



EUREMS – Background, Structure and expected Outcomes

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Background

- European patients including PwMS face huge inequalities in terms of access to treatments and care, quality of life, etc.
- Wide range of socio-economic factors: geographic location, living and working conditions, education, income, etc.
- In a Europe built on values such as solidarity and equity, this is unacceptable.

- MS-ID project (2007-2009) developed and piloted a model for a European MS database
- Participants: Five MS societies with the cooperation of neurological units and MS centers as national data collection points
- Data entries at national level in 2008 for a six-month pilot phase
- Data collected included clinical data, indicators for socio-economic and quality of life situation of all registered PwMS

Across the European Union there is currently a widely recognized lack of data on:

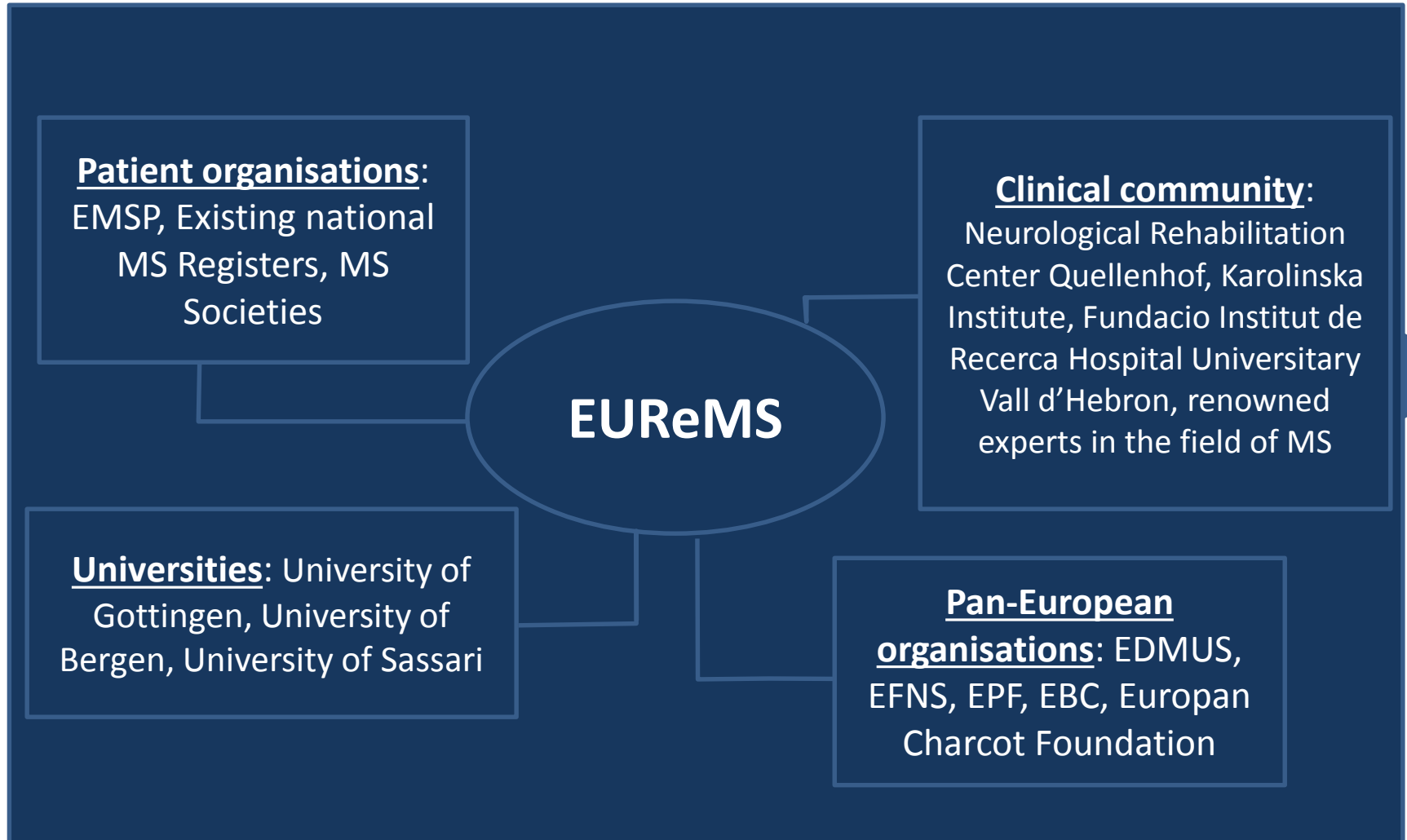
- Disease epidemiology, including age and gender specific trends;
- Actual access to new disease modifying and symptomatic treatments;
- Long-term efficacy, safety and cost-effectiveness of disease modifying drugs;
- Societal costs and ways to best allocate socioeconomic resources;
- Degree of access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

- EUReMS will provide the infrastructure for data collection, data analysis, interpretation and dissemination of results in MS with European cross-border validity;
- EUReMS will serve as a tool for epidemiological surveillance of MS in Europe;
- 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.

- Associated Partners
- Collaborating Partners
- Scientific Advisory Board

A truly European project







The application writing group, Feb 2010

**EUREMS Consensus
Statement and
Meeting**

Amsterdam
19.10.2011

**EUREMS
Data Mask and
Charter**

**Start of the testing
Phase of EUREMS**

**Results of the
EUREMS Test Phase**

2011

2012

2013

2014

**Terms of
references**
of EUREMS
Associated Partners

**EUREMS Working
platform and 1st
version of
nomenclature server**

**Contracts with
EUREMS
Data Providers**

**Design new
Research projects**

Clinical

- Have an agreed set of **core medical data** on MS patients being fed into EUREMS by 10 national registries

Political

- Have an agreed set of **core socio-economic data** on MS patients being fed into EUREMS by 10 national registries

Scientific

- Have created the base for a **first scientific research project using EUREMS data coming from ten national registries**

Outlook

- Be ready for the next step: a **DG RESEARCH funded MS research project** on European level, using EU funds also for the expansion of the EUREMS network

Main Partner: European Multiple Sclerosis Platform (EMSP)



Associate Partners:



DMSG

DEUTSCHE MULTIPLE SKLEROSE GESELLSCHAFT
KUNDENVERBAND e.V.



MS Nationaal Multiple Sklerose
REGISTER

Cemcat  Centre d'Etudes
Multiple de Colmar



MS
Multiple Sclerosis Society

UNIVERSITÄTSMEDIZIN
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 **Neurologisches
Rehabilitationszentrum
Quellenhof**



 Executive
Agency for
Health and
Consumers



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