symptoms can vary from person to person, and in the same person over time (even throughout the day). This can impact many physical activities such as walking, transferring, sexual activity, washing, dressing, and picking up objects. If muscle spasticity/spasms and their accompanying symptoms cause an individual to fall, their safety may be compromised. These troublesome symptoms may also have an emotional impact, for example on mood or

self-image. It's important to note that muscle stiffness can sometimes be helpful, especially for individuals with leg weakness. It can provide stability and strength when standing, walking or moving from one position to another.

A number of factors play a role in the amount of stiffness and spasms an individual may experience. For example, lack of movement often worsens spasticity. Unpleasant sensations, such as hunger, pain or a full bladder/bowel can have the same effect, as can anything that constricts the limbs, such as a cast, brace or tight-fitting clothing. Some women find that their spasticity is worse during a



menstrual cycle. Any infection can aggravate stiffness and spasms until it has resolved, including urinary tract infections, an infected tooth and common illnesses like a cold, flu or stomach bug. Being overtired or stressed can also temporarily worsen symptoms, as can being too hot or too cold. People with MS may also experience higher levels of spasticity during an exacerbation, or when they are treated with certain [disease modifying therapies](#) or [antidepressant medications](#). Some find it helpful to keep a journal of when spasticity occurs, including their activities and other environmental factors. Being aware of and managing potential triggers for spasticity is key to successful treatment. Once they are dealt with, muscle stiffness and spasm may ease without medication.

A variety of drug-free approaches are often used to treat muscle spasticity and spasms. [Research](#) shows that physical activity is helpful in this regard, however it's important to note that people with MS should consult with their healthcare team before beginning a new exercise regimen on their own. As discussed in our [November 2019 newsletter](#), a physical therapist can teach specific stretches and exercises to help relax muscles, provide advice on



posture or different ways of moving and positioning the body to keep comfortable. An occupational therapist can provide guidance on making daily tasks easier. Research results on the effectiveness of hot and cold therapy for stiff muscles are mixed. A [2019 study](#) suggests that ice

packs are effective at providing relief. On the other hand, a [2013 study](#) concludes applying heat makes muscles more flexible and cold treatment may have the opposite effect. Yoga, massage and relaxation techniques like meditation and deep-breathing exercises can also be beneficial to improve flexibility.

A variety of medications are also used to treat spasticity, often in combination with non-drug approaches when they don't provide sufficient relief. [Baclofen](#) is commonly prescribed to treat this condition. It can be taken orally, or via infusion directly into the spinal cord (intrathecally). This involves the placement of a catheter into the space around the spinal cord (the thecal sac). The catheter connects to a reservoir and pump that is surgically implanted in the abdomen and programmed to continuously deliver baclofen directly to the spinal cord. The pump is comfortable for most people and doesn't hamper movement. Refills are done by subcutaneous injection into the pump's port. A [2017 review](#) found up to 75 percent of patients experience adverse side effects including fatigue, dry mouth, dizziness and nausea when taking oral baclofen. When given intrathecally, much more of the medicine reaches the spinal cord (so less is needed), resulting in fewer side effects. Researchers conclude that, while oral baclofen is effective in the management of spasticity, intrathecal baclofen is a viable option for those that cannot tolerate taking it orally, or those that do not respond to the maximum recommended oral dose.



Other drugs used to treat increased muscle tone include [Zanaflex](#) (tizanidine), [Dantrium](#) (dantrolene), [Klonopin](#) (clonazepam) and [Neurontin](#) (gabapentin). [Valium](#) (diazepam) is also effective in this regard, however it has the potential for dependence and addiction. All of these medications cause sleepiness, dry mouth, dizziness and fatigue, which can be problematic. Timing when to take these medications during the day will often maximize their effectiveness. For some, taking a dose a few minutes before getting out of bed works best. For others, it may be better to wait until after getting up because some leg stiffness is necessary to get out of bed safely.



