BigMSData Network

NMOSD and MOGAD Data collection

The big Multiple Sclerosis data network

Background

Several registries participating in the Big MS Data Network collect longitudinal real-world data on NMOSD and MOGAD, encompassing demographic, clinical, radiological, laboratory, and treatment-related variables. Despite heterogeneity in registry design and data availability, the network offers a unique platform for collaborative research, enabling the generation of large-scale evidence on rare neuroimmunological disorders across different countries and healthcare settings. This is a unique opportunity to generate large-scale real-world evidence on rare demyelinating diseases through international collaboration. Join the Network!

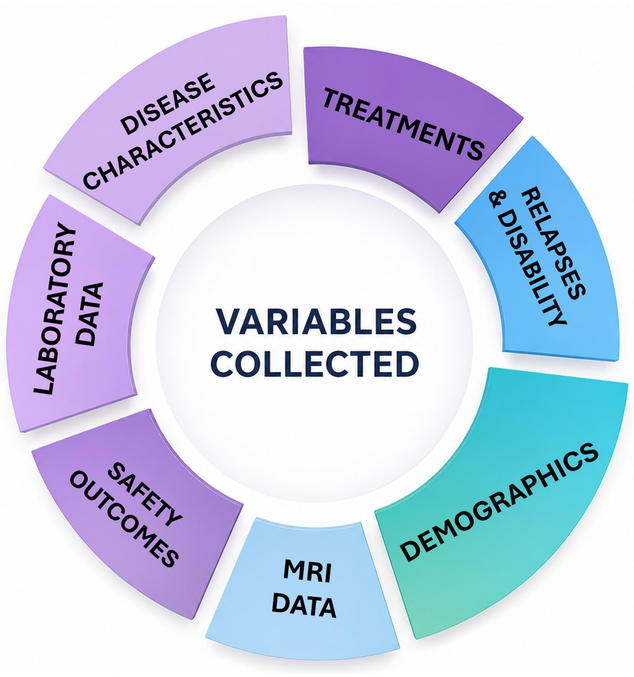
	NMOSD population	NMOSD AQP4+ population	MOGAD population
ReMuS	156	117	108
DMSR	96	63	115
OFSEP	1389*	921	1361*
RISM	765	500	376
SMSreg	95	65	113
MSBase	2541	995	513

*Estimated national coverage > 80%



NMOSD AQP+ population

	ReMuS	DMSR	OFSEP	RISM	SMSreg	MSBase
Sex F, n (%)	103 (88)	55 (87.3)	799 (86.8)	423 (84.6)	54 (83)	810 (81.4)
Age at onset, ys, mean (SD)	46 (16.3)	46.3 (18.7)	42 (17.2)	43.2 (15.5)	44.4	36.7 (14.9)
Age at diagnosis, ys, mean (SD)	43.1 (16.9)	49.1 (17.9)	46.6 (16.7)	47.2 (14.5)	47	37.3 (13.7)
Current age, ys, mean (SD)	59.4 (14.2)	57.9 (17)	52.7 (16.4)	56.1 (14.1)	55.7	45.3 (15.8)
Subjects in treatment with DMTs, n (%)	71 (60.7)	49 (77.8)	768 (83.4)	448 (89.6)	53 (82)	854 (85.8)



MOGAD population

	ReMuS	DMSR	OFSEP	RISM	SMSreg	MSBase
Sex F, n (%)	65 (60.2)	56 (48.7)	736 (54.1)	233 (61.2)	77 (68)	318 (61.9)
Age at onset, ys, mean (SD)	34.5 (17.1)	35.1 (14.3)	33.8 (17.4)	33.5 (16.8)	34.8	35.1 (15.1)
Age at diagnosis, ys, mean (SD)	42.7 (13.2)	37.9 (14.2)	36.5 (17.6)	36.9 (17.1)	36.2	36 (14.3)
Current age, ys, mean (SD)	40.7 (17.3)	42.8 (14.3)	39.8 (17.8)	41.7 (17.2)	40	41.4 (14.9)
Subjects in treatment with DMTs, n (%)	40 (37)	60 (52.2)	501 (36.8)	240 (63.5)	96 (85)	336 (65.5)