

January 2023 Newsletter



Deepening Our 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 2022 Leadership Summit to discuss the future direction of the initiative. The key focus of this year's meeting was deepening our impact. The meeting brought together a diverse group of individuals. Almost one third of attendees were people living with MS. Other stakeholder groups present included researchers (12%), representatives from other MS advocacy organizations (11%), members of the iConquerMS governance (10%), members of other iConquerMS activities (10%), healthcare providers (7%), care partners (6%), funders (5%), and representatives from industry (2%). Most of this year's participants were from the western US, followed by the mid-Atlantic and the southwest US.



PURPOSE

To improve health, healthcare, and quality of life for people affected by multiple sclerosis (MS) by connecting those with MS, care partners, clinicians, and researchers, and to work together to accelerate innovation, research, and the application of new knowledge.

PRIMARY ASSUMPTION:
Participant Powered Research is a key pathway to curing MS and improving the quality of life for people affected by the disease.

HOW DO WE DEEPEN OUR IMPACT?

PROMOTE a PATIENT-CENTERED MODEL of RESEARCH
 ENGAGE with RESEARCHERS
 DEVELOP PARTNERSHIPS
 CONDUCT RESEARCH STUDIES
 DISSEMINATE the EVIDENCE

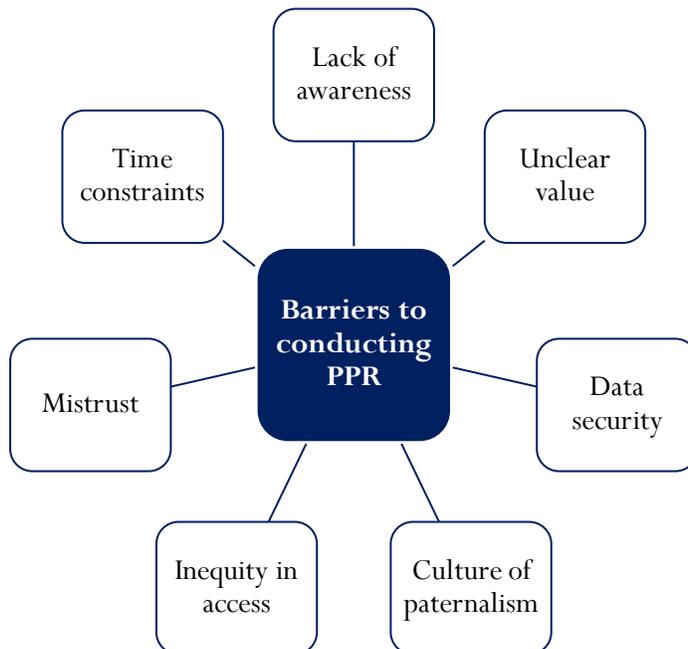
VISION:
People affected by MS are driving new ways of conceiving, designing, conducting, and disseminating MS research that centers on their needs and results in significant improvements in their health and quality of life.

OUR GUIDING PRINCIPLES:

WHAT is in the WAY of ACHIEVING OUR VISION?

EMPOWERING PEOPLE AFFECTED by MS
 TRANSPARENT and TRUSTING RELATIONSHIPS
 GOOD STEWARDSHIP
 SUSTAINED COMMUNITY
 HIGH-QUALITY RESEARCH
 INCLUSIVITY
 TRANSFORMATIONAL COLLABORATION

This year’s attendees kicked off day one of the Summit by reviewing iConquerMS’s purpose, vision and guiding principles. They celebrated the [progress](#) the initiative has made increasing the awareness of and engagement in [participant-powered research](#) (PPR). Participants divided into stakeholder groups and considered the following questions – “What gets in the way of your group fully committing to PPR?” and “What needs to change so PPR can become the rule and not the exception for your stakeholder group?” A number of key barriers to conducting PPR emerged from these discussions, which are summarized below. Day two was focused on pursuits that would break down these barriers and further advance PPR.