Intramuscular injections of [BOTOX](#) (botulinum toxin) or [phenol](#) are used to treat those with spasticity affecting a small area (focal spasticity), or those who do not get relief from oral medications. These injections are usually administered during a clinic visit. Botulinum toxin and phenol are powerful neurotoxins that temporarily block connections between the nerves and the muscles, resulting in short-term relaxation of the targeted muscle. A BOTOX injection typically takes effect in three to seven days and lasts for three to six months. It's important

to note that it's possible to build up antibodies to BOTOX, making it less effective over time. Phenol typically takes effect immediately and lasts four to twelve months.

Surgery is sometimes used to help manage spasticity. As mentioned above, individuals requiring intrathecal baclofen must have their pump implanted in the abdomen. Surgical procedures, such as lengthening tendons or fusing joints, can also be used to correct any permanent deformities that spasticity may cause.

As mentioned in our [September 2018 newsletter](#), it is becoming more common for people with MS to use cannabis to alleviate many of their symptoms, including muscle spasms and spasticity. There have been numerous studies conducted to evaluate its effectiveness in this regard. The [CAMS \(Cannabinoids in MS\) study](#) looked at 630 people with MS that were assigned to receive a cannabis product or placebo twice daily for 15 weeks. Those taking cannabis reported significantly greater improvements in spasticity, spasms, and sleep compared to those taking placebo. The [MUSEC \(MS and Extract of Cannabis\) trial](#) looked at patients' perceptions of changes in muscle stiffness. In this study, 279 people with MS took either a cannabis product or placebo for 12 weeks. Those taking cannabis had almost twice as much relief from muscle stiffness as those taking placebo and they also had improvements in spasms and sleep. [Sativex](#) (nabiximols), a cannabis-based oral spray, is the only drug approved for treating MS symptoms. According to a [review](#) published by the American Academy of Neurology (AAN), Sativex, [oral cannabis extract](#) and [tetrahydrocannabinol](#) (THC) are at least somewhat effective at reducing MS-related spasticity and pain. Researchers conclude there is not enough evidence to assess the effectiveness of smoked cannabis for treating MS symptoms or the long-term safety of marijuana use. It should also be noted that medical marijuana is only legal in some states, which affects its accessibility.



Muscle stiffness typically interferes with movement and function, but it can sometimes be helpful. One of the biggest challenges in making treatment decisions is achieving the optimal level of muscle tone for a given individual. Recognizing and fully addressing aggravating triggers for spasticity is important. Once resolved, further treatment may not be necessary. There are a variety of drug and non-drug approaches available which can be used together to achieve the best outcome. The ideal therapy will differ from person to person, and in the same person from time to time. It's essential for people with MS to work

with an [interdisciplinary healthcare team](#) to manage muscle spasticity and spasms. Open communication with one's healthcare providers about symptoms, daily challenges and the effectiveness of treatments will help provide clarity in how to achieve the best outcome and quality of life.



May 2021 iConquerMS Spotlight



Calling all caregivers!

MS caregivers play an integral role in the health and wellbeing of their loved ones. They can also be instrumental in contributing their insights and experiences to MS research, including the development of new treatments, through a process called patient-focused drug development (PFDD). Our first survey for MS caregivers is now available! If you are a care partner to someone with MS, please share your thoughts about the caregiver role in PFDD through this [10-minute survey](#). Thank you! Not already a member of iConquerMS? Please consider [joining](#) the community with your loved one today!

May 2021 Research Spotlight

RESEARCH OPPORTUNITIES



The Evolution Studies are enrolling now

The Evolution Studies are researching an investigational medication for adults with relapsing multiple sclerosis (RMS).

You, or someone you care for, may be able to take part if you/they:

- are 18–55 years of age
- have RMS (RRMS or SPMS with relapses)
- have had 1 or more relapses in the past 2 years.

There are also some other requirements for taking part.

Eligible participants receive all study-related health assessments and study-related medication at no cost.

Click [here](#) to find out if you may be eligible by completing the study sponsor's brief questionnaire.

This content has been sponsored by EMD Serono. For more information, see the study descriptions on [clinicaltrials.gov here](#) and [here](#).



