Harnessing the Power of the Patient Perspective

There is a growing recognition of the importance of incorporating the patient perspective into clinical decision making and research. People living with conditions like MS are often faced with treatment choices in the course of their disease. They are the experts on what it’s like to live with chronic illness and the impact of treatments on their quality of life. The patient’s point of view can be used to deepen the understanding of living with such conditions. It can also inform research priorities and mold decisions and policies that shape the way medical products are developed and brought to the marketplace. There is a movement underway in the pharmaceutical industry to include the patient perspective in every step of the research and development of new treatments. Improving patient engagement throughout the industry and incorporating the patient voice into the design of products and services has great potential to improve patient outcomes which will, in turn, benefit everyone.

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 “patient-powered” (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-powered research focuses on the things that matter to people with the condition under study, such as symptoms, how well they can carry out day to day activities, how their illness and treatment affects their overall quality of life and takes their individual preferences and needs into consideration. Going a step further, “participant-driven” research is 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. 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 as true partners in research has the potential to improve research, leading to better, safer treatments that target what patients really need and want. It is increasingly viewed as an essential component of developing sustainable, high quality and efficient care.

As discussed in our March 2018 newsletter, doctors rely on changes in health status (otherwise known as health outcomes) to determine a course of treatment. Health outcomes are classified according to the source from which they are collected. A physician reported outcome is one collected by a physician in the course of clinical care (for example, the physical exam, imaging scans or lab tests). A patient reported outcome (PRO) is one directly reported by the patient who experienced it. PROs are most often factors that are important to the patient,
such as symptoms, functioning and quality of life. Although physician reported outcomes are useful in assessing disease activity and severity, they do not help clinicians fully understand the true impact of illness on patients. PRO and physician reported outcomes measure different components of a patient’s well-being and should ideally be used together to assess a patient’s health status and to provide individualized treatment.

As part of the Patient Protection and Affordable Care Act of 2010, the U.S. Congress created the Patient-Centered Outcomes Research Institute (PCORI). This independent, non-profit organization was founded on the premise that patients, their families, and clinicians should have reliable information to decide which treatment or other care option is best for them. PCORI’s mission is to enable research that is informed by the people who are most affected by the results – patients, caregivers and others in the broader healthcare community. One of their primary goals is to increase the amount and quality of PRO data available to support healthcare decisions.

PCORI funded the development of PCORnet®, the National Patient-Centered Clinical Research Network, to make it easier and more efficient to conduct patient-centered research. By requiring that the health systems, clinicians, and patients who generate data be involved in all aspects of the governance and use of those data, PCORnet aims to facilitate the shift from researcher-driven to patient-centered research. iConquerMS was initially formed with funding from PCORI with the primary goal of improving the health, healthcare, and quality of life for people affected by 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.
iConquerMS is a people-powered research network developed to advance and accelerate people-powered research in MS. This initiative was co-designed with people affected by MS and all research done through the initiative is done in close collaboration with its members. Network members participate in many kinds of activities, such as participating in research, helping design studies and products, and making suggestions about future research they’d like to see performed. In addition, iConquerMS participants provide data about their first-hand experience living with MS by completing their REAL MS™ surveys and through other means. These data are made available to investigators, and also to help inform the healthcare decisions of others living with the disease. This collaboration between people affected by MS and the research community is part of an effort to transform MS research, improve the quality of care for MS patients and may one day play a significant role in finding a cure. iConquerMS leads the way in bringing the patient voice front and center in MS research.

The initiative has played a significant role in responding to the COVID-19 crisis and its impact on people with MS. As the pandemic unfolds across the globe, the demand for data on the impact of the virus on the MS community grows rapidly. This information is crucial for those living with the disease and their healthcare providers to make evidence-based decisions on how to manage their condition during the pandemic or in case of a COVID-19 infection. ACP joined an international data collection created by the MS Data Alliance and the MS International Federation. As part of this effort, a survey was launched on iConquerMS to learn more about how network members are dealing with the pandemic and what their personal experience has been with the new coronavirus. These data may help researchers gain insight into such important questions as whether or not the risk factors for COVID-19, or the proportions of severe coronavirus outcomes in people with MS differ from those seen in the general population. In addition, does the type of MS treatment an individual may be taking have an effect on COVID-19 outcome? This powerful international collaboration aims to act as a stimulus to steer ongoing and future scientific research.
The COVID-19 pandemic has caused many MS healthcare visits to be conducted over phone or video. ACP is working with researchers from the Veterans Administration to learn more about telehealth during this uncertain time. The iConquerMS community was surveyed just before the start of the pandemic and again more recently to determine how many people with MS had a telehealth visit in recent months and what they thought of their remote visit. Their responses will be used to advocate for healthcare options that are the most helpful for people with MS.

