



iConquerMS™ — Unique Force in the World of Research

On a recent not-so-warm spring day in Washington, DC, the Patient-Centered Outcomes Research Institute (PCORI) that funds iConquerMS™ and 19 other patient-powered research networks, convened an unusual conference. The topic was not about the goals of research or research milestones or research protocols...or any of the usual topics. It was about the **Trustworthiness** of the research enterprise as we practice it.

As such, the conference was a moment for serious reflection and self-examination of how those who want to study a disease can and should interact with individuals who live with that disease. While there has been considerable evaluation of different groups and their levels of trust in clinical research, the conference called participants to turn this evaluation inward to ask how the research community can best *earn* this trust. What is the social contract that enables researchers to make their discoveries while at the same time ensuring that they are respectful of those whose lives are so deeply affected by the disease and who may be making considerable sacrifices to participate in research?

There were many expert speakers – both researchers and those who live with disease. Case studies were presented about research projects that have developed a warm and abiding handshake with the disease community; as well as studies where trust has not been earned. Many views were represented; and several themes emerged suggesting that iConquerMS™ is on the right track. Yet, as trustworthiness is a continuously-earned trait, we constantly look for ways to do even *better* in future:

- **Listening.** A consistent theme is that often researchers are focused on their planned study, and do not consider the wishes or preferences of *those who are being studied*. A trusting relationship requires listening, and at iConquerMS™ we intend to continue our surveys and other vehicles, such as research studios, where those living with the disease can express their ideas and provide input.
- **Being respectful of privacy of data and research output.** What may appear to be merely data points to researchers may in fact represent significant and sensitive information to those living with a disease, and privacy can therefore be paramount both for protecting a person's dignity and ensuring their rights. Moreover, usage of information and biosamples should never be taken for granted; wherever possible, any new use of such resources should be respectfully requested from the person living with a disease. Beyond the dry language of a consent form, authentic and personal communication is key if trustworthiness is to be achieved.
- **Keeping participants informed and involved.** Too often, the end of a research study can be the end of any role for those who participate as research subjects. But after a study is completed, the outcomes analyzed, and the scientific papers published, those with the disease remain curious and tied to the clinical questions. The responsibility for sustaining the bridge between researchers and those with a disease is ongoing – not a one-time event, but a process.

iConquerMS™ aspires to be a trustworthy research initiative. In that light, we have consistently sought to listen to those with the disease – not only those in our leadership group, but everyone who gives us feedback at the portal and in surveys and in live meetings. We attempt to nurture a culture of listening.

As described in detail at the www.iconquerms.org portal, we also make strenuous efforts to keep all data well protected. We take that responsibility very seriously, and attempt to be diligent stewards of the data so that it can yield the fruits of discovery that its donors intend.

And, we try to feed back to participants 'all the news that's fit to print'. Through this newsletter, and email updates, and features at the portal, we strive to let all iConquerMS™ stakeholders know what we are doing, why, and with what result.

If you have ideas about trustworthiness in research, please let us know. If you write to (info@iconquerms.org), we commit to give thoughtful consideration to all input.

In the next issue of this newsletter, we look forward to updating you on plans for the iConquerMS™ Longitudinal study.

Best wishes,



Robert McBurney, Ph.D.

Principal Investigator, MS Patient-Powered Research Network
President and CEO, Accelerated Cure Project for MS

Add to our Numbers!

In honor of World MS Day on May 25, we have set a goal of 3500 iConquerMS™ registrants.

By sharing your health data and ideas, you can help researchers better understand MS, develop better treatments, and ultimately cure MS.

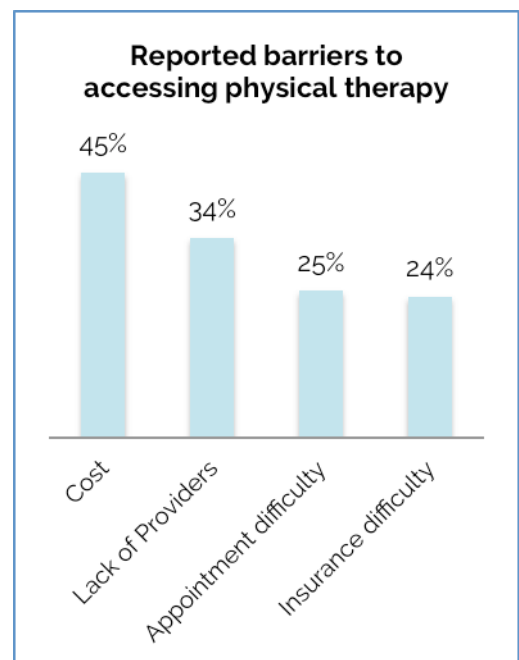
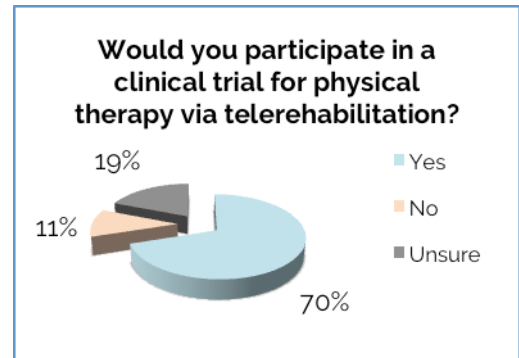
Join Now at <https://www.iconquerms.org/join>

