

NARCOMS History

NARCOMS, a project of the CMSC, was started in 1993 with a goal of becoming a global, longitudinal, self-report registry of persons with MS. Enrollment began in 1996, with longitudinal follow up beginning in 2000:

- 1986: 1st CMSC organizational Meeting (www.ms-care.org)
- 1987: 1st Annual CMSC Meeting in Minneapolis, MN
- 1992: June Halper named Executive Director, CMSC
- 1993: NARCOMS is founded
- 1996: NARCOMS begins enrollment
- 2000: NARCOMS begins update surveys for longitudinal follow-up
- 2013: NARCOMS celebrates 20th Anniversary!

There are over 37,000 participants enrolled in NARCOMS with follow up information provided by over 25,000 persons with MS. 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 Participants

At time of enrollment and update surveys, participants voluntarily provide information via an online (70%) or paper survey (30%) on:

- **Common socio-demographic information:** age, sex, race, height, weight, place of birth, locations of residence, employment status, family status
- **Lifestyle:** smoking and alcohol use, exercise frequency
- **MS Disease History & Current MS Status**
- **MS Treatment History:** DMTs and symptomatic therapies
- **Relapse History**
- **Comorbidities & Healthcare Utilization**

In addition, NARCOMS facilitates additional research initiatives through the update surveys, external surveys, and recruitment assistance for external studies. All persons with MS are invited to enroll and participation is free. All participants receive the quarterly magazine *NARCOMS Now*. All projects receive applicable IRB approval.

Interested?

please visit

www.narcoms.org/becomingaparticipant

Enrollment Summary

NARCOMS enrollment began in 1996, since then over 37,000 participants have completed the enrollment survey (Figure 1).

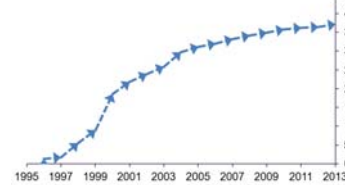


Figure 1. NARCOMS enrollment by year

NARCOMS is open to any person with MS, with 98% of participants residing in the US at the time of enrollment (Figure 2). Complete primarily in English, the surveys are also available in Spanish. At the time of enrollment participants report:

- 73.8% Female
- Median age:
 - 37 at MS diagnosis
 - 29 at MS symptoms
- Median time diagnosis to enrollment:
 - 6 years
 - Since 2004: 3 years
 - 20% within 1 year
- Median PDDS of 3 (Gait Disability)



Figure 2. NARCOMS in the US

NARCOMS, Race & Ethnicity: Participants self-report single or multiple race and ethnicity groups at enrollment with periodic updates to reflect changing and expanding racial and ethnic group definitions. As expected in an MS population, the most participants, 84.8%, self-report as single race White/Caucasian (Table 1).

Table 1. NARCOMS Race & Ethnicity

Racial, Ethnic Group	%	% of NARCOMS if Single or Multiple Designation				
		White / Caucasian	African American	Hispanic	Asian	Other
Single Only	82.5%	84.8%	4.0%	1.5%	0.7%	0.3%
Including Multiple	0.7%	88.3%	4.1%	2.0%	1.6%	0.5%

1. Participants include more than one race or ethnic group.
2. 2.3% indicated Other (Race or Ethnicity) (Please Specify) (not reported).

Update Summary

Since 2000, NARCOMS has included semi-annual update surveys for participants to report current and changes to their MS status, General Health, Healthcare Utilization & Lifestyle. Over 25,000 participants have provided at least 1 update survey (Figure 3). For those that have completed an update:

- Average time in NARCOMS is 6 years (1-17 years, Figure 4)
- 50% of follow up participants have 5 or more updates
- 5-years of NARCOMS follow up for over 11,000 participants
- 10-years for more than 7,000 participants

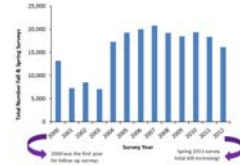


Figure 3. NARCOMS Update Surveys by Year

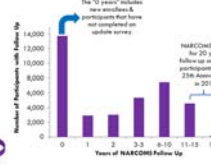


Figure 4. NARCOMS Follow Up Time (years)

NARCOMS & Disease Status: Since 2001, every update survey contains the PDDS & Performance Scales, excepting Bedridden (8), there are over 15,000 reports of every level of the PDDS (Figure 5).

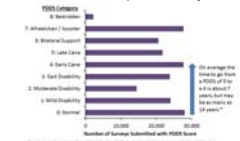


Figure 5. PDDS score distribution

The mean change in PDDS at 5-years is 0.5 points but the change depends upon the PDDS at enrollment (Figure 6).

Those starting at a 0 have a mean increase of 1 point. With 10 years of follow up, PDDS scores 0-6 increase 1 point at 10 years, except those starting at a 7 or 8 having no change overall.

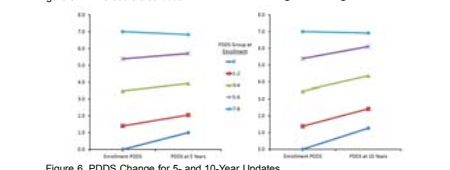


Figure 6. PDDS Change for 5- and 10-year Updates

NARCOMS & MS Therapies: NARCOMS enrollment and update surveys include questions regarding MS disease modifying therapies (DMTs), other treatments, and symptomatic therapies. Through 2010, more than 1,700 participants reported taking the same DMT (any IFN or GA) for at least 5 years. Over the same time period, over 4,300 participants reported changing, adding or discontinuing MS treatment.

Between 2004 and 2011, the section on immunotherapy was completed by 20,413 participants in at least 1 update.

Of these participants, 81.9% indicated having taken at least 1 therapy since their MS diagnosis. Of these participants, 60.4% indicating having taken at least 1 Interferon since their MS diagnosis (Figure 7).

NARCOMS & Comorbidities: Other medical conditions are collected at enrollment and annually in update surveys, including:

- weight & BMI
 - cancer
 - depression and anxiety
 - other immunologic related conditions such as RA and Lupus
 - cardiac diseases
 - kidney disease
- More specialized comorbidities research has been conducted: Marrie, et al reported that in Fall of 2006, 18.5% of NARCOMS participants reported ≥1 other autoimmune disease; most commonly thyroid disease. Smoking was associated with 23% increased risk in developing an autoimmune disease after MS diagnosis (*Neuroepidemiology*, 2009;32(1):72-79).

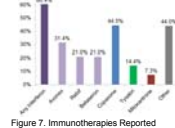


Figure 7. Immunotherapies Reported

Summary

NARCOMS is the largest patient-driven registry of MS, with extensive disease history and disability information. With longitudinal follow-up data collected since 2000, NARCOMS provides a unique resource for researchers on a broad cohort of persons living with MS. With over 37,000 participants enrolled and follow up on more than 25,000 participants, NARCOMS is a valuable resource for researchers interested in expediting MS research through observational self-report data.

Contact Information

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

For Participants: www.narcoms.org/becomingaparticipant