Big Multiple Sclerosis Data (BMSD) Network

First published: 16/01/2026

Last updated: 19/02/2026

Network

Network identification

Network ID

1000000867

Network countries

- Australia
- Czechia
- Denmark
- France
- Germany
- Italy
- Sweden

Network website

https://bigmsdata.org/

ENCePP partner

No

Network description

The Big Multiple Sclerosis Data (BMSD) network was initiated in 2014 and currently includes the national multiple sclerosis (MS) registries of: the Czech Republic (ReMuS), Denmark (DMSR), France (OFSEP), Italy (RISM), Sweden (SMSReg), Germany (German MS-Register), and the international MSBase database. The BMSD network is made up of well-developed registries, with reasonable coverage of local MS patients, providing a reliable framework for the network and containing data from a large number of people with MS. The data collected and the governance frameworks are a result of many years of improvement and have evolved by consensus within each registry organization. BMSD harmonized the datasets of each registry to develop a common data model (CDM) that standardizes variables, definitions, and data structures. This CDM aims to establish shared standards for real-world evidence in MS and to enable the study of clinically meaningful variables that are central to MS research. All BMSD registries are designed to collect serious adverse events (SAEs), constituting the optimal basis for post-authorization safety studies (PASS). To ensure a standardized approach to conducting PASS projects, BMSD has developed a core PASS protocol that includes a minimum dataset to be adopted by all members. BMSD has also addressed the ethical, legal, technical, and governance-related challenges for data sharing. 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. For more information:

- Glaser, A., Butzkueven, H., van der Walt, A. et al. Big Multiple Sclerosis Data network: an international registry research network. J Neurol 271, 3616–3624 (2024). https://doi.org/10.1007/s00415-024-12303-6
- Trojano, M., Iaffaldano, P., Copetti, M. et al. Big multiple sclerosis data network: novel modelling approaches for real-world data analysis. J Neurol 272, 754 (2025). https://doi.org/10.1007/s00415-0

Network details

Network primary therapeutic area:

- Disorders of the central nervous system

Network funding:

- - Pharmaceutical company and other private sector

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