Summit attendees had a robust discussion about making PPR mainstream. One pathway forward involved transforming the education of healthcare providers, involving people affected by MS in continuing education presentations. This would get physicians used to considering the patient perspective, putting them in a better position to conduct PPR. The group stressed the importance of spreading the word about PPR with a unified voice (in collaboration with all MS stakeholders). One possible way to do this would be to create educational resources describing the nature of PPR and make them available electronically, or in the form of pamphlets for waiting rooms and pharmacies.

The group also talked about ways to promote PPR in the research community. One suggestion was to make the inclusion of the patient perspective a funding requirement for prospective studies, targeting organizations that generate a lot of research funding (for example, foundations and pharmaceutical companies). A legislative approach was also proposed, which would involve appealing to Congress to put pressure on government funding agencies to comply with this requirement. All agreed that educating researchers and funders about the value of PPR and how it streamlines the research process should be a big part of this effort.

Raising awareness about iConquerMS was another main focus of this impactful weekend. The importance of building trust in the initiative (and research in general) was emphasized. The group talked about different ways to promote iConquerMS, for example, by connecting with other MS organizations, through social media, and asking current members to spread the word about the initiative.

To boost enrollment, participants in this year's Summit thought it would be helpful to make iConquerMS more personal and welcoming. Creating "advocate pods" is one possible way to do this. iConquerMS is very large network that may seem overwhelming to some. Creating smaller communities, each with its own advocate, would allow members to work in smaller groups. Pod advocates could follow up with individuals that fall silent to see how they are doing and if they need any assistance. These micro-communities would create an increased sense of fellowship, engender greater trust in the initiative and enable more consistent data collection. Another suggestion was to focus on accessible topics, such as lifestyle habits, as a gateway or entry point into iConquerMS.



Easy, relevant topics like this could engage people and they would have the opportunity to participate in more complicated or technical studies down the line. The group also explored alternate ways of collecting data (for example, using [wearables](#)) to make participation easier.

Summit attendees discussed the importance of expanding research recruitment efforts to low-income populations. One idea was to furnish the tools necessary for participation, such as cell phones (or other devices) and internet access, to those that need them. The end result would be increased access to PPR opportunities (like iConquerMS), other MS resources and better overall healthcare. An offshoot of this conversation focused on creating training programs for those that are not familiar with devices. The group proposed reaching out to existing programs that provide this type of assistance for guidance and seeking funding for this effort from our MS coalition partners, telecommunication companies and government agencies.



Conveying information to research participants and collecting their feedback are two important aspects of PPR. Summit attendees agreed that a participant newsletter would be an excellent means to accomplish both of these goals. The consensus was that the ideal format would be a single page that could be sent by mail or electronically on a cadence that makes sense for a given study. It should be educational (including hyperlinks for language that people might not understand) and visually pleasing. Including such a publication in research budgets and protocols would pave the way for its distribution.

The iConquerMS community has made many studies possible over the years. Making research results available and understandable has been a continuing thread at past Leadership Summits. Our new [Research Projects](#) page is a wonderful byproduct of last year's meeting. It is a convenient place to track the status of studies and review their findings. The general consensus this year was that not enough people know about this wonderful resource and all agreed to help spread the word about it within their networks. With regard to the dissemination of research results in general, attendees agreed that getting funders to approve related costs as part of a PPR budget would help ensure that dissemination protocols are in place.



One [breakout session](#) at this year's Summit focused on transforming healthcare and medical research to be more holistic. Participants talked about [social determinants of health](#) and the importance of fresh air, green spaces, the availability of healthy food. With regard to research, the consensus was that we need to work together with other disease groups and focus more on the prevention of disease. A proposed way to advocate for this change was to be more present at scientific meetings, challenge the status quo and speak up on behalf of those living with chronic illness.

The iConquerMS Leadership Summit is a celebration of the work being done through the initiative in partnership with its stakeholders. Participants strengthen relationships with each other and it is through these connections that good ideas and solutions emerge. The theme of this year's meeting was deepening our impact so that PPR becomes the rule and not the exception. The Next Steps Committee is energized to take the baton and move the work of the Summit and iConquerMS forward. We look forward to an exciting and productive New Year! Stay tuned!

