

EUREMS – the future of MS data collection

Eva Havrdova,
Dpt. Of Neurology, Charles University in Prague



!!! Important !!!

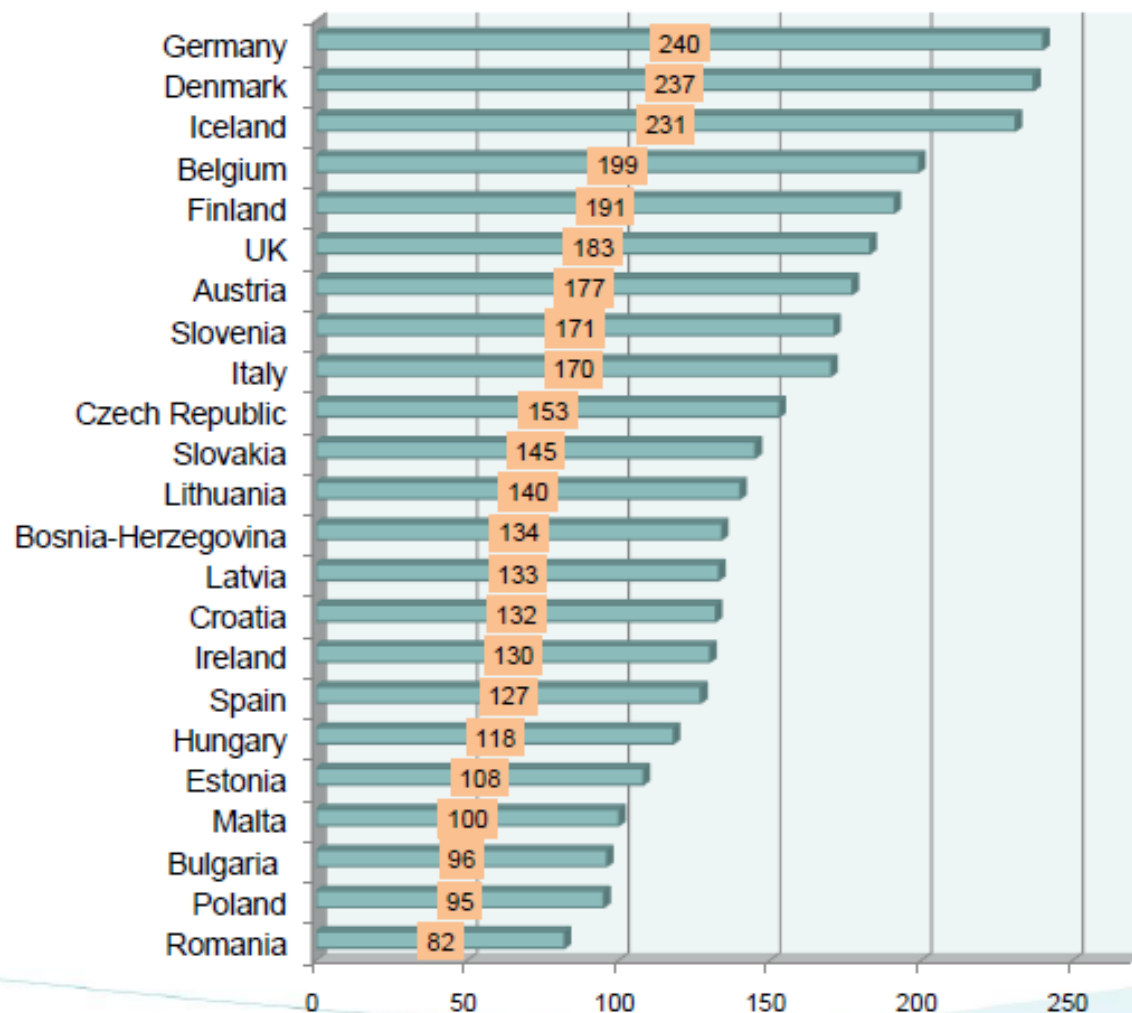
European Register of MS =

new database on the European Level,
which adds value, but does not replace or
even interfere with current and future
national or cross-border MS registries and
databases.

!!! Important !!!