Complete your REAL MS surveys!

In the summer of 2016, the iConquerMS initiative launched REAL MS (Research Engagement About Life with MS), a longitudinal study of MS. Participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. **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. The information collected 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. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS!

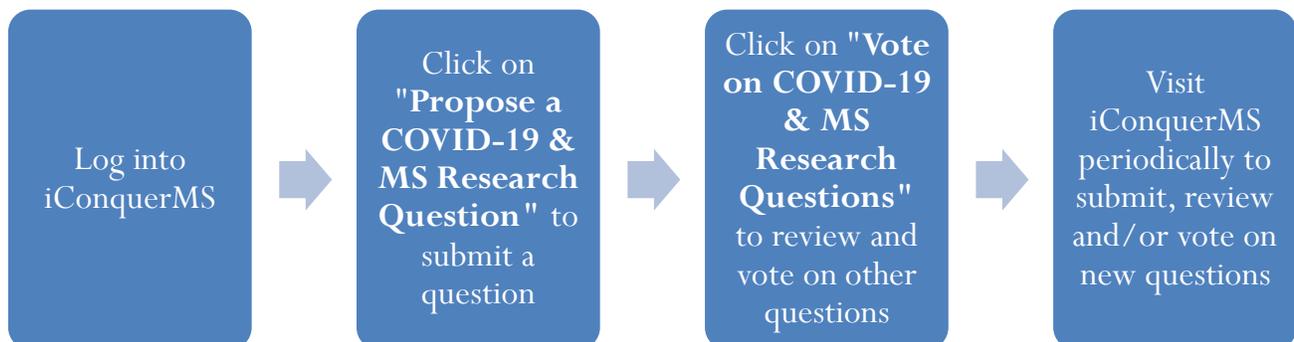


Announcing a New Program for iConquerMS Members!

iConquerMS is leading the movement to include the patient perspective in every step of MS research. Now, network members can play a larger role than ever before in initiating and collaborating with researchers on studies that will expand knowledge in areas that matter most to people affected by MS.

iConquerMS members have always been able to submit research questions to the initiative. It's now possible to comment and vote on questions submitted by the community through the newly launched [Our Questions Have Power](#) program. Questions that are high priority for the iConquerMS community will be shared with researchers, who will work in collaboration with the iConquerMS community to develop them into research studies.

Participation is easy!



If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Add your voice to those working together to improve MS care and bring us closer to a cure!



Share your experiences with COVID-19 vaccines

[iConquerMS](#) is now collecting information from people affected by MS related to their experiences with COVID-19 vaccines. The data collected will be securely shared with researchers studying the effects of COVID-19 vaccination on people affected by MS. If you are an iConquerMS member that has received a COVID-19 vaccine, please [login](#) today and share your experience by clicking on “Participate in the COVID-19 Vaccination Study.” Not yet a member? Please [join](#) iConquerMS now and start adding your data!

NEW RESEARCH RESULTS



The COVID-19 Pandemic Experience in MS

In May 2020, investigators at the University of Reading invited iConquerMS members to participate in a survey on psychological support in MS. Preliminary [results](#) were recently published in the journal, Neurology and Therapy. Data suggest that younger individuals, those with progressive MS, and those with psychological symptoms, such as anxiety and depression, are particularly vulnerable to the negative effects of lockdown during the pandemic and may benefit from further support. According to researchers, people with the best experience during this difficult time have used a number of helpful coping strategies, such as self-care/rest, seeking relevant information, limiting exposure to negative news, adopting secure COVID-19 practices, building friendships and relationships, adapting to new routines, having an appreciation of the benefits of lockdown and being accepting of a post-COVID 19 world. These data serve as a wellbeing guide, as well as call to action for more MS support moving forward, particularly in those identified as being most vulnerable.

Anyone still interested in taking part in the survey can either go to the [University of Reading website](#) and click the 'start' button at the bottom of the page, or directly access the survey by clicking [here](#). The research team will use this information to design a psychological intervention that reflects the views of the MS community and is tailored for people living with the disease.