Each autumn, the iConquerMS governance and other stakeholders in the MS community gather at the initiative’s Leadership Summit to discuss the future direction of iConquerMS. iConquerMS has made significant progress in many areas of focus discussed at recent meetings. For example, to learn more about the unmet needs of caregivers, ACP partnered with a sister organization supporting families coping with Alzheimer’s disease on a survey about the challenges and concerns of providing care to a loved one with MS.

Network members who are caregivers and partners to those members living with MS, provided input on how caregiving affects their health and quality of life, as well as how they feel about interactions with healthcare providers. Data collected from the survey will be used to create educational materials for caregivers and healthcare providers alike. Ageism in MS research and care was another area of focus suggested at a previous Leadership Summit. Historically, MS clinical trials have had age restrictions that have limited the participation of people with MS over the age of 55 (resulting in missing important data). To fill in these gaps and to determine a pathway forward, network members of all ages have provided information about the care they receive and researchers have ready access to these data.

iConquerMS participants are able to suggest research topics or questions for future study. To shed light on the subject of MS, reproduction and parenthood, EMD Serono, in collaboration with ACP, recently released a 5-part educational podcast series, called “Uncovering Sex in MS: A Dialogue About Sex, Parenthood and Hormones.” A number of network members participated in this opportunity. The podcast series, hosted by Jon Strum of RealTalk MS, offers practical perspectives from clinicians on their experiences with female and male preconception
The iConquerMS network has also been instrumental in investigating alternative approaches to MS disease management. Research shows that exercise is good for people with MS and may decrease symptoms and improve health and walking ability. STEP for MS is a clinical study comparing the outcomes of a 16-week exercise program conducted at home to a program conducted in a gym. The iConquerMS portal is being used for data collection, and to communicate with participants. The researchers conducting the study hope that the findings will make exercise and its benefits more available to people with MS who have problems walking. Qigong is a Chinese exercise technique that involves controlled movements, breathing and meditation. Researchers at TheSwitchVR and Virginia Tech are developing a study to understand how people with MS think and feel about practicing Qigong using an online library of videos. Not only will input from the iConquerMS community play an instrumental role in improving and finalizing the study design, but researchers hope to use the iConquerMS portal for data collection and invite network members to participate in the study.

iConquerMS is working with Icometrix, a company that has developed software and services that help healthcare providers view, store, and analyze medical images. Network members have provided information regarding whether people with MS have access to their own MRI files and if they're interested in viewing, understanding, and/or sharing their MRIs. These data will be used to determine if it is feasible to conduct future research studies that involve MRIs.

ACP and iConquerMS are leaders in the growing patient-focused drug development (PFDD) movement. PFDD is a systematic approach to ensure that patients’ experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation. iConquerMS members have been invited to participate in several different focus groups and advisory boards organized by non-profit organizations and
pharmaceutical companies. These activities are aimed at better understanding what people with MS are looking for in terms of the benefits provided by future MS drugs, and obtaining their input on clinical trial design elements such as study activities and outcome measures. This type of input has great potential to influence the therapies that become available for people with MS in the future and the ways in which they are studied. At the end of 2019, EMD Serono initiated a clinical trial (**EVOLUTION RMS 1**) studying the efficacy and safety of evobrutinib. Prior to the initiation of the trial, ACP entered into a year-long partnership with EMD Serono to ensure the patients’ complete MS experience was captured and meaningfully incorporated into the design and implementation of this trial. As part of this collaboration, eight members of the iConquerMS community were invited to participate in a PFDD Council. The Council worked closely with the iConquerMS project team and team members from EMD Serono. The collaboration between iConquerMS and EMD Serono is the first of its kind in MS drug development research. Feedback from the Council has had a lasting effect in the whole spectrum of what is important in drug development throughout the industry.