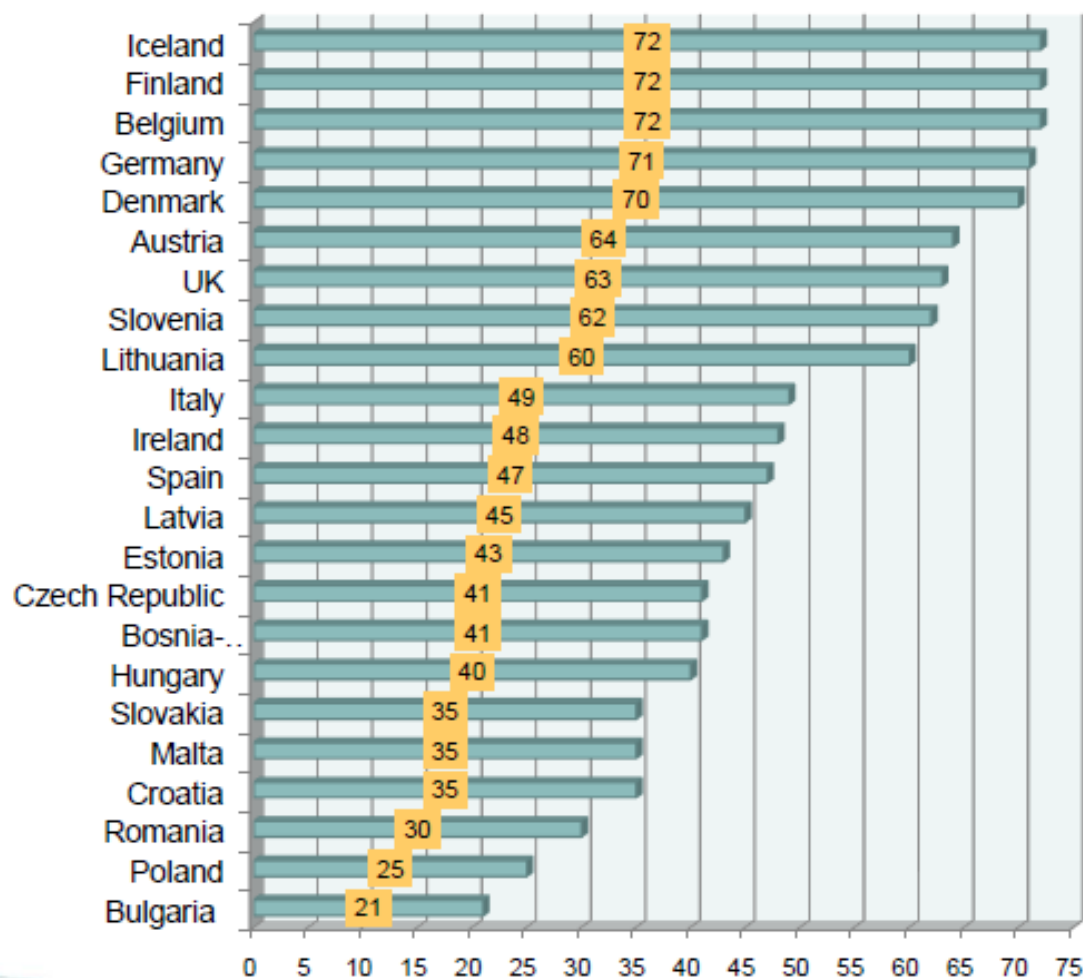
WHY?

