

## Addressing a major public health challenge through better data

- Multiple sclerosis (MS) is a chronic inflammatory disease of the central nervous system, mostly affecting young people between the age of 20 and 40.
- It affects twice as many women as men.
- In Europe, more than 700,000 people live with MS.
- Severity of the condition varies from person to person, from mild symptoms to major disability.
- Half of those with MS lose their jobs, on average, three years after diagnosis.
- Managing MS attracts total costs of up to 15 billion euros per year in Europe.
- There is no cure for MS yet, but access to specialists and treatment helps people manage the condition.
- EUReMS addresses a widely recognised lack of data across Europe on:
  - age and gender
  - causes and triggers
  - availability, access and effectiveness of drugs
  - costs and resources

**Better data brings better outcomes on the road to ultimately beat MS!**



EMSP represents more than 700,000 people living with MS in Europe and has a network of 39 member societies in 34 European countries. En route to our ultimate vision of a world without MS, we aim to improve quality of life as well as access to treatment, care and employment and we work to ensure that people with MS have a real voice in determining their own priorities – [www.emsp.org](http://www.emsp.org).

**The EUReMS project (2011-2014) enables MS-data sharing at European level. It focuses on epidemiology, long-term therapy outcome, healthcare and quality of life of people with multiple sclerosis.** The EUReMS project is co-funded by the European Commission under the Health Programme.



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## Improving Multiple Sclerosis Management in Europe:

# Better Outcomes with Better Data

[www.eurems.eu](http://www.eurems.eu)

## Why EUREMS?

### Filling the data gap

To better understand and ultimately beat MS we need more and better data.

As a pioneer in this field, EUREMS has identified and pooled MS-related data from different registries – hospitals, MS societies and research centres around Europe – and has created a cross-border partnership for its safe and effective storage, analysis, interpretation and dissemination.

EUREMS data enables analysis of:

- costs and resources,
- age and gender-specific trends,
- disease-modifying drugs and their impact.

The project is closely aligned with the European Commission's efforts to fight health inequalities faced by European citizens. More and better data can drive policy improvements and provide incentives for new research.

#### Project Partners

- Association of MS Societies of Croatia
- Department of Clinical and Experimental Medicine, University of Sassari, Italy
- German MS Society
- Karolinska Institutet, Medical University, Sweden
- MS Centre of Catalonia – Cemcat
- Multiple Sclerosis Society, UK
- Neurological Rehabilitation Center Quellenhof, Germany
- Polish MS Society
- Romanian MS Society
- University of Bergen, Norway
- University Medical Center Göttingen, Germany

## Collecting high-quality and comparable data on MS across Europe

### Data management

The information gathered through EUREMS is being managed by and stored at the Medical Centre of the University Göttingen, Germany. Its dissemination is coordinated by EMSP through the Secretariat in Brussels, on the basis of access regulations developed within the EUREMS Scientific Board.

The aim for the post-2014 period is to use the newly created data infrastructure in collaboration with existing and emerging registries. This will eventually lead to a pan-european data pool to better assess the situation of people with MS.

### Looking ahead

EMSP aims to build on the knowledge, experience and momentum achieved between 2011 and 2014 to encourage a growing number of MS registries across Europe to adopt EUREMS protocols of data pooling and analysis.

Another important goal is to extend the project by considering the financing opportunities available under EU and industry programmes and frameworks.

### Protecting patient data

EUREMS studies exclusively work with anonymised data.

## Main deliverables

EUREMS identified 20 MS registries across Europe; 12 of them started pooling their data in accordance with an agreed protocol to harmonise heterogeneous MS information.

The inclusion of the patients' perspective adds significant value to the project.

The first data pooling process was completed in August 2014 and formed the basis for four test studies addressing EUREMS' objectives:

- **EPI-1-d Study: *Estimating Prevalence and Incidence of MS in Europe from EUREMS data collection***, coordinated by Prof. M Pugliatti;
- **EPI-1-s Study: *Comparison of the effect of the month of birth across Europe***, coordinated by D Ellenberger and Prof. M Pugliatti;
- **DMD-1 Study: *Comparison of access and effectiveness of DMD treatment for people with MS across Europe***, coordinated by Prof. J Hillert;
- **PRO-1 Study: *Assessment of people with MS' quality of life, the burden of disease and influence of employment from the patient's perspective across European countries***, coordinated by Prof. P Flachenecker.

