

Background

- In the absence of a mandatory national multiple sclerosis (MS) registry, MS research conducted in the US often relies on voluntary databases both for data access and study recruitment.
- Such databases, maintained either by commercial parties or non-profit organizations, have become increasingly common. Despite their redundancies, each database can offer unique insights to clinical disease course, treatment patterns and patient perspective.
- However, the magnitude and nature of the overlap ping participation in these databases are currently not known, which hinders prevalence estimates, recruitment efforts and potential collaborations.

Objective

To facilitate future collaboration in MS database research by analyzing and characterizing affiliation patterns among North American Research Committee on MS (NARCOMS) registry participants

Methods

- NARCOMS operates a large voluntary self-report registry for people diagnosed with MS. Participants are asked to complete a questionnaire at enrollment and semi-annually thereafter. The registry currently contains data submitted by over 37,000 people over a period of 25 years.
- In addition to the routinely asked disease, therapy and quality of life related questions, the spring 2012 NARCOMS update survey also inquired about other MS organizations with which the registry participants were affiliated at the time.
- We analyzed the responses together with previously collected background information using descriptive statistics.

TABLE 1 Demographic and Clinical Characteristics of the responders

	NARCOMS ONLY N=2250	1 or more affiliations N= 6705	ALL responders N=8955
Women	76.9 %	78.3 %	77.9 %
Men	23.1 %	21.7 %	22.1 %
Age in 2012 (mean, SD)	58.1 (10.0)	56.6 (10.5)	57.0 (10.4)
Took the survey online	75.0 %	69.0 %	69.9 %
	Median [IQR]	Median [IQR]	Median [IQR]
PDDS * (0 to 8)	3 [1, 6]	4 [1, 6]	4 [1, 6]
Visual dysfunction (0 to 5)	1 [0, 2]	1 [0, 2]	1 [0, 2]
Cognitive dysfunction (0 to 5)	1 [1, 2]	1 [1, 2]	1 [1, 2]
Depression (0 to 5)	1 [1, 2]	1 [0, 2]	1 [0, 2]

*Patient Determined Disease Steps (PDDS) disability levels: 0= normal 1= mild 2= moderate 3= gait disability
4=early cane 5= late cane 6= bilateral support 7= wheelchair/scooter 8= bedridden

Results

- 8955 registry participants responded to the survey question on MS organization affiliation. They were predominantly women (77.9%), had a mean (sd) age of 57.0 (10.4) years and median [IQR] PDDS* level 4 [1,6] (TABLE 1)
- 2250 responders (25.1%) reported no affiliation with any other MS organization while 38.7% reported only one, 21.0% two and 15% three or more affiliations (FIGURE 1)
- The largest reported overlap within NARCOMS was with the National MS Society (71%), followed by MS Association of America (20.5%), MS Foundation (17.2%) and United Spinal Association (11.6%) (FIGURE 2)
- Of the 550 NARCOMS responders from New York state, only 14.9% reported being in the New York State MS Consortium registry. Overall, the responders reported affiliations with over 60 different MS organizations or groups (FIGURE 2)
- As compared to the rest, the group of NARCOMS participants reporting no involvement in any other MS organization were older (58.1 [10.0] vs. 56.6 [10.5] yrs) but had a lower median [IQR] disability level (PDDS 3 [1,6] vs. 4 [1,6]). The group also had a higher proportion of men (23.1% vs. 21.7%) and online responders (75% vs. 69%) (TABLE 1)
- 71.3% of those with three or more affiliations took the survey online vs. 68.1% and 63.5% among those with 2 or 1 affiliation, respectively.

FIGURE 1

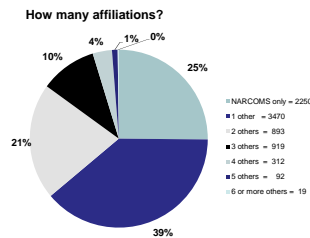
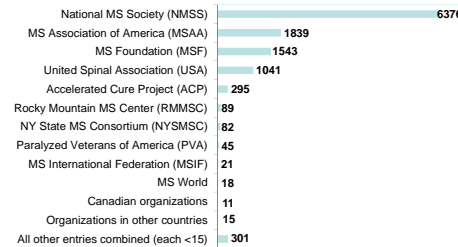


FIGURE 2 NARCOMS spring 2012 update survey responders affiliated with other MS organizations



Conclusions

- The NARCOMS Registry includes a sizable number of participants affiliated with several other MS organizations, providing intriguing opportunities for collaboration.
- Registry data submitted by the otherwise non-affiliated segment of NARCOMS participants can offer important insight to the experiences of individuals typically not reached.

Contact Information

Registry Website: www.NARCOMS.org
 Magazine: www.NARCOMS.org/NARCOMSNow
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