

May 2021 Newsletter

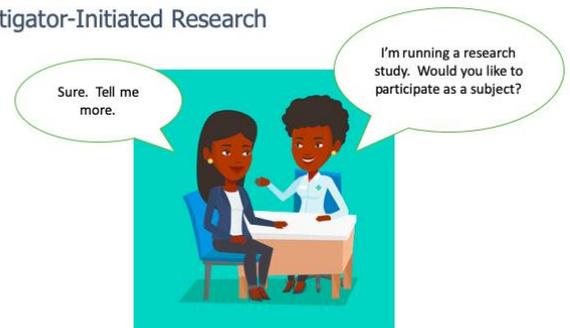


Are You in the Driver's Seat?

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

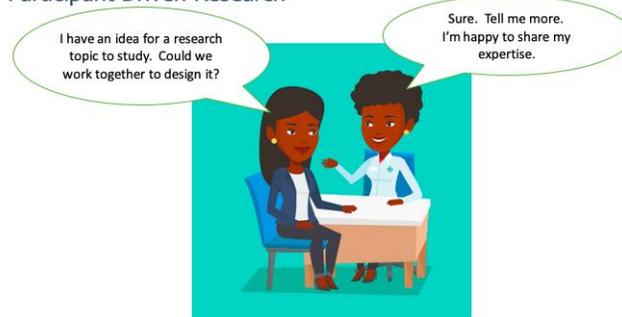


more involved in designing the study in collaboration with the researcher. Going a step further, “**participant-driven**” research (PDR) is where the question to be answered comes not from a researcher but from a person affected by the disease of interest who then works with a researcher to co-design 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.

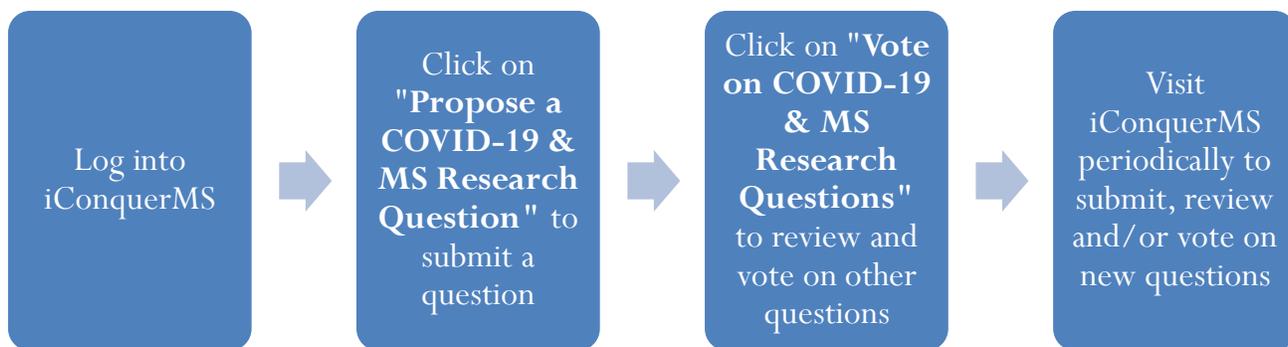


Now, it's possible for iConquerMS participants to play a larger role than ever in guiding MS research! The newly launched [Our Questions Have Power](#) program gives network members the opportunity to submit MS research questions on topics they deem important and would like answered, and also comment 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!

