

## ***EUREMS Consensus Statement***

### **Rationale behind EUREMS**

The European Commission through its latest Communications on health issues has expressed its will to tackle more efficiently health inequalities faced by EU citizens e.g., the provision of health services, the design of health promotion and health protection activities, as well as the improvement in living and working conditions.

With regard to Persons with Multiple Sclerosis (PwMS), across European countries there is currently a widely recognized lack of data on:

- Disease epidemiology, including age and gender specific trends;
- Actual access to new disease modifying and symptomatic treatments;
- Long-term efficacy, safety and cost-effectiveness of disease modifying drugs;
- Societal costs and ways to best allocate socioeconomic resources;
- Degree of access to health care services and their quality;
- Quality of life priorities of PwMS.

A comprehensive approach to data collection in MS is needed addressing these issues, building on existing systems for MS data collection, but bridging their gaps and limitations by incorporating additional purposes, standardized methodological strategies and ensuring its validity across different European populations.

### ***EUREMS' Vision***

EUREMS strives to become an infrastructure for data collection, data analysis, interpretation and dissemination of results in MS with European cross-border validity, aimed at ultimately improving the quality of life of PwMS in Europe, and minimizing regional inequalities in MS management, including the access to EMA approved MS disease modifying and symptomatic treatments, and to standard quality health care services.

EUREMS will serve as a tool for epidemiological surveillance of MS in Europe and will contribute to better understanding and management of MS, and to defining the actual societal burden of the disease. EUREMS will ultimately support PwMS and their carers in their daily lives as well as MS health professionals and the scientific MS community at large.

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## **EUREMS' Mission**

In order to fulfil its aims, EUREMS' mission will pivot on four areas of actions:

1. MS epidemiological and clinical surveillance across European countries, including the assessment of the 'MS burden' in Europe
2. Assessment of long-term efficacy, safety and cost-effectiveness of MS disease modifying and symptomatic treatments across European countries
3. Assessment of provision and quality of health care services across European countries, and
4. Assessment of PwMS' quality of life, the burden of symptoms and socio-economic aspects from the patient's perspective across European countries

In particular, these actions will imply the following outcomes:

- a. provide reliable and validated data from different sectors (health care, public health, lay community/PwMS), over large population-based and clinical cohorts of PwMS with varying susceptibility to the disease and different health care and health economic contexts;
- b. provide longitudinal data on medical and socioeconomic status of PwMS to be used as outcome measures in order to assess and compare the impact of medical and social services offered to PwMS, and possible disparities, across European countries;
- c. provide large scale data on the long term effectiveness, safety, and comparative effectiveness of disease modifying as well as symptomatic drugs in relation to the socio-economic impact, by aggregating data at European level;
- d. monitor trends in MS epidemiology in Europe, including gender and age specific incidence and prevalence; it will provide insights on the role of possible etiological agents, the causes and disease natural history across European populations;
- e. comprise patient-reported outcome measures;
- f. enable reliable comparisons across European countries by common shared methodology, standardized data collection and tools to access and analyse data from various sources.

The outcomes of EUREMS' mission from the four different areas will have *short-term* and *long-term* impacts in the MS domain. The former representing the actual EUREMS' project products, the latter representing EUREMS sustainability over time.

## **EUREMS' Overall Strategy**

EUREMS will:

- Use a formal description of data quality, over large population-based and clinical MS cohorts to enable comparisons across European countries;
- Jointly develop standard definitions of terminology, specifications of data structure, data collection and data management processes to allow corresponding comparability of data and comprehensive data analysis at a European level;
- Customize methodology and strategies to collect and validate MS data from different sectors (health operators, PwMS, lay community, MS societies, local health policy makers) and to comply to the Mission;
- Establish a working platform (eg. a European Reference Platform for MS) to support collaboration and ensure sustainability.