Multi-Registry Analysis of Patients with Multiple Sclerosis and Neuromyelitis Optica to Improve Capture of Demographic Data and Compare Visual Outcomes

Heather E. Moss, MD, PhD[1,2]; Lauren Wiener, MS[2]; Shrujal Baxi, MD, MPH[2]; Manan Kocher, Phd[2]; Aracelis Z. Torres, PhD, MPH[2]; Michael Mbagwu, MD[2]

[1]Departments of Ophthalmology, Neurology & Neurological Sciences, Stanford University, Palo Alto,, California, US; [2]Verana Health, San Francisco, California, US

Objective

To combine Axon de-identified data from the American Academy of Neurology Institute (AANI) Axon Registry® and American Academy of Ophthalmology IRIS® Registry (Intelligent Research in Sight) data to reduce missingness of demographic information and characterize visual outcomes in patients with Multiple Sclerosis (MS) and Neuromyelitis Optica (NMO).

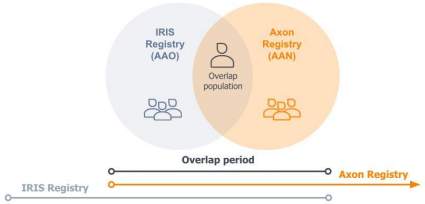
Background

Some data in the Axon Registry are incomplete (e.g., demographics) and some relevant outcomes are not systematically captured in neurology documentation (e.g., visual acuity [VA]). The IRIS Registry may complement Axon Registry-derived data to enhance understanding of real-world outcomes.

Design & Methods

In this cross-sectional study, participants were included if they had ≥3 ICD-9/10 codes for MS or NMO in the Axon Registry and overlapped temporally in both registries.

- Age, sex, race, ethnicity and US census region were extracted from both registries and classified as conflicting, missing, and not missing in the combined data set.
- VA data, obtained from the IRIS Registry at the start of the overlap period, were averaged between eyes and compared between MS and NMO participants



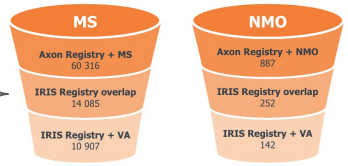
Results

Number of MS participants with missing data

N = 14,085	Axon Registry	IRIS Registry	Combined missing	Combined conflict
Age	0 (0%)	0 (0%)	0 (0%)	1 (0.007%)
Race*	2,005 (14.2%)	2,238 (15.9%)	477 (3.4%)	197 (1.4%)
Ethnicity*	3,876 (27.5%)	3,438 (24.4%)	1,112 (7.9%)	200 (1.4%)
Sex*	17 (0.1%)	45 (0.3%)	0 (0%)	30 (0.2%)
Location*	2,430 (17.3%)	2,415 (17.1%)	574 (4.1%)	117 (0.8%)

Reduction in missing data when registries are combined p<0.05.

Data Availability for Overlap Population



Among overlap participants 4 612 (33%) with MS and 52 (21%) with NMO had ≥ 3 ICD-9/10 codes for their condition in the IRIS® Registry.

VA was worse in patients with NMO (0.17 logMAR; 95% CI: 0.12, 0.21, p<0.0005, linear model with age, gender).

Visual Acuity (averaged between eyes), unadjusted comparison

	MS	NMO
VA available	10 920 (77%)	142 (61%)
VA (logMAR, mean, 95% CI)	0.097 (0.0, 0239)	0.176 (0.049, 0.398)

P < 0.0005 Mann Whitney

Conclusions

Using data from two registries reduced missing data for race, ethnicity and location and enabled examination of outcomes captured in the IRIS Registry (i.e., VA) for conditions that are diagnosed more frequently in the Axon Registry (i.e., MS and NMO), demonstrating the utility of a multi-registry analysis.

Neurology 2009, 73: 302-8; Ophthalmology, 2019: 126:44; Rudick et al, Arch Neurol, 1992; Salter, Multiple Sclerosis 2013:19:953; Talman, Ann Neurol, 2009; Gordon-Lipkin et al, 2007; Kenny et al, neurology 2022; Costello, JNNP 2015; Button et al, Neurology, 2017

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