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Abstracts

European MS registries

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The MS registry landscape in Europe is evolving and comprises regional and national registries with considerable heterogeneity in terms of their organisation, purposes, collected core data elements, follow-up time and data collection platforms.

A growing number of MS registries and databases have started to collect data from large cohorts of patients with MS treated with disease-modifying therapies. Collection of additional data, such as MS-associated symptoms, quality of life and activities of daily living is desirable, and the value of MS registries and large databases is becoming increasingly recognised for patients, healthcare providers and regulators.

A recent registry survey has identified 19 MS registries in Europe and gives an informative and updated overview of the MS information currently collected in Europe.[1]

Real-world studies conducted in unselected but well-defined cohorts can provide longitudinal information on the effectiveness, safety and tolerability of drugs and can contribute to defining predictive tools for personalised patient management.[2] This could provide a useful basis for combining data from different MS registries to carry out larger and more statistically powerful studies than what is possible at a national or local level. The availability of complete and valid registry data plays a key role in conducting post-authorisation studies that evaluate safety and effectiveness.

There are examples of international collaborations such as Big MSData,[3] which is a collaborative effort that was initiated in 2014, between the French, Danish, Italian and Swedish MS registries and MSBase. To provide valid answers to emerging questions in MS research, registry holders must agree on core common data elements with standardised terminologies and definitions to be collected in all registries, to establish robust quality assurance procedures, and to establish procedures for data sharing with stakeholders.

References
1. Glaser A, Stahmann A, Meissner T, et al. Mult Scler Relat Disord 2019; 27: 171–8.
2. Ziemssen T, Kern R, Thomas K, et al. BMC Neurol 2016; 16: 124.
3. Iaffaldano P, Butzkueven H, Hillert J, et al. Poster presented at ECTRIMS 2017. P738. Available at:
http://www.ofsep.org/ECTRIMS/2017/P738_BIG%20MS%20DATA_poster1.pdf