iConquerMS has a number of ongoing initiatives which continue to advance patient-centered MS research. **REAL MS™ (Research Engagement About Life with MS)** is a longitudinal study of MS. Participants complete detailed questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. A ninth round of REAL MS surveys was recently released through the iConquerMS portal. The information collected through these surveys will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. In addition, ACP and the National MS Society are working in partnership on the Society’s [Pathways to Cures](#) research plan. Data collected from iConquerMS members is being used to inform Pathways to Cures activities by providing both quantitative and qualitative feedback from the iConquerMS community, representing the broad perspective of those affected by MS.
Looking to the future, iConquerMS will continue to focus on the needs and priorities of the MS community. The initiative’s diversity, equity and inclusion task force will continue to work to expand outreach channels to reach minority communities, as well as methods to evaluate the success of these efforts. For example, iConquerMS is conducting a special outreach to communities of color to tell them about the initiative and their ability to influence COVID-19 research in MS. iConquerMS also hopes to expand its scope to include pediatric participants. The initiative will continue to work to further PFDD and address the unmet needs of caregivers. Want to be a part of the movement to put patients at the center of MS research? If you haven’t already done so, please consider joining the iConquerMS community today and add your voice to the thousands already driving people-centered MS research forward!
EMD Serono, in collaboration with Accelerated Cure Project, has released a 5-part educational podcast series, hosted by Jon Strum, called “Uncovering Sex in MS: A Dialogue About Sex, Parenthood and Hormones.” The topics covered in the podcast series were developed based on input from the iConquerMS community—another example of how iConquerMS members are driving and shaping MS research and care!

Women are nearly 3 times more likely to develop MS than men. Because the majority of these women are diagnosed during their childbearing years, clinicians and patients are encouraged to incorporate family-planning discussions into their ongoing MS management conversations. Optimal patient care involves coordination among a woman’s neurologist, obstetrician/gynecologist, and primary care provider to ensure alignment on the woman’s individual family-planning choices and preferences.

Episode 1 features 3 unique perspectives on preconception planning for women with MS: Dr. Lori Travis, a neurologist who specializes in treating patients with MS; Dr. Erkan Buyuk, a reproductive endocrinologist, and Ms. Shannon Green, a pregnant woman living with MS.

Family planning is not just a concern for women with MS. Men with MS also need to be involved in these discussions. They have different concerns about fertility and pregnancy than women with MS. Thus, optimal MS care involves coordination and communication...
among a man’s neurologist and other care team members, such as reproductive endocrinologists and urologists.

**Episode 2** features 3 unique perspectives on preconception planning for men with MS: Dr. Lori Travis, a neurologist who specializes in treating patients with MS; Dr. David Ryley, a reproductive endocrinologist with experience in treating men with MS; and Mr. Josh Evitt, a male patient with MS who has experienced fertility concerns during the family-planning process.

For pregnant women with MS, preparing for the birth of a child can be a time of excitement and anxiety. Each woman should work closely with her neurologist and other care team members to determine how best to manage her MS in the postpartum period. In addition to postpartum disease management, postpartum depression should also be assessed, because although the data are limited, it appears that new mothers with MS may have an increased risk of postpartum depression.

**Episode 3** features 3 unique perspectives on postpartum planning for new mothers with MS: Ms. Melanie Huff, a nurse practitioner who specializes in MS; Dr. Adam Kaplin, a mental health specialist; and Lindsey, a mother with MS who has first-hand experience with the postpartum period.

Up to 90% of men with MS and up to 85% of women with MS will experience at least one form of sexual dysfunction, a higher prevalence than that of the general population. Whether the goal is to have biological children or a simple desire for intimacy and a healthy sex life, sexual dysfunction can take a toll on the physical and emotional aspects of a person’s quality of life.

**Episode 4** features 3 unique perspectives on how neurologists and patients can recognize and address concerns regarding sexual dysfunction: Dr. Barbara Green, a neurologist specializing in MS, and a male and female patient with MS; Brooke and Jim, both of whom have experienced sexual dysfunction.

