ABSTRACT

Background and Rationale: There has been an explosion of research related to Multiple Sclerosis (MS) with important scientific advances in all aspects of this chronic disease. New insights of the immuno-pathogenesis of MS and in measuring the central nervous system have provided ideas for novel therapeutic approaches. This has provided the patient with more choices along with the burden of making more difficult decisions. It is evident that there is a need for a systematic method not only to disseminate the wealth of knowledge available but also to put this knowledge in the hands of our patients and into actual use. Objectives: To develop a research informed outcomes manual for MS patients that provide information to patients on relevant outcomes, provides advice for self-assessment and monitoring, and provides recommendations to improve outcomes. Methods: Using Graham’s Knowledge-to-Action (KTA) process, for this proposal development phase we will first, create a knowledge tool and then tailor it specifically needs of MS patients: (1) Identify a problem that needs addressing: The problem is the lack of information on the life impact of people with the MS. As such, information for the manual will be created from relevant literature and the Gender and Life-Impact Study completed by Dr. Mayo and colleagues. This Gender study has identified several areas where MS has a strong impact. These areas are remedial with fairly simple interventions. (2) Identify, review, and select the knowledge or research relevant to the problem (e.g. practice guidelines or research findings): Some of the important areas identified are: exercise capacity, muscle strength, pain, fatigue, balance, walking capacity, spasticity, incontinence, exercise interventions, exercise barriers, illness intrusiveness. (3) Adapt the identified knowledge or research to the local context: We will interview key stakeholders in the MS community to identify if there are any local (Montreal or Quebec) issues to address other than preparing documents in both languages. (4) Assessing barriers: Our MS informants will help to identify barriers to dissemination and barriers to uptake of knowledge. (5) Select, tailor and implement interventions: Once we have the prototype for the Getting on with your Life with MS journal we will be better prepared to identify how best to intervene to improve health outcomes. Research Steps: This project will develop a manual for “Getting on with Your Life with MS”. There will be several main activities: (i) assembling the research material to be disseminated; (ii) create a user-friendly presentation for the material; (iii) assemble a group of people with MS to provide feedback on content and format; (iv) identify and get feedback from other key MS stakeholders such as people from the MS Society and from the MS clinic multidisciplinary team.