Abstract Preview - Step 3/4

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Topic: Epidemiology and genetics

Keywords: Europe, Register, epidemiology

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

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Text: **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 longitudinally collected data as well as shared analytical plans and interpretation of results.

Objectives: To fulfill one of EUReMS missions: MS epidemiological and clinical surveillance across European countries, including the assessment of the MS burden in Europe; to test the ultimate research hypothesis that MS in Europe is changing over time and space.

Methods: A survey was conducted between July 2013 and February 2014 by administering an ad hoc questionnaire (EPI-Q) to the leaders of eligible existing European databases, to collect data on database management and governance, contents (demographics, MS course, year of onset/diagnosis, diagnostic 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.

Results: Out of 18 databases contacted, EPI-Q was successfully administered to Croatia, Czech Republic, Denmark, Finland, Germany, Italy (Liguria, Tuscany, iMED), Norway, Poland, Serbia, Spain, Sweden and United Kingdom. Population-based epidemiological data collected since 2003 can be integrated into a database of ca. 17,000 MS patients over a total population of 18,000,000 for sub-areas in Catalunya/Spain, Italy, Sweden, UK, Norway, Finland and Serbia, despite some heterogeneity across regions.

Conclusions: Benefitting from EUReMS architectural infrastructure, and from previous work on purposes and constructs 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 will be computed, likely ensuring the 'best estimate' of the MS burden in Europe available to date.

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