

December 2021 Newsletter



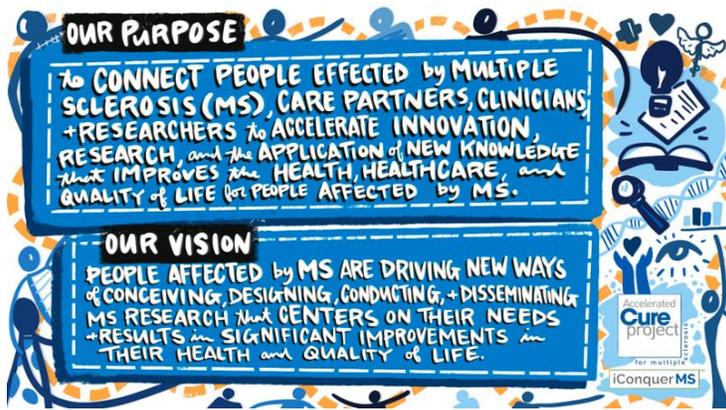
Aligning Vision With Impact

[iConquerMS™](#) 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. Through iConquerMS, people affected by the disease are driving new ways of conceiving, designing, conducting, and disseminating MS research that centers on their needs and results in significant improvements in their health and quality of life.

In November, the iConquerMS governance and other stakeholders in the MS community gathered virtually at the 2021 Leadership Summit to discuss the future direction of the initiative. The key focus of this year's meeting was aligning iConquerMS's key priorities with our vision and desired impact. The meeting brought together a diverse group of individuals. One quarter of attendees were people living with MS. Other stakeholder groups present included researchers (13%), members of the iConquerMS governance (11%), members of other iConquerMS activities (11%), representatives from other MS

A graphic of the year "2021" in a large, bold, orange and yellow font with a textured, fiery appearance.

advocacy organizations (10%), care partners (7%), healthcare providers (7%), and representatives from industry (2%). Most of this year's participants were from the Boston area, followed by the Western US and the mid-Atlantic US.



This year's attendees kicked off day one of the Summit by discussing the importance of [equity and access](#) in MS research. Attendees revisited iConquerMS's guiding ideas (its purpose and vision), the initiative's role in MS research and what it is ideally

sued to do. They celebrated the [progress](#) the initiative has made increasing the awareness of and engagement in [participant-driven](#) (PDR) and [participant-powered research](#) (PPR). The group was challenged with the following question – “If iConquerMS, in partnership and as part of the MS community, is able to achieve its vision in 5 years, what would we need to either start doing, do differently or do more of?” Participants brainstormed what would bring iConquerMS closer to its vision, what they were excited to be a part of, and what would they like to make happen. The group explored what tools, resources, capacities, or partnerships would be necessary to move these topics and ideas forward. A number of proposed priority activities for iConquerMS emerged from these discussions, which are described below. Day two was focused on prioritizing these activities.

All in attendance at the Leadership Summit agreed that the initiative should keep listening to and amplifying the voice of people with MS in research. Priorities for the coming year include exploring ways to improve quality of life for people with MS, further expansion of the network's infrastructure, conducting more research through iConquerMS, and having more research questions driven by participants.

iConquerMS participants contribute their insights, expertise, and valuable health information to shed light on many aspects of living with MS. Summit attendees discussed ways to improve and use these valuable data to inform our priorities



and foster equity of research and care. All agreed on the importance of knowing the demographics of individuals in the database to ensure the research questions presented met the needs of the diverse population participating in iConquerMS. Additionally, attendees agreed that disaggregating the database as much as possible would enable a richer and more meaningful understanding of the various groups engaged.

