Prevalence and incidence of multiple sclerosis estimated in European Register for Multiple Sclerosis (EUReMS): Study protocol of the 1-st study

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Background

The attempt to define the burden of MS in Europe is hampered by the variability of the surveyed populations and the different ascertainment across studies. To overcome this, epidemiological indices should be derived based on standardized procedures for data collection. This requires a consolidated collaborative network, harmonizing data structure and capturing, designing a registry system for both existing and prospective longituidally collected data as well as shared analytical plans and interpretation of results.

Objectives

To fulfill one of EUReMS missions: MS epidemiology and clinical management across European countries, including the assessment of the MS burden in Europe;

To test the ultimate research hypothesis:

"MS in Europe is changing over time and in space"

Method

A survey was conducted between July 2013 and February 2014 by administering an ad hoc questionnaire (EQ-5) to the leaders of eligible existing European databases, to collect data on database management and governance, contents, demographics, MS course, year of onset/diagnosis, diagnosis validation through lab and instrumental tests, EDSS, format and quality of data. Specific focus was given to detect the possibility for generating population-based estimates on better-ascertained sub-areas [5].

Results

Out of 18 databases contacted, EQ-5 was successfully administered to 6 countries: Croatia, Czech Republic, Denmark, Finland, Germany, Italy (Lugenia, Tuscany, IMED), Norway, Poland, Serbia, Spain, Sweden and United Kingdom. Overall population-based epidemiological data collected since 2003 was integrated into a database of ca. 17,000 MS patients over a total population of 18,000,000 for sub-areas in Catalonia/Spain, Italy, Sweden, UK, Norway and Serbia, despite some heterogeneity across regions.

As of beginning of September 2014, we are able to present preliminary data on MS incidence and prevalence estimates in some of the populations participating to EUReMS (Table 1 and Table 2).

Conclusions

Benefiting from EUReMS architectural infrastructure, and from previous work on purposes and constructions of existing MS databases in Europe, population-based sex- and age-specific incidence and prevalence from well-defined geographic sub-areas and over time, temporal trends of gender-ratio, age at onset and diagnostic delay can be computed. This will ensure the current ‘best estimate’ of the MS burden in Europe, as well as indicators of registry accuracy.

References


EUReMS Consortium

Group 1: Data providers
- MS Register of Belgrade Region (Jelena Drudak, Tajačka Pepelemeze), Mirjana Popovic – University of Belgrade, Serbia, National MS Register of Croatia (Irina Etovska, Marija Lješić Sumuljak – University of Tampere, Finland; Register of ECoMSMulitple Sclerosis (Croatia Montalban) - EPEC/MCS, Belgrade, Serbia; Spain), Svenska Multiple Sclerosis registry (SMSreg), Sweden (Jan Ilbert – Karolinska University, Sweden); Apcis MS Register (Maria Troyna und Pietro belmessini – University of Bari; Vito Lepore – Maggiore Nord Savigliano, Italy).
- Group II: EUReMS-EaRtH Working Group

Disclosures

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