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Dr. Penny Smyth, Associate Professor, University of Alberta

Helping researchers achieve outcomes for MS patients

Many researchers who connect with the AbSPORU Consultation and Research Services Platform come from different disciplines and specialties. “Part of our role is to understand their needs and help them every step of the way through their patient-oriented research journey” said Dr. Yazid N. Al Hamarneh, Associate Director/Scientific Officer of the Consultation and Research Services (CRS) Platform. Dr. Penny Smyth, Associate Professor, Department of Neurology, University of Alberta, recently benefited from the platform’s expertise on her research project. “We helped her to design a randomized trial to assess the impact of a community-based nurse practitioner-led program on the quality of life in patients with multiple sclerosis,” said Dr. Al Hamarneh. The platform also provided assistance with budget development, obtaining the funding required to conduct the study, case report form development and database creation and management. “The experience of working with the CRS Platform to develop a multiple sclerosis (MS) clinical trial, come up with relevant outcome measures, and the practicalities of clinical trial logistics has been invaluable to a clinician such as myself,” said Dr. Smyth. “We will be starting trial recruitment in the upcoming months, and I am confident that we will meet our goals and provide valuable outcomes that are useful in the health care delivery to MS patients.” Learn more about the services available through the the [Consultation and Research Services Platform](#).

What is patient-oriented research?

Recently Sandra Zelinsky, Patient Partner and Dr. Maria Santana the Associate Director of the Alberta SPOR SUPPORT Unit [Methods Support & Development Platform](#) shared their thoughts on patient-oriented research through a [Tools for Better Health](#) podcast. Patient-oriented research refers to a continuum of research that engages patients as partners, focuses on patient-identified priorities, and aims to improve patient outcomes. For those researchers, who may not know the role and value patients bring to research, the [Alberta SPOR SUPPORT Unit](#) is a source of knowledge and expertise. “Patients with lived experience and expertise make a valuable contribution to the research

process”, says Zelinsky. “There may be times researchers are surprised by co-designing a research study with a patient partner that their priorities might shift after learning what the patient priorities are.” Patients can get involved in all aspects of the research process from design to knowledge translation. “There is no cookie cutter way of involving patients in research,” says Dr. Santana. “Building a partnership among patients, researchers, clinicians and all members of the team is what solidifies collaboration and makes a project relevant.” This directly ties into the Strategy for Patient Oriented Research (SPOR) of making the outcome of research projects more relevant to patients and communities with the objective of improving our health care system. If you’re a researcher or patient interested in learning more about patient-oriented research [learn more](#).