Already a member? Help grow the iConquerMS™ community by sharing this newsletter with friends with MS, self-help group members, and your health providers!

iConquerMS™ Survey Results Help Shape Telerehabilitation Studies

Research *by and about people living with MS* is the trademark of iConquerMS™. So when two researchers—from the Veterans Administration MS Centers of Excellence and the Shepherd Center—proposed research studies last year comparing clinic-based physical therapy with physical therapy performed at home with online interactive video guidance, we went to iConquerMS™ participants to ask for input! Almost 450 people responded, with some expected and unexpected results:

- A majority (70%) said they would be willing to participate in a clinical trial using interactive video to receive physical therapy rehabilitation in their home or other non-clinic location.
- Technology clearly wasn't an issue: 90% said they had access to a computer, tablet, or cell phone that could support two-way audio and video communication.
- 80% of respondents reported having used physical therapy in the past, but many people also described the barriers to obtaining therapy at some time. These issues included cost, lack of local providers, difficulty getting an appointment, and insurance difficulties.
- While some respondents expressed concerns about an approach that did not involve direct or physical contact, others saw benefit for those whose circumstances limited traditional in-clinic therapy.



Based on this input, there is clearly value in learning from a study about the relative effectiveness of in-clinic vs. online rehabilitation programs. Both research proposals are under review for funding. ❖

"...we desperately need research on treating, modifying and perhaps one day curing MS. And the studies need to be patient centered to develop options that fit a patient's illness, circumstances, and wishes."

Philip Posner, Ph.D.
Blog March 7, 2016
Member, Advisory Panel on Patient Engagement,
Patient Centered Outcomes Research Institute (PCORI)

It's All About Us: the Need for Patient-Centricity

We at iConquerMS™ agree, Dr. Posner!

Dr. Posner, a neuroscientist who has lived with MS for 3+ decades, and now serves on both the iConquerMS™ Research Committee and the PCORI Advisory Panel on Patient Engagement, recently blogged about the need for patient engagement in research. (To read the full text of Dr. Posner's blog, see <http://www.pcori.org/blog/multifaceted-disease-requires-patient-centered-response>)

He describes iConquerMS™ as a place where those with MS can provide their health information into a data repository and then have the network collaborate with researchers to perform patient-centered studies.

iConquerMS™ is at the vanguard of a new patient-centric research model where those with the disease participate throughout the research process, as illustrated below – and the more who join, the more effective research can be! ❖



While this model is still very new, it is increasingly driving the national discussion about the kind of shifts that are needed to keep biomedicine as a force for innovation and improved health.

Please visit www.iconquerMS.org to learn more, or just take the plunge and register at <https://www.iconquerms.org/join>

Second Annual iConquerMS™ Leadership Summit Draws Dedicated MS'ers to Boston from all Corners of the Country

A national initiative intended to revolutionize biomedical research isn't easy to design or implement – it takes hard work for planning and execution, and the involvement of many dedicated people who are willing to work hand in hand with the kind of persistence that adds up to success.

iConquerMS™ has a forceful cadre of such individuals – many living with MS and still more who care about changing the landscape of the disease – who serve on its Governance Board, committees and as part of the larger community of supporters.

At the 2nd annual iConquerMS™ Leadership Summit, hosted in Boston by the Accelerated Cure Project for MS on January 15-16, 2016, more than 40 individuals came together to focus on the building of online communities, and to draw lessons from model endeavors in other fields. Steve Kaufer, the CEO of the hugely successful Trip Advisor spoke of the 'secrets' of their success, including frequent communication with Advisors, ranking systems to recognize contributors at all levels, and expanding opportunities for community members to contribute. Kristin Masoud, Director, Client and Consumer Services, C Space Health described their 'rules of engagement' such as creating an environment that fosters creativity, participation, and a sense of community and echoing the need for frequent and bidirectional communication with members.

The iConquerMS™ corps then did its own brainstorming of ideas to recruit participants and keep them engaged in MS research, and these prioritized ideas will be cascading out into the online community throughout the year. ❖

"I feel like when you are diagnosed with a chronic disease, you want to feel as if you have some control over it...and I think iConquerMS™ gives everybody the ability to feel some some control...that they are doing something that is making a difference to how quickly we'll find a cure."

Summit participant

"When I first heard iConquerMS™, I was right there ...automatically drawn to it. And I want to be part of the solution vs. being part of the problem."

Summit participant

Added bonus: iConquerMS™ member and talented videographer Alan Weinberg produced an on-site video at the Leadership Summit. Watch it here!
https://www.youtube.com/watch?v=t_tHvOphHUA



iConquerMS™ by the Numbers

50 U.S. States with
iConquerMS™ registrants

53 COUNTRIES WITH iCONQUERMS™ REGISTRANTS

2900
Registered Participants

8 RESEARCH
PROJECT
APPLICATIONS

iConquerMS™ at the 2016 Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC)

iConquerMS™ is often featured at professional society conferences, where interest is growing about patient reported outcomes among the researchers and healthcare professionals focused on multiple sclerosis and other neurological diseases.

The Annual Meeting of the CMSC is the largest North American meeting on MS, with typically over 2000 delegates in attendance. This year, June 1-4 in National Harbor, Maryland, a poster entitled "***Development and Use of the iConquerMS™ Research Network for Patient-Centered Research***" will be presented.