



Correspondence

Letter to the editor on “Multiple sclerosis registries in Europe – An updated mapping survey” published in Multiple Sclerosis and Related Disorder 27 (2019) 171–178



Sir,

To our surprise the MS registry run by the German doctors network NeuroTransData (NTD) was not approached nor mentioned in this survey, as it was not in the previous survey in 2014 (Flachenecker et al., 2014). Limiting the inclusion criteria to the previous survey and the European Multiple Sclerosis Platform creates an artificial selection and excludes registries like the REGIMS registry of the Kompetenznetz Multiple Sklerose (KKNMS) and the NTD registry in Germany. This is even more surprising as the authors are familiar with at least the NTD registry, as we all contribute with our work to the progress of real-world evidence in the field of MS in personal exchange, congresses and publications.

NTD is a Germany-wide network founded in 2008, owned and run by physicians in the fields of neurology and psychiatry. Currently, 78 neurologists and psychiatrists in 153 offices work in NTD practices serving about 600,000 outpatients per year. Each practice is certified according to network-specific and ISO 9001 criteria. Compliance with these criteria is audited annually by an external certified audit organisation. The NTD MS registry includes about 25,000 patients with MS, representing about 15% of all MS patients in Germany. In the database, demographic, clinical history, clinical variables and patient-reported outcomes are captured in real time during an average of 3.7 visits and Expanded Disability Status Scale (EDSS) assessments per year per patient. All types of data in Table 3 of the publication and all clinical categories listed in Table 4 are captured in the NTD MS registry. Standardized clinical assessments of functional system scores and EDSS calculation are performed by certified raters (<http://www.neurostatus.net/>). Patient-related outcomes include EQ-5D, FSS, MFIS beside other neuropsychological and psychiatric assessment scales.

All personnel undergo regular training to ensure quality of data in the database. Quality of the data is monitored by the NTD data management team. Data input is checked for inconsistencies and errors also using an error analysis program. Both automatic and manually executed queries are implemented to further ensure data quality. All data are pseudonymised and pooled to form the MS registry database. The codes

are managed by the Institute for Medical Information Processing, Biometry and Epidemiology (Institut für medizinische Informationsverarbeitung, Biometrie und Epidemiologie (IBE)) at the Ludwig Maximilian University in Munich, Germany, acting as an external trust centre. This data acquisition protocol was approved by the ethical committee of the Bavarian Medical Board (Bayerische Landesärztekammer; June 14, 2012) and re-approved by the ethical committee of the Medical Board North-Rhine (Ärztekammer Nordrhein, 25.04.2017).

Real-world data gain increasing acceptance both in the medical and scientific community but also in regulatory authorities. As initiatives are started to explore possible frameworks for cooperation between registries we favour an integrative approach respecting the different “ecosystems” of each registry and its structures based on our mutual dedication for a continuous improvement of patient care as leading motivation.

Conflict of interest/role of funding sources

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Reference

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