

# December 2019 Newsletter



## A Meeting of the Minds – Strengthening Participant-Driven Research

[iConquerMS™](#), the only people-powered research network in MS, was established to enable and accelerate MS research and other innovations with the goal of improving the health, healthcare and quality of life of people affected by MS. The initiative does this by connecting those with MS, care partners, clinicians, and researchers, and encouraging them to work together to accelerate innovation, research, and the application of new knowledge. In 5 years, the network has grown to over 5,000 registered members, more than 3,000 of whom have contributed data about themselves and their experiences of living with MS as part of [REAL MS™](#) (Research Engagement About Life with MS), a research study focused on capturing the essence of what it means to live with MS. iConquerMS collaborates with researchers and organizations to enable and accelerate research projects focused on the highest priority needs and interests of people affected by MS. We anticipate reaching groundbreaking milestones in the New Year!

**2020**

In September, the iConquerMS governance and other stakeholders in the MS community gathered at our fifth annual Leadership Summit to discuss the future direction of the initiative. The key focus of this year’s meeting was enabling participant-driven research. One might ask, what is participant-driven research? 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. Types of clinical research include clinical trials, which test new treatments for a disease, and natural history studies, which collect health information to understand how a disease develops and progresses over time. Most research today is “investigator-driven” where the idea for the research topic to be studied comes from a researcher or scientist. In recent years, “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 now people living with the disease are more involved in designing the study in collaboration with the researcher.

**Participant-driven research (PDR)**, however, is research where the question to be answered comes not from a researcher but from a person affected by the disease in question who then works with a researcher to co-design the study. iConquerMS is a great example of **participant-powered** research in that the initiative has been co-designed with people affected by MS and the research conducted via iConquerMS is done in close collaboration with its members. Participants in iConquerMS have contributed to the design of multiple research studies, providing their insights and experiences to researchers in order to ensure the research study not only

Investigator-Initiated Research



Participant-Powered Research (People-Powered Research)



Participant-Driven Research



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 in the research. **PDR** is an emerging type of research and ACP and iConquerMS are at the forefront of driving it forward in MS.

During the year following each Leadership Summit, the Next Steps Committees (NSCs) work to keep the momentum going and advance the work begun at the Summit. Last year's NSCs focused on such topics as increasing enrollment in research, diversity and inclusion of underrepresented populations in research, caregiver health and well-being, engaging with pharmaceutical companies, nutrition and ageism. This year's attendees kicked off day one of the Summit by celebrating these efforts and working to expand on them.

An important discussion centered on increasing enrollment in patient-powered research initiatives, like iConquerMS. Several strategies were proposed to accomplish this, including recruiting in "sweet spots" like MS centers, educational organizations, support groups, at clinical/research conferences, through social media, a celebrity, or even just word of mouth. Other suggested ways to facilitate enrollment included accommodating the participant's lifestyle and using technology to create wider access to research. The iConquerMS Leadership agreed educating people about research is key. It's essential to get this information to the people who will use it and can create an impact, such as people with MS, support partners, healthcare providers, insurers, pharma, and patient leaders/influencers. Social media, webinars and publication in peer-reviewed journals were proposed as effective dissemination methods.



As we discussed in our [February 2018 newsletter](#), diversity and inclusion are key to ensuring medical research benefits all. Summit attendees agreed minorities may be conditioned to not trust clinical studies based on significant historical events where people from minority populations have been taken advantage of in research. To increase confidence in research, the importance of keeping communications understandable (avoiding "legalese") was, again, emphasized. It's essential to develop study materials in

such a way as to be inclusive (in different languages and using a variety of images). Researchers need to change the “if we build it, they will come” mentality they often have surrounding their studies. This can be done by actively engaging participants of all races and ethnicities by whatever means of communication they are most accustomed to using (for example, social media). For iConquerMS, knowing the initiative’s story and telling it in a number of different ways was proposed as a powerful way to reach many different people. It’s necessary to learn who the leaders are in underrepresented populations (social, church, respected medical professionals, or even celebrities) and enlist them in outreach efforts. If the individuals involved in these efforts are willing to share about their MS experience, mistrust and misconceptions can hopefully be minimized. Keeping research participation convenient and easy also helps. Overall, the group agreed on the importance of being intentional at every step. Individuals of all races and ethnicities need to know the importance of patient-reported data to their healthcare and to understand no matter how MS may impact them, they can contribute.

