

Background

NARCOMS, a project of the CMSC, was started in 1993 as a long-term self-report registry of persons with MS. Enrollment began in 1996, with longitudinal follow up beginning in 2000. There are over 37,000 participants enrolled in NARCOMS with follow-up information provided by over 25,000 persons with MS.

Since 1997, researchers have utilized data collected through NARCOMS in over 200 presentations, papers and magazines:

- First Abstract: 1997
- First Manuscript: 1999
- First Platform Presentation: 2003
- First Issue of the *Multiple Sclerosis Quarterly Report (MSQR)*: 2009
- First Issue of *NARCOMS Now*: Spring 2012

Sharing NARCOMS data and results with the scientific community via a wide range of journals and conferences is an important way to spread knowledge and insight gained from analyzing Registry data and to inspire further studies in MS. Disseminating NARCOMS results also helps practitioners get the latest information as quickly as possible, while providing a reliable source of information for health care policy and advocacy initiatives.

NARCOMS Research

Prospective researchers work with the NARCOMS Executive Committee and research team to plan potential projects. Projects may involve data collection that would:

- use existing NARCOMS data
- gather new data via a regular NARCOMS semi-annual update
- create a survey designed with input from the Executive Committee
- have NARCOMS contact participants for external studies

Study designs may be cross-sectional or longitudinal, retrospective or prospective. Studies may aim to gather data from all NARCOMS participants or from a targeted subgroup, depending upon the specific project. The NARCOMS research team will work with you to design your research proposal to get the most out of the information collected via NARCOMS participants. All projects require applicable IRB approval.

Interested?

please visit

www.narcoms.org/researchers

www.narcoms.org

Abstracts & Conferences

Since 1997, 138 abstracts utilizing NARCOMS have been accepted for poster, platform, workshop, or short course presentations (Figure 1).

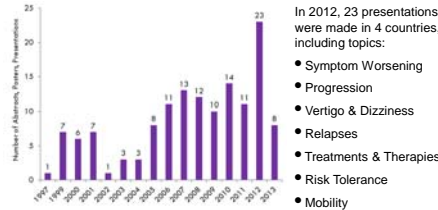


Figure 1. NARCOMS presentations by year

In 2012, 23 presentations were made in 4 countries, including topics:

- Symptom Worsening
- Progression
- Vertigo & Dizziness
- Relapses
- Treatments & Therapies
- Risk Tolerance
- Mobility

NARCOMS research has been presented at 12 unique conferences in the US and internationally (Figure 2 & 3). Most recently there were 9 presentations in Europe at the ECTRIMS & ENS meetings covering research on:

- Navigating Treatment Options: Effectiveness, Switching & Risk Tolerance
- Symptom Changes & Predicting Relapse
- Cognitive Reserve & Disability Progression
- Marriage Stability in MS
- Patient Determined MS Severity Scale

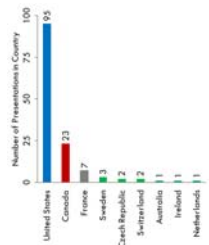


Figure 2. NARCOMS presentations by Country

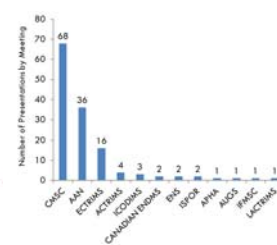


Figure 3. NARCOMS presentations by Conference

Publications

Since 1999, 65 manuscripts have been published with an average of 5 annually (Figure 4). There has been an increase in the number of publications since 2008 coinciding with increased longitudinal follow up.

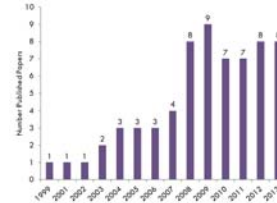


Figure 4. NARCOMS publications by year

The manuscripts have been published in 26 different journals with multiple publications in numerous neurology and MS specific journals:

- *Acta Neurologica Scandinavica* (2)
- *Quality of Life Research* (4)
- *Neuroepidemiology* (2)
- *Neurology* (8)
- *Disability & Rehabilitation* (3)
- *IJMSC* (9)
- *J of Neuroscience Nursing* (3)
- *Multiple Sclerosis J* (14)
- *Multiple Sclerosis & Related Disorders* (4)

In addition, the results have focused on many areas important to MS research (Figure 5).

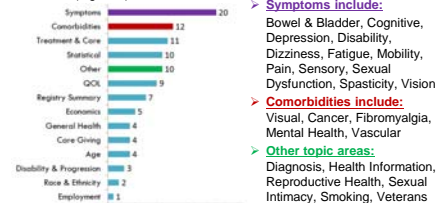


Figure 5. NARCOMS publications by primary topic

- **Symptoms include:** Bowel & Bladder, Cognitive, Depression, Disability, Dizziness, Fatigue, Mobility, Pain, Sensory, Sexual Dysfunction, Spasticity, Vision
- **Comorbidities include:** Visual, Cancer, Fibromyalgia, Mental Health, Vascular
- **Other topic areas:** Diagnosis, Health Information, Reproductive Health, Sexual Intimacy, Smoking, Veterans

NARCOMS Now

NARCOMS participants receive the free quarterly *NARCOMS Now* magazine as a part of their participation in NARCOMS. Also, *NARCOMS Now* is distributed to all participating CMSC centers. *NARCOMS Now* was first published in Spring 2012 and every issue contains NARCOMS research results & news, global MS news, interviews with MS clinicians and researchers, MS feature stories, and a NARCOMS participant story of living with MS in "Faces of NARCOMS".



- Recent articles contributed by MS researchers:
- MS & Pelvic Floor Disorders (Sangeeta Mahajan, MD)
 - Progressive MS: *The Next Frontier* (Robert Fox, MD)
 - Tremor in MS as Measured Using the NARCOMS Tremor & Coordination Scale (Ruth Ann Marrie, MD)

Including interviews with:

- Why MRI? An interview with Jerry Wolinsky, MD
- A Conversation with June Halper from CMSC
- The "Amazing Race" to End MS. A Conversation with Phil Keoghan, host of The Amazing Race



Summary

With over 37,000 participants enrolled and 10,000+ active annually, NARCOMS is a valuable resource for researchers interested in expediting MS research through observational self-report data. In addition, NARCOMS can be utilized for targeted recruitment for external research projects. NARCOMS has collaborated with students, young investigators, clinical researchers, and industry. Research efforts involving NARCOMS have resulted in 185 presentations and publications in 16 years of active research.

Contact Information

Registry Website: www.NARCOMS.org
 Magazine: www.NARCOMS.org/NARCOMSNow
 Telephone: 1-800-253-7884 (toll free US)
 Email: MSRegistry@narcoms.org
 For Researchers: www.narcoms.org/researchers

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