Most patients with MS are diagnosed in early adulthood and live most of their lives with the disease. Various age-related changes can affect the disease course of MS over time. Sex hormones, including estradiol and testosterone, have been found to have neuroprotective
effects. These hormones often decrease in patients as they approach their 50s, potentially impacting the disease course in patients with MS.

*Episode 5* features 3 unique perspectives on the effects of sex-hormone changes and age-related hormonal changes on the MS disease course: Ms. Amy Perrin Ross, an advanced practice nurse specializing in MS; and 2 patients with MS, Mr. Dan Melfi and Ms. Kathey Carr, who discuss how these age-related hormonal changes have affected their disease and overall quality of life.

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**RESEARCH OPPORTUNITIES**

A research team based at Johns Hopkins University is looking to interview adults who have multiple sclerosis (MS), and who have experience with clinical trials as part of their treatment. The aim of this research is to improve the understanding of people’s experiences living with multiple sclerosis and their participation in clinical trials. The project's goal is to create a web-based resource to support and inform other people who have this condition and who are considering participating in a clinical trial as part of their treatment for multiple sclerosis, as well as their families, friends, health care professionals, and many other audiences. A module will be created on the Health Experiences USA website: [https://healthexperiencesusa.org/](https://healthexperiencesusa.org/). Participants will partake in an interview about their experience living with multiple sclerosis, diagnosis, treatment, and participation in MS clinical trials. Interviews will last approximately 2 hours, and you will be eligible for a $50 gift card.

You can participate in the study if you:

1) have been diagnosed with multiple sclerosis, and
2) were diagnosed at least 1 year ago, and
3) have completed, dropped out or declined to participate in a clinical trial, and
4) can comply with all study procedures and are available for the duration of the study.

If you are interested, please complete the study’s quick eligibility survey here: https://jhsph.co1.qualtrics.com/jfe/form/SV_6Vby6gNKY1gYVRH. If you are eligible for the study, a member of the research team will contact you to discuss the study and the possibility of your participation. You can also directly contact the study team via text or call (443) 863-9990, or email healthexperiences@jhu.edu, with any questions or concerns, and someone from the research team will contact you.

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**Call for Older Adults with Multiple Sclerosis**

Are you 60 years or older and living with MS? Are you interested in receiving the HALT MS Research Center Newsletters? Do you want to know more about our events, research activities and findings, or general information about healthy aging and MS?

If the answers to these questions are yes, researchers at the University of Alabama at Birmingham (UAB) invite you to take part in the HALT MS Registry.
What will you do?
You will be asked to register and provide your name and email address.

Why is this registry important?
During the HALT MS Research Center Symposium and Focus group, researchers at UAB learned that people with MS would like to have a channel for learning about our center activities such as new study findings, events, and general news of aging and MS, as examples. To that end, one purpose of this project is to establish a registry as an information dissemination mechanism for the HALT MS Research Center.

What’s in it for me?
You will be helping us to build the registry that will be used to help researchers at UAB to communicate our research activities, events, and findings about aging and MS.

Will I be compensated for my time?
No, there will be no compensation for registration.

If you are interested in participating in this registry, please click the link below or e-mail Trinh Huynh at enrl@uabmc.edu. 
https://uab.co1.qualtrics.com/jfe/form/SV_3RcRnwQVX6iptU9

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Interviews with People Taking Vumerity®: Understanding Your Treatment Experience

Researchers are seeking 20 people in the U.S. with relapsing forms of Multiple Sclerosis including clinically isolated syndrome (CIS), relapsing-remitting multiple sclerosis (RRMS), and active secondary progressive disease (SPMS) to participate in a 1-hour telephone/online interview. The purpose of the interview is to gain insights
from people about their experience when taking Vumerity® treatment. The results from this research will be used to gain a better understanding of patients’ experiences with Vumerity® and inform how to better support current and future MS patients

Participants must have taken Vumerity® for at least 5 weeks within the past 6 months; participants may currently be taking Vumerity® or may have discontinued Vumerity® within the past 6 months.

