P383 - Opportunities and challenges for conducting research on Secondary Progressive Multiple Sclerosis across International Multiple Sclerosis registries through a research network collaboration

A. Glaser[1], M. Trojano[2], P. Laffaldano[2], S. Vukusic[3,4], D. Horakova[5,6], R. Nicholas[7], R. Middleton[8], A. Stahmann[9], M. Soilu-Hänninen[10], M. Magyari[11], C. Lines[12], N. Adlard[13], J. Hillert[1] [1]Karolinska Institutet, Stockholm, Sweden, [2]Department of Basic Medical Science, Neuroscience and Sense Organs, University of Bari Aldo Moro, Bari, Italy, [3]Department of Neurology, Hopital Pierrre Wertheimer, Hospices Civils de Lyon, [4]Observatoire Français de la Sclérose en Plaques (OFSEP), Lyon, France, [5]Department of Neurology and Center for Clinical Neuroscience, First Medical Faculty, Charles University, [6]General University Hospital, Prague, Czech Republic, [7]Centre for Neuroinflammation and Neurodegeneration, Imperial College London, London, [8]Swansea University Medical School, Swansea, United Kingdom, [9]MS-Register, MS Forschungs- und Projektentwicklungs-gGmbH, Hannover, Germany, [10]Division of Clinical Neurosciences, Turku University Hospital, Turku, Finland, [11]The Danish Multiple Sclerosis Registry, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark, [12]IQVIA, [13]Novartis Pharma AG, Basel, Switzerland

Introduction: Clinical registries provide real-world evidence (RWE) for Multiple Sclerosis (MS). However, RWE studies of secondary progressive MS (SPMS) face challenges, given the absence of consistent prevalence data and uncertain consistency in adherence to criteria by clinicians to diagnose SPMS.

Objective: To identify opportunities and challenges in RWE studies of SPMS across international MS registries, and to identify data gaps to be filled for future studies.

Methods: A survey was conducted to complement published data on data captured in registries that may be used to identify SPMS patients and the feasibility of two pilot studies was evaluated.
The pilot studies aim to measure variance in SPMS prevalence as a function of diagnostic criteria/ method of assignment and describe characteristics and treatment patterns of SPMS patients in routine clinical practice.

Results: Eight MS registries aspiring to join a collaborative effort on MS, a research collaboration network (RCN) were assessed. Of the clinical variables relevant for these studies, the Expanded Disability Status Scale is captured in all 8 registries, and likewise all registries have information on the number of relapses in the last 12 or 24 months and capture information on patients' current and previous treatment with DMTs. Key diagnostic data from Magnetic Resonance Imaging is captured in 7 of the registries. Relevant comorbidities are available from 7 registries, of which 5 can provide co-medication information. Mortality data is captured by all 8 registries. In some countries, some of the above information can be obtained by linkage to population-based registries. Finally, other measures such as cognition and fatigue are collected in 4 and 5 registries, respectively.

Conclusions: Most of the clinical data needed for the pilot studies are comprehensively covered in international MS registries. However, several variables that can potentially improve the identification of SPMS patients often lack. Thus, a Research Collaboration Network may shed light on SPMS already now and could facilitate future studies by prompting improvements in data collection.

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