BigMSData Network

The home of MS Real World Evidence

BIG MS

The big Multiple Sclerosis data network

Background

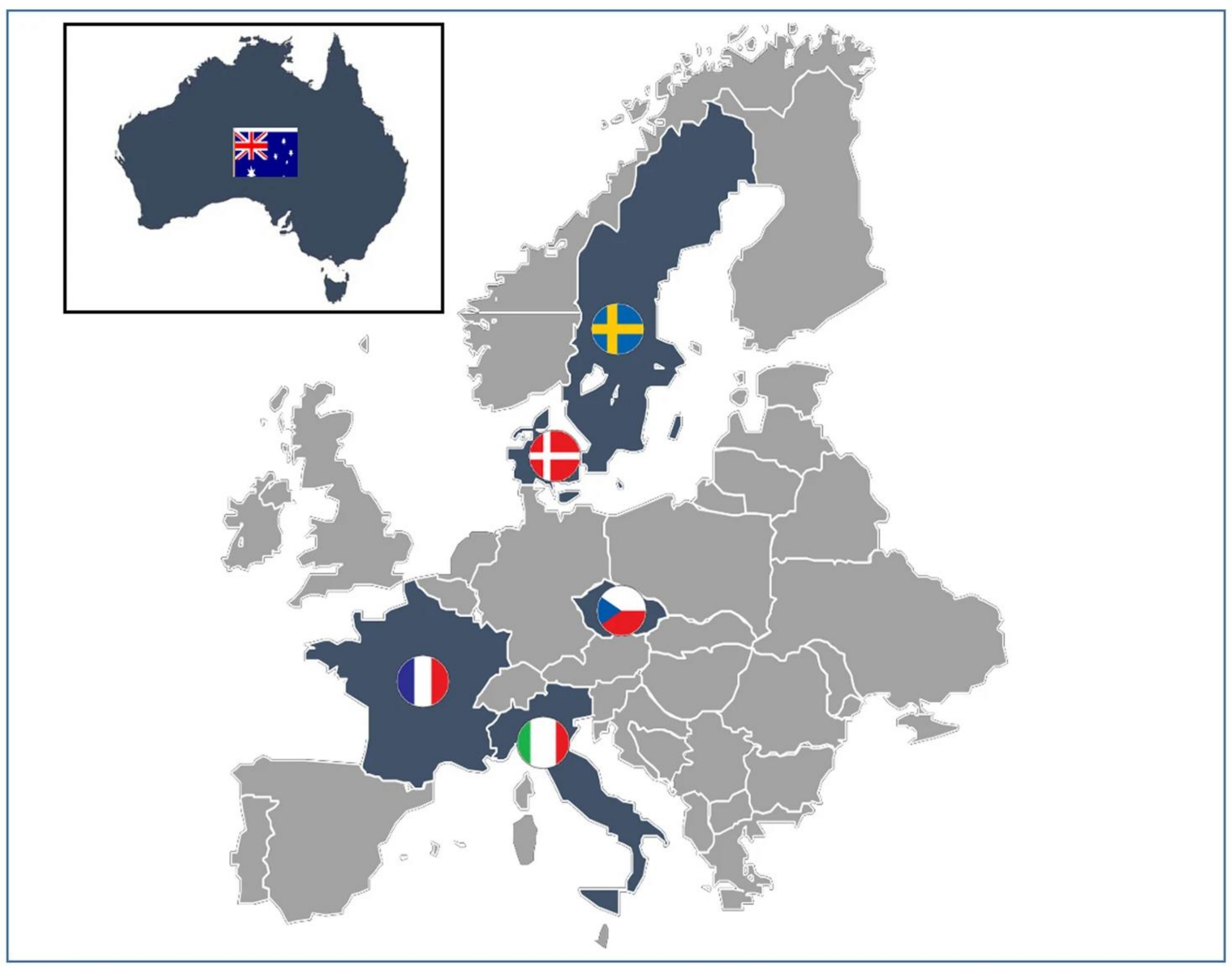
Multiple sclerosis (MS) registries, both national and international, have a long history of gathering structured longitudinal clinical data.

These registries have contributed significant information about MS, particularly regarding long-term outcomes in studies of the disease's natural course and the efficacy of therapeutic interventions like disease-modifying therapies.

In MS 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 (MS) registries of the Czech Republic, Denmark, France, Italy, and Sweden as well as the international MSBase registry. The BMSD network comprises well-developed registries with a high coverage of national MS 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, 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 the MS research field. 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 MS. 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 MS 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	24,030 (June 2025)	90%
Denmark	DMSR	34,720 (August 2025)	95%
France	OFSEP	86,180 (August 2025)	55%
Italy	RISM	95,294 (July 2025)	70%
Sweden	SMSreg	24,780 (August 2025)	90%
International	MSBase	122,604 (August 2025)	variable