

# October 2020 Newsletter



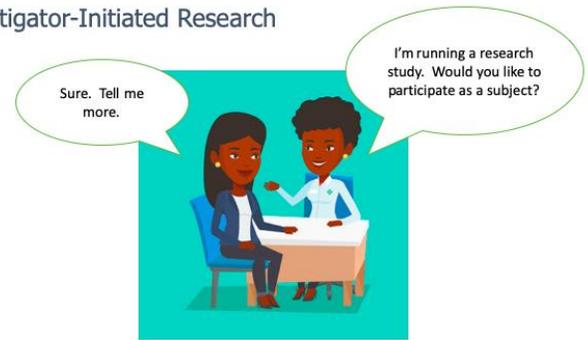
## Harnessing the Power of the Patient Perspective

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.

#### Investigator-Initiated Research



#### Participant-Powered Research (People-Powered Research)



#### Participant-Driven Research



## PROs

- ✓ Health-related quality of life (HRQOL)
- ✓ Symptoms
- ✓ Function
- ✓ Satisfaction with care or symptoms
- ✓ Adherence to prescribed medications or other therapy
- ✓ Perceived value of treatment

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.