The dissemination of research results was another main area of discussion. The group agreed the network should create a plan for the dissemination of research results in easily understandable language and include this plan in the design of all research done through the network. This would ensure that research has more of a direct impact on health and quality of life of those in the MS community. Attendees suggested that sharing results broadly with the MS community (instead of just with participants that completed a given survey) would engage researchers and increase their involvement in iConquerMS. It would also serve to attract people with MS to the initiative and increase enrollment. Another suggestion for improving the dissemination of research results was sharing “raw” data (instead of data that has been digested into “outcomes”) with network members and then convening groups to discuss the data. This would have the added benefit of not just sharing results, but also helping people understand them.



A number of exciting ways to increase the awareness of iConquerMS among all stakeholder groups were proposed during this impactful weekend. This would not only help expand the network, but also help build trust and equity by broadening engagement with a wider community in research. One idea was to develop a formal communications strategy and calendar which would communicate information about the initiative in an understandable way to a larger audience. Increasing the initiative’s presence on social media may also help in this regard, for example by making photos and posts more personal (featuring network members) or attracting more social media-savvy individuals to promote iConquerMS’s vision. Other ideas included connecting with individuals and groups that don’t use smart phones or computers and making better connections with people in rural communities. This could be



accomplished by creating a printed newsletter for dissemination to places where people might not have access to internet or web resources. The group discussed other outreach approaches like connecting with researchers and informing them of the value of iConquerMS, doing market research to

determine people's preferences for hearing information, and developing an engagement strategy for groups like the newly diagnosed and those that are not already engaged with iConquerMS.

Engaging with healthcare providers about iConquerMS and the benefits it could provide for their patients was another important topic of discussion. The group agreed that educating clinicians and researchers about the needs and priorities of people affected by MS should be a priority in the coming year. Helping them understand that hidden symptoms such as sleep disorders, bladder issues, bowel dysfunction, depression, and [social determinants of health](#) can have a huge impact on those living with the disease. Teaching researchers and study personnel about appropriate language to use when interacting with individuals with MS (for example, using "person" or "individual" rather than "patient" and not using acronyms like "PwMS") may help with recruitment efforts.

Summit participants discussed ways to diversify the iConquerMS membership. The conversation yielded some interesting pathways forward, including determining what historically underrepresented populations need and want from research. What do they need from a research network like iConquerMS? What is most important to them? Other proposed solutions were meeting with minority community leaders, conducting the research in under-served communities, and focusing on representation for minorities.

All agreed that improving the iConquerMS user experience would likely increase enrollment in the initiative. The importance of teaching and providing more support/training to all iConquerMS participants, ensuring they understand research

fundamentals, was stressed. Educational resources about living with MS could be



based on information obtained from the iConquerMS community. Improving usability and options for new members were also suggested as ways to boost enrollment.



The majority of Summit participants felt that iConquerMS should continue its efforts to grow the network’s community, fostering communication with and between iConquerMS members. Gathering and sharing individual stories within the network was one idea to boost camaraderie among members. Attendees also stressed the importance of diversifying the network and how it is important to continue to value the representation of all people and stakeholders within it.

The group brainstormed ways to enhance and build collaborations with other MS groups and influencers in the upcoming year. This could be accomplished by gathering information about collaborative processes from industry. For example, what has worked for them in reaching diverse groups of patients? Partnerships relating to pediatric MS may be expanded by sharing information about iConquerMS through the channels that young people use, for example social media platforms like Instagram. Attendees also discussed ways to increase the initiative’s political advocacy, perhaps by forming a Social Action Subcommittee to influence MS-related policy.

One of the biggest hurdles for the iConquerMS initiative to overcome is how to raise enough money to accomplish these goals. Summit attendees agreed that it’s important to align the network’s interests and priorities with all stakeholders to create momentum behind funding opportunities.



The 2021 Leadership Summit was a celebration of the work that has been done through iConquerMS in partnership with its stakeholders. This year participants deepened relationships and connections with each other. Over the course of the

weekend, attendees developed a shared understanding of the initiative's vision and what is needed in order to achieve it. The Next Steps Committee is focused on carrying the work of the summit and iConquerMS forward. We look forward to an exciting and productive New Year! Stay tuned!

