



vice versa. Verification of findings plays a key role in scientific research. Replication of data by different researchers may also confirm the validity of a conclusion.

[EMD Serono](#) researchers strive to improve the lives of people living with MS by offering better therapies and support services, made possible by cutting edge research. Until now, input from people living with MS hasn't been considered in the drug development process throughout the industry, leaving many important questions



unanswered (for example, what symptoms and quality of life improvements matter most, or what therapeutic benefit/risk tradeoffs would people with MS be willing to make). The U.S. Food and Drug Administration (FDA) recently released guidance related to Patient-Focused Drug Development (PFDD) that defines PFDD as a systematic approach to ensure that patients' experiences, perspectives, needs and priorities are captured and meaningfully incorporated into drug development and evaluation. ACP and EMD Serono have entered into a groundbreaking collaboration that is well aligned with this guidance. This partnership will ensure patients' complete walk with MS is captured and meaningfully incorporated into the drug development process. As part of this program, members of the iConquerMS community will be invited to participate in a PFDD Council. The Council will work closely with the iConquerMS project team and team members from EMD Serono to undertake truly patient-focused drug development. The iConquerMS patient portal will be used to gather new PRO data and iConquerMS participants will provide input across all stages of the study through workshops, document reviews, focus groups and surveys. The collaboration between iConquerMS and EMD Serono, the first of its kind in MS research, is an important opportunity for the collective voices and insights of people with MS to be heard and to drive real progress in research, drug development, and ultimately in the fight against MS. According to Robert McBurney, CEO of ACP, this partnership will "break silos and advance the engagement of patients across the entirety of the clinical research process."

ACP is working with individuals and organizations worldwide to facilitate MS research toward better diagnoses, treatments and a cure for MS. One such organization is the [Italian MS Society](#). There are many treatment options for MS with varying levels of therapeutic benefit and risk. Unfortunately, there isn't enough information available regarding the effects of various treatments on the symptoms, disabilities and quality of life of people with MS. This makes it difficult for people with MS and their



physicians to make therapeutic choices. As discussed in our [March 2018 newsletter](#), a patient reported outcome (PRO) is one directly reported by the patient who experienced it. [iConquerMS](#) and the Italian MS Society are both focused on collecting PRO data for MS research and healthcare. As PROs are an emerging field in MS and of increasing interest to researchers, there are a very large number of surveys designed to collect this important information, with little standardization or harmonization. Researchers need to determine how these varied data can be translated and used to improve healthcare and quality of life for

people with MS. To address this issue, ACP and the Italian MS Society are working together to standardize and unify PRO measures across cultures. This collaboration aims to establish a system and

tools for the collection, presentation and interpretation of PRO data for use in research and in shared healthcare decision-making, allowing all stakeholders involved to speak the same language. The end result will bring outcomes that matter most to people affected by MS into every aspect of their care and in research to improve treatments worldwide.



As discussed in our [March 2018 newsletter](#), RealTalk MS is a successful podcast series (established by Jon Strum), which currently reaches an audience of over 3,400 listeners. Weekly episodes offer both information and inspiration to people affected by MS. With the joint goal of promoting and communicating research results and activities to the MS community, ACP and Jon Strum will work together to increase the reach and visibility of both RealTalk MS and iConquerMS. This partnership holds great promise for both programs. The increased visibility through Jon's podcasts has the potential to boost

iConquerMS enrollment, and enables more effective communication of iConquerMS research activities and results to the MS community. RealTalk MS will receive input on podcast topics of interest to people affected by MS, as well as connections to potential interviewees who are doing important and interesting work in MS. In addition, both teams will work together to seek funding to support these activities, which increases their sustainability.

Since its inception, collaboration has been central to ACP's mission. In COO, Sara Loud's words, "To me, the collaborative nature of our work is most exciting. Back when ACP started, it was rare to have researchers from different disciplines collaborate across their fields. A complex disease like MS is unlikely to be cured in a fragmented research environment. The ACP Repository is really such a brilliant (and definitely novel) approach to fostering collaboration by requiring researchers to return their research results back to us so that we can share them with other researchers. What started as a sort of virtual collaboration approach has morphed into a more outright collaborative approach as the research environment has changed for the better and as we work with more and more researchers. It's not uncommon for us to not only share one researcher's data with another but to connect them so they can explore working together. We've taken this collaboration a giant step further through iConquerMS by bringing the most important experts on MS, the people affected by the disease, front and center into research. The 'people-power' of iConquerMS means that people affected by the disease are driving, shaping, and contributing to MS research in brand new ways — ways that will ensure that research gets done on topics that matter most to them."