MS Barometer 2008: overall results



Average for
23 countries = 152 points

Access to treatments & therapies



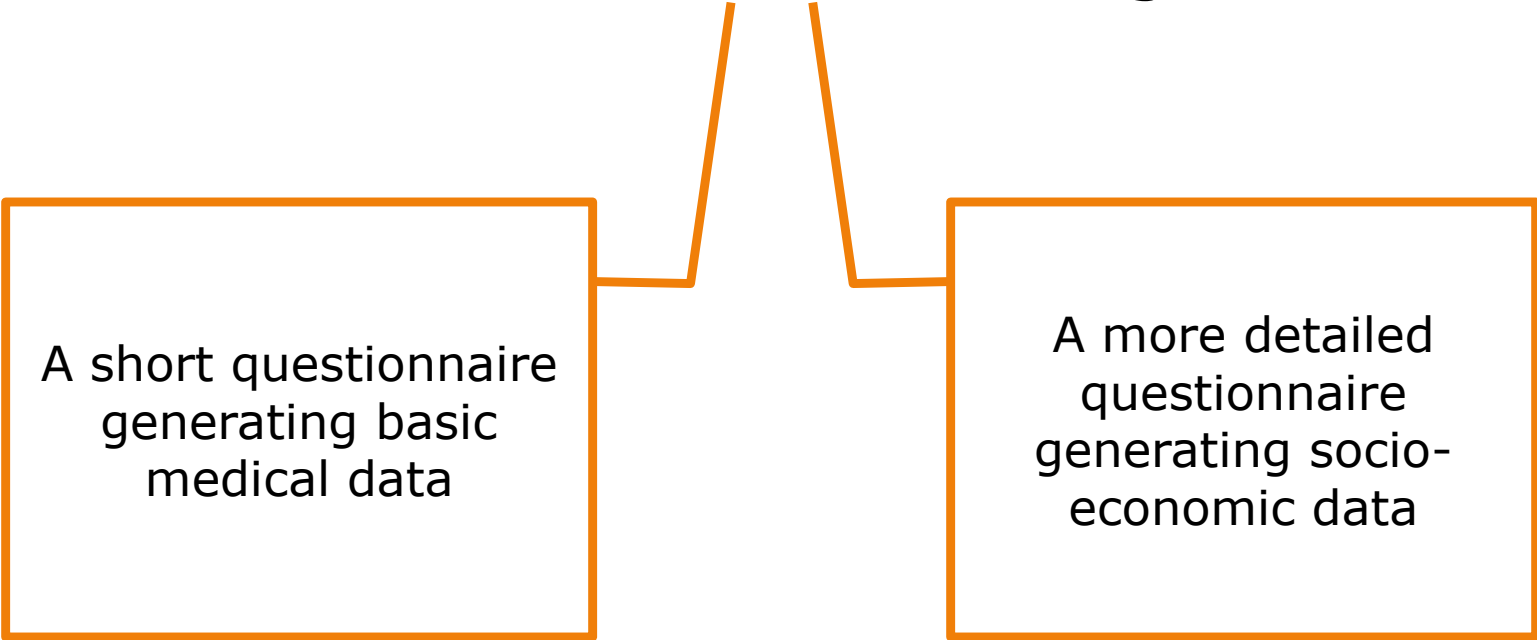
Average for
23 countries = 50 points

- European patients including Persons with MS face huge **inequalities** in terms of access to treatments and care, social benefits, 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 situation is **unacceptable**

