



In this issue of the *International Journal of MS Care*, we celebrate 25 years of data collection by the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry, the world's largest self-report registry for MS. The development and long-term success of the NARCOMS Registry reflect the vision, persistence, and support of Dr. Timothy Vollmer, the first director of the registry, and June Halper, chief executive officer of the Consortium of Multiple Sclerosis Centers (CMSC). The NARCOMS Registry is one of several registries worldwide that have contributed to our understanding of epidemiology and outcomes in MS, thus expanding our understanding of the disease experience. In the continuing education article herein, Marrie et al discuss the value of disease registries as well as conceptual issues related to registry design using NARCOMS as an example.

Three studies in this issue illustrate the potential applications of the registries to address issues that are topical and clinically relevant. The first study, by Salter et al, addressed the longer-term effects of dimethyl fumarate on disability and employment outcomes in the real world, complementing short-term clinical trials that typically assess outcomes for only 2 to 3 years. In the second study, Salter et al found that one in three NARCOMS participants had tried cannabis to manage their symptoms of MS, and one in five participants reported ongoing use to address spasticity, pain, and sleep disturbance. These findings point to the limitations of existing approved therapies for managing these symptoms, including small number of choices, costs, and adverse effects, and the need for more information about the long-term safety of chronic cannabis use. Finally, Miller et al surveyed participants in two registries, the NARCOMS Registry and iConquerMS, and participants in the National Multiple Sclerosis Society Minority Advisory Council regarding their insurance coverage.

## Happy Anniversary: NARCOMS

Just over 25 years ago, the Consortium of Multiple Sclerosis Centers (CMSC) organized a unique meeting, "What Do We Know About MS Care?," that examined the roots of the organization with the goal of developing long-term strategies for its committees, special interest groups, and task forces. This unique gathering yielded three outcomes: a research agenda for the CMSC, which subsequently generated several useful clinical practice guidelines; a project comparing the comprehensive care model to current models of care; and a patient registry that might provide answers to questions of therapeutic importance, particularly disease modification. Named NARCOMS, this registry's mission would be to develop a better understanding of the MS disease course and the effects of interventions with a longitudinal design. Dr. Timothy Vollmer was selected to head a

steering committee to move NARCOMS forward. The rest is history.

Although most participants had health insurance, uptake of disability insurance and long-term care insurance was low. Rammohan et al highlight one of the most recently developed North American MS registries, the North American Registry for Care and Research in Multiple Sclerosis (NARCRMS). This clinician-driven registry is another effort of the CMSC, supported by the pharmaceutical industry, aimed at better understanding the evolution of MS and the factors that contribute to disease progression. As more registries emerge in North America and worldwide, it becomes increasingly important to ensure that investigators are aware of these efforts, and understand their strengths and limitations. Furthermore, investigators seeking to work with registries need to understand what information is being collected to determine which registries might meet their needs. Geys et al discuss meta-data catalogues and their role in enhancing the awareness or findability of registries and other observational studies, and the characterization of the data collected by these studies.

Registries have the potential to study outcomes and multiple other facets of the MS experience. However, these registries cannot be created or sustained without the participation of people living with MS, clinicians, and funders with the vision to support these efforts long term.

—Ruth Ann Marrie, MD, PhD  
*Guest Editor*

Departments of Internal Medicine and Community Health Sciences  
Max Rady College of Medicine, Rady Faculty of Health Sciences  
University of Manitoba  
Winnipeg, Manitoba, Canada

—Amber Salter, PhD  
*Guest Editor*

Department of Neurology  
Section on Statistical Planning and Analysis  
UT Southwestern Medical Center  
Dallas, Texas

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Since its inception, NARCOMS has been a valuable resource for research by students, academicians, clinicians, and patients. It has generated information about comorbidities related to MS and has inspired the adoption of many wellness measures. Data regarding smoking, obesity, and employment have resulted in changes in the clinical practice of professionals and lifestyle changes in those affected by MS. NARCOMS has become nationally and internationally known for its contribution to knowledge, research, and clinical care in MS. It has set an example for numerous other registries and is a source of pride for the leadership of the CMSC and its members. Happy anniversary, NARCOMS!

—June Halper, MSN, APN-C, MSCN, FAAN  
*CEO, Consortium of Multiple Sclerosis Centers*