If you are interested and meet these criteria, please submit your information here:

https://www.research.net/r/InterviewOp_AcelCure
(Copy this link into your browser if the link does not work)

All participants who complete the 1-hour interview will be compensated.
Participation is strictly voluntary, and your responses will remain anonymous.

Endeavour provides research opportunities to patients, caregivers, and healthcare providers, helping organizations who research and develop therapies. By participating in research, your experiences, perspectives, and opinions help researchers better understand diseases and treatment effects from your point of view. For information about our privacy policy, visit http://endeavour-clinical.com/privacy/. For questions regarding this opportunity, email research@endeavour-clinical.com.
In the summer of 2016, the iConquerMS initiative launched REAL MS, a longitudinal study of MS. REAL MS participants complete questionnaires online twice each year on a variety of subjects, including health history, diet, exercise and their experience with MS. A ninth round of REAL MS surveys are now available through the iConquerMS portal. Completing these surveys is one of the simplest ways you can accelerate MS research. The information collected will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. If you are not already a member, please consider joining iConquerMS, the only people-powered research network for MS. Already a member? Please log in to your account and complete your open surveys!
New Year, New You

**Study Title:** Step for MS (Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis)

**Study Purpose:**
New research shows that exercise is good for people with MS and may decrease symptoms and improve health and walking ability. An exercise study called *STEP for MS* will compare the outcomes of a 16-week exercise program conducted at home to a program conducted in a gym. The researchers conducting the study hope that the findings will make exercise and its benefits more available to people with MS who have problems walking.

**This Study Involves:**
Participants will exercise two times per week for about one hour each session for 16 weeks. A trained “coach” will help participants learn how to exercise and will provide encouragement throughout the program. Participants will take assessments before starting the program, two months into the program, at 16 weeks when the program ends, and at 6 and 12 months after starting the program.

**Eligibility:**
If you are between the ages of 18 and 65 years and you have Multiple Sclerosis you may qualify if you:

- Can walk but you have some difficulty, with or without a device
- Do not exercise regularly
- Have not had a relapse in the past month
- Can commit to train 2 times a week for 16 weeks
- Can drive to study site for assessments and potentially for exercise training
- Have reliable internet access
Participating Locations:

- Massachusetts General Hospital, Boston, MA (new site now open!)
  **Contact:** Dr. Plumer 617-724-3103/ PPlummer@MGHINP.EDU
- Shepherd Center, Atlanta, GA
  **Contact:** Erica Sutton at 404-367-1305
- Cleveland Clinic, Mellen Center, Cleveland, OH
  **Contact:** Darlene Stough at 216-445-5877/ stoughdl@ccf.org
- University of Colorado, Denver
  **Contact:** Alexa Vareldzis: neurologyresearchpartners@cuanschutz.edu / 303-724-4644
- University of Alabama, Birmingham
  **Contact:** Petra Silic at 205-975-1306/ petra09@uab.edu
- University of Georgia, Athens
  **Contact:** Megan Ware at 423-260-5045/ megan.ware20@uga.edu
- Marquette University, Milwaukee, WI
  **Contact:** Heidi Feuling at 414-288-6209/ Heidi.feuling@marquette.edu
- University of North Carolina, Chapel Hill
  **Contact:** Rachel Keen at 704-877-5636/ rayray@live.unc.edu

For more information, please visit our website: [https://www.iconquerms.org/welcome-step-ms](https://www.iconquerms.org/welcome-step-ms)
Share your experience with COVID-19

As a supporter of Accelerated Cure Project, you know one way to deal with the uncertainty of MS is to act – to be proactively involved in research and to contribute your insights, expertise, and information so that key questions about MS may be answered.

The COVID-19 crisis has added an additional level of complexity and urgency for those affected by MS.

In response, we have launched a survey on iConquerMS to learn more about how people affected by MS are dealing with the COVID-19 pandemic and what their personal experience has been with COVID-19.

We are interested in responses from all – those with and without MS, whether or not you have been diagnosed with COVID-19 – and hope the information gathered through this survey will help people affected by MS and their doctors during the current pandemic and in the case of future viral outbreaks.

Participating in the COVID-19 in MS study is easy. If you are not already a member, please consider joining iConquerMS. Your voice matters! Already a member? Please login to your account and complete your COVID-19 survey. Thank you for your participation!