Care partners play an essential role in the lives of people with MS. They are also a valuable resource of information for MS research. Care partners may be aware of areas of decline that are not appreciated by the person with MS. They can provide information about symptoms or problems their loved one with MS may be downplaying,



or about how the disease impacts everyday living and quality of life. However, industry and healthcare advocacy groups tend to overlook this important point of view. Summit attendees discussed the significance of care partners in the grand scheme and explored ways to affect change so caregivers are seen as facilitators in MS research. Additionally, the health and well-being of the care partners themselves are often compromised by the demanding and relentless role they hold. Summit attendees discussed efforts underway to address the health needs and priorities of care partners and elaborated on ways to ensure that care partners are provided the resources and support they need from day one – the point of diagnosis of their loved one with MS. The role of the care partner in research, as an observer to the person living with MS and in their own right, will be an area of major focus for iConquerMS and ACP in 2020 and beyond.

The iConquerMS leadership discussed the importance of engaging with pharmaceutical companies in meaningful ways that benefit the MS community. Thoughtful and patient-centered engagement with industry would pave the way to valuable discussions to help industry understand the diversity of people living with MS. When dealing with the pharmaceutical industry, the issue of trust (or lack thereof) is an issue from many perspectives. People with MS feel companies should make more of an effort to make their research more patient-focused and understand their needs consistently. Pharmaceutical companies are looking to expand their commitment of resources to patient engagement and to recognizing that many patients want to be involved, and there are many ways a person affected by MS can contribute. Industry needs to involve people with MS early in the research process and sustain a relationship with them over time. They need to obtain more feedback from patients and work with care partners to better understand the quality of life in people with MS. Healthcare professionals also need to be part of the conversation with pharma. In order to make these changes, there needs to be an evolving engagement between industry, patient groups and advocacy organizations, as well as collaboration between pharma and initiatives like iConquerMS.



The group also explored the concept of food as medicine. Summit attendees discussed the importance of studying the clinical outcomes of good nutrition, including supplements. They exchanged ideas about how to provide a good diet in a different way (for example, meal delivery programs). It was even suggested that food be studied from the perspective of being a poison (for example, food sensitivities or allergies). The importance of providing information on how to read and understand complex labels on food was also covered.

Summit attendees dove deeper into the subject of ageism in MS. They explored why clinical studies have age restrictions and often limit the participation of people with MS over the age of 60 (resulting in missing important data). The group agreed that all stakeholders need to work together to affect change. Specifically, older people with MS need to volunteer for research studies, when



they are comfortable doing so. Researchers, in general, need to increase the age limitations in clinical trials. They should steer their outreach more to the aging population, possibly through less electronic and more live interaction or engaging other support organizations, like AARP. Healthcare providers should widen their scope to include such factors as whether or not the risk/benefit profile of MS treatments change as patients age, as well as the impact of other health concerns (comorbidities, falls, employment, ability to drive, or cognition, to name a few). Clinicians might also consider how insurance or pharmacy benefits may limit access to disease modifying therapy, or whether they would cover home safety evaluations, nutrition, and exercise/wellness activities.

Switching gears on day two of the Summit, attendees worked to come to a shared understanding of what PDR is, including how different stakeholders view this type of research and what each needs to make it successful. All agreed on the importance of keeping research understandable, as well as maintaining trust and good communication between all parties involved.

As the attendees dug deeply into how iConquerMS can successfully drive forward PDR, suggested areas of focus for the coming year included engaging researchers and informing them of the potential iConquerMS holds as a powerful resource for their studies, creating research plans collaboratively and helping investigators better understand the patient perspective and what may or may not work with different approaches. Other resolutions centered on facilitating funding for participant-driven research. Many potential sources of funding currently exist. Attendees discussed the importance of matching proposals and funders according to mutual processes and characteristics. All agreed on the importance of engaging funders as early as possible, building relationships with them and maintaining good communication with them.

The 2019 Leadership Summit concluded with attendees expressing their hopes for iConquerMS initiative in the coming year. The general sentiment was a desire to change the landscape of MS research through collaboration, a mutual respect for different perspectives and a wider, more diverse engagement to raise awareness of and participation in participant-powered research in the MS community. Participants pondered answers to such exciting questions as “what will we do next?” and “what will researchers do?” in order to affect this transition. The Next Steps Committee is focused on advancing and

strengthening iConquerMS participant-powered **and** participant-driven research in the coming year. We look forward to an exciting and productive New Year! Stay tuned!