Basic Structure of the EuReMS

2 Obligatory minimum datasets being collected through

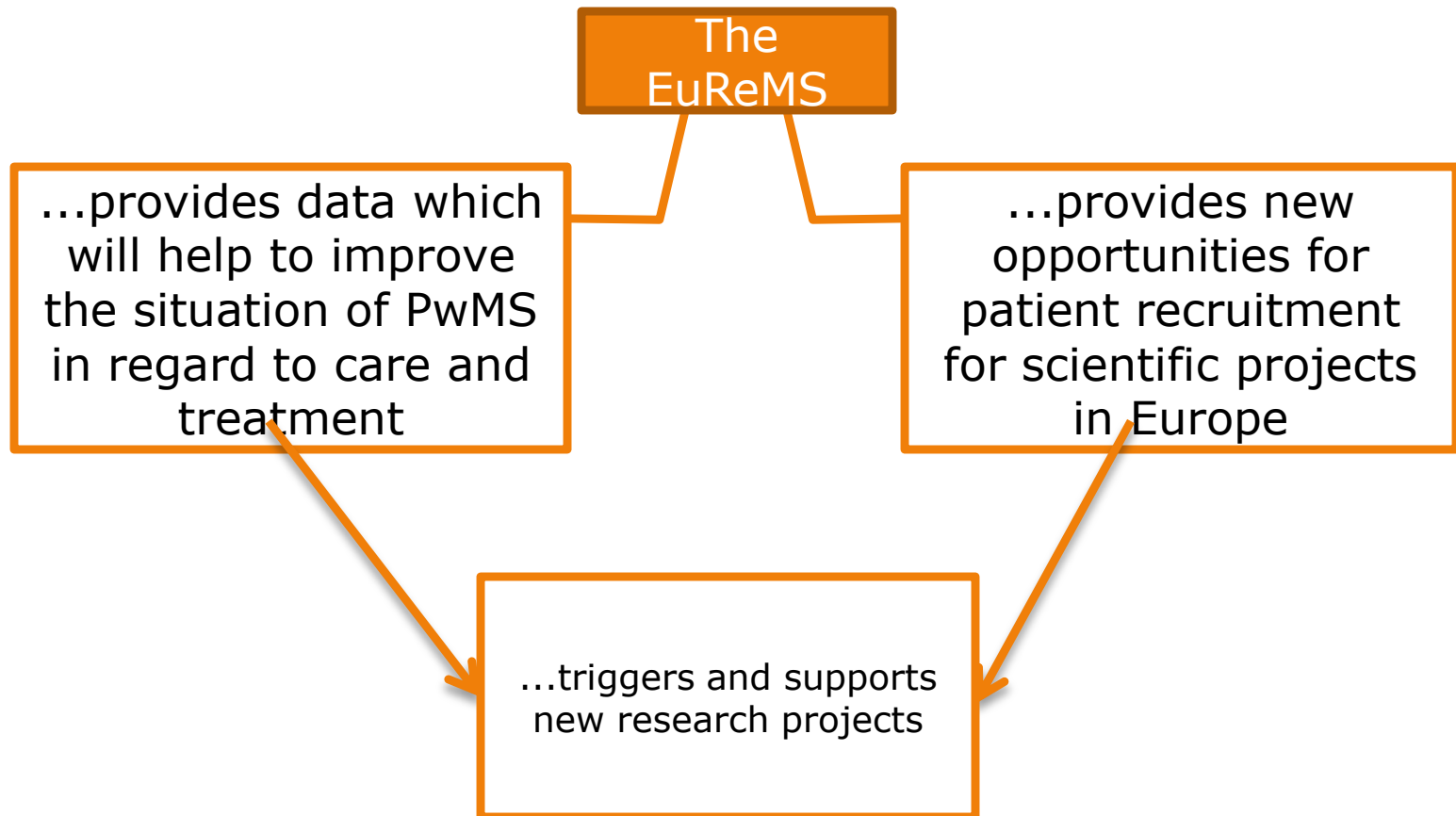


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graph TD; A[A short questionnaire generating basic medical data] --- B[A more detailed questionnaire generating socio-economic data]; A --> C[2 Obligatory minimum datasets being collected through]; B --> C;
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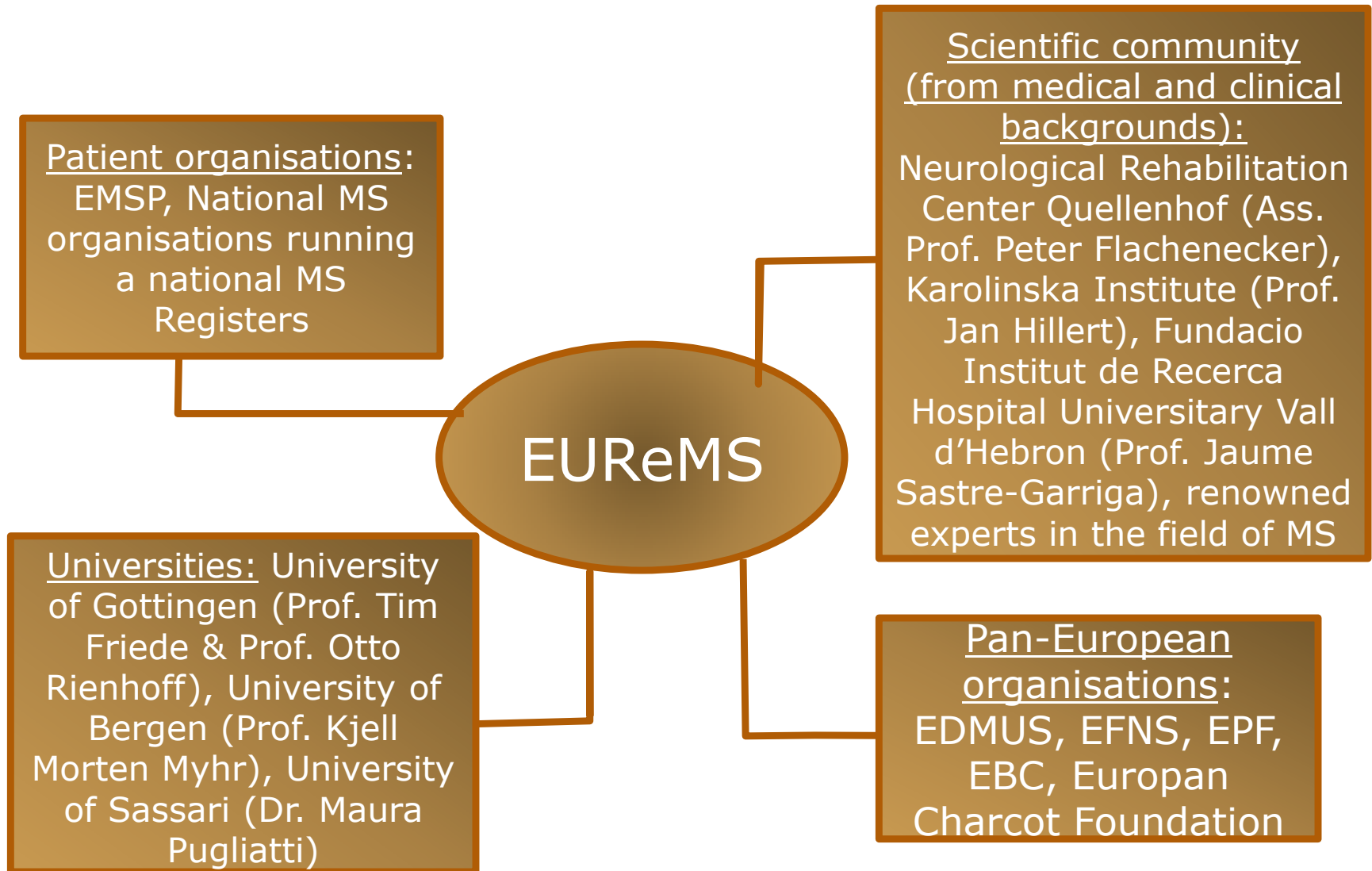
A short questionnaire
generating basic
medical data

A more detailed
questionnaire
generating socio-
economic data

Main objectives



EUReMS - Multidisciplinary partnership



EUREMS - Methodologies

Development of **analysis strategies and models** for the exploration of the perspective of PwMS and the evaluation of long-terms effects of immunotherapy

Development of **data providers network** for the EUREMS

Development of a data mask to gather appropriate epidemiological, clinical and socioeconomic data on MS

> **Data for scientific research and MS health policies**

Development of **ethical principles, procedures/policies and good governance** for establishing and managing an MS register based upon existing national regulations

Data collection and data quality

- Focused data management and defined quality standards in cooperation with ECTRIMS
- Medical data filled by medical expert
