BigMSData Network

The home of MS Real World Evidence

BIG MS

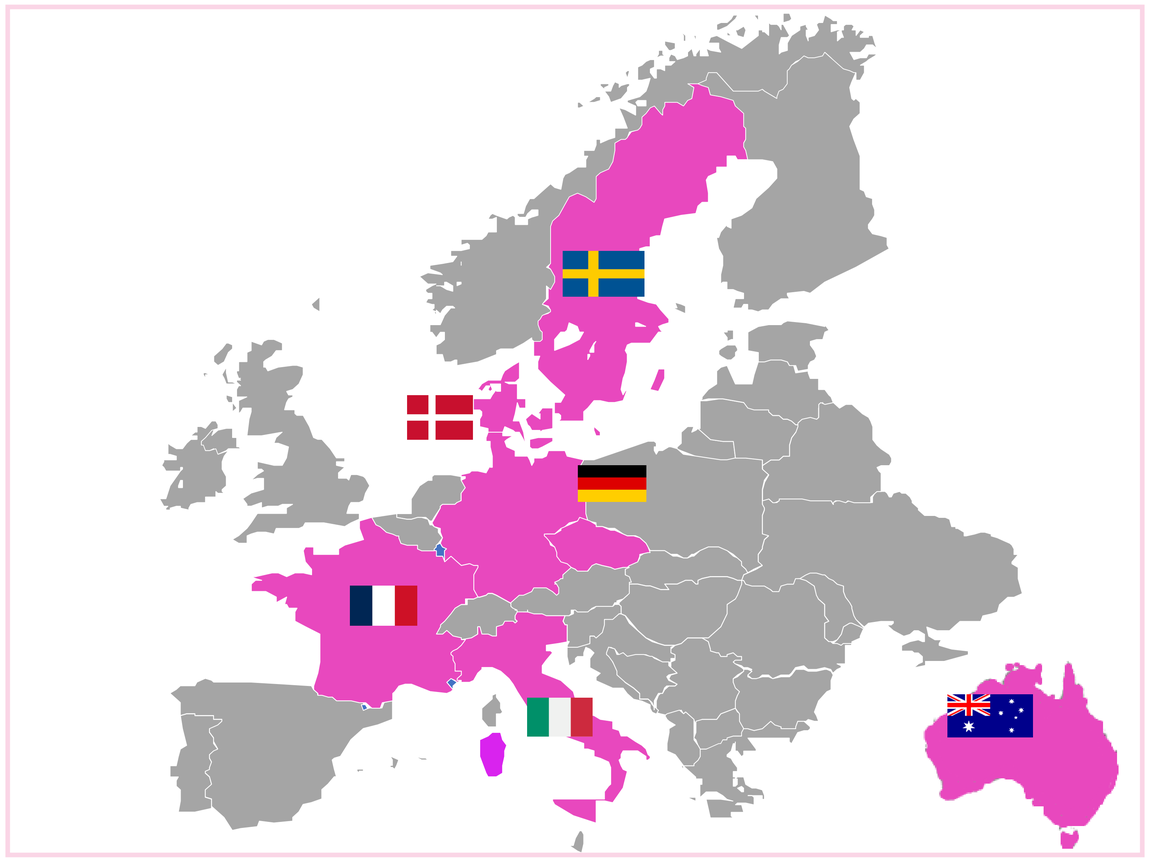
The big Multiple Sclerosis data network

Background

Multiple sclerosis registries, both national and international, have a long history of gathering structured longitudinal clinical data.
These registries have contributed significant information about multiple sclerosis, particularly regarding long-term outcomes in studies of the disease's natural course and the efficacy of therapeutic interventions like disease-modifying therapies.
In real-world evidence studies, statistical power is often challenging due to the complexity of clinical data, necessitating the use of large, high-quality longitudinal datasets.

The Big Multiple Sclerosis Data (BMSD) network (*https://bigmsdata. org*) was initiated in 2014 and includes the national multiple sclerosis registries of the Czech Republic, Denmark, France, Germany, Italy, and Sweden as well as the international MSBase registry. The BMSD network comprises well-developed registries with a high coverage of national multiple sclerosis, NMOSD and MOGAD patient cohorts, providing a reliable framework for the network and containing a huge amount of validated data. Each of these registries has been well-established as a data source for multiple scientific publications over the years.

Map of MS registries. The national MS registries of Czech Republic, Denmark, France, Germany, Italy, Sweden and the international MSBase registry based in Australia.



Data collection, management and analysis

The data collected by the registries and their governance frameworks are a result of many years of improvement and have evolved by consensus within each registry organization. Despite the independent nature of data collection, the similarities are striking and reflect a common aim to study variables that hold a crucial clinical significance in multiple sclerosis research. BMSD mapped the member registry datasets to create a minimum dataset and a common data model (CDM) of variables, definitions, and data structure. BMSD has been developing this general CDM to set standards for real world evidence in multiple sclerosis. All BMSD registries are designed to collect SAEs, constituting the optimal basis for post-authorization safety studies (PASS).

BMSD aspires to pioneer further development of federated approaches for joint analyses of data, including federated learning, to allow more complex analyses without merging data. Furthermore, another aim of BMSD is to actively promote the standardization of definitions and procedures in RWE research. BMSD has also addressed the ethical, legal, technical, and governance-related challenges for data sharing.
The BigMSData Network welcomes initiatives for prospective collection of data or retrospective analysis of existing data performed by academic partners. New registries that wish to join the group and possess the high caliber of data and protocols that define the network are also welcome to join the BMSD.

Country	MS registry	Number of people with MS included	Estimated coverage of prevalent MS population
Czech Republic	ReMuS	25,000 (June 2026)	70%
Denmark	DMSR	35,000 (June 2026)	95%
France	OFSEP	82,600 (June 2026)	60%
Germany	GMSR	91,000 (July 2026)	50% within DMT exposed
Italy	RISM	100,000 (July 2026)	70%
Sweden	SMSreg	25,500 (June 2026)	86%
International	MSBase	124,200 (July 2026)	variable