- Socio-economic data filled in by patient plus dedicated documenter

COMMISSION DECISION

C(2010)7593 of 27 October 2010

on the awarding of grants for proposals for 2010 under the second Health Programme (2008-2013)

http://ec.europa.eu/health/programme/docs/award_decision2010.pdf

ANNEX V

Second programme of Community action in the field of health (2008-2013)

Call for proposals 2010 – List of proposals in reserve for the award of a financial contribution to specific actions in the form of Projects

Reference number	Marks	Title	Acronym	Main organisation	Ctry	Area	Action	Accepted amount
100893	77	Preventing Depression and Improving Awareness through Networking in the EU	PREDI-NU	University of Leipzig	DE	(HP-2010)	3.3.2.5 Mental health (MH)	1 099 306
101003	77	Screening for Hepatitis B and C among migrants in the European Union	EU-HEP-SCREEN	Erasmus University Medical Center Rotterdam	NL	(HS-2010)	3.2.1.1 Develop prevention and control of existing or emerging Communicable diseases	800 000
100870	77	European Register for Multiple Sclerosis - A tool to assess, compare and enhance the status of People with MS throughout the EU	EUREMS	European Multiple Sclerosis Platform	BE	(HP-2010)	3.3.2.7 Prevention of major and chronic diseases and rare diseases	987 198
3								2 886 504

Total number of proposals:	3
Total accepted amount:	2 886 504

**Thank you
for future co-operation!**

Dr. Eva Havrdova