

The European Multiple Sclerosis Platform

Other EMSP projects in 2013 –
what is in for me?



european multiple sclerosis platform aisbl

Three EMSP projects potentially being relevant for You in 2013 /2014

- **European MS Barometer** – a bi-annual survey (2008, 2009, 2011, 2013 work in progress) used in national roundtables for monitoring & benchmarking)
- **European Register for Multiple Sclerosis EUREMS** (2011-2014)
- **UNDER PRESSURE** = European MS Photo campaign & photojournalistic translation of the Barometer (Phase I :2011-2012 / Phase II: 2013 -???)

MS Barometer

A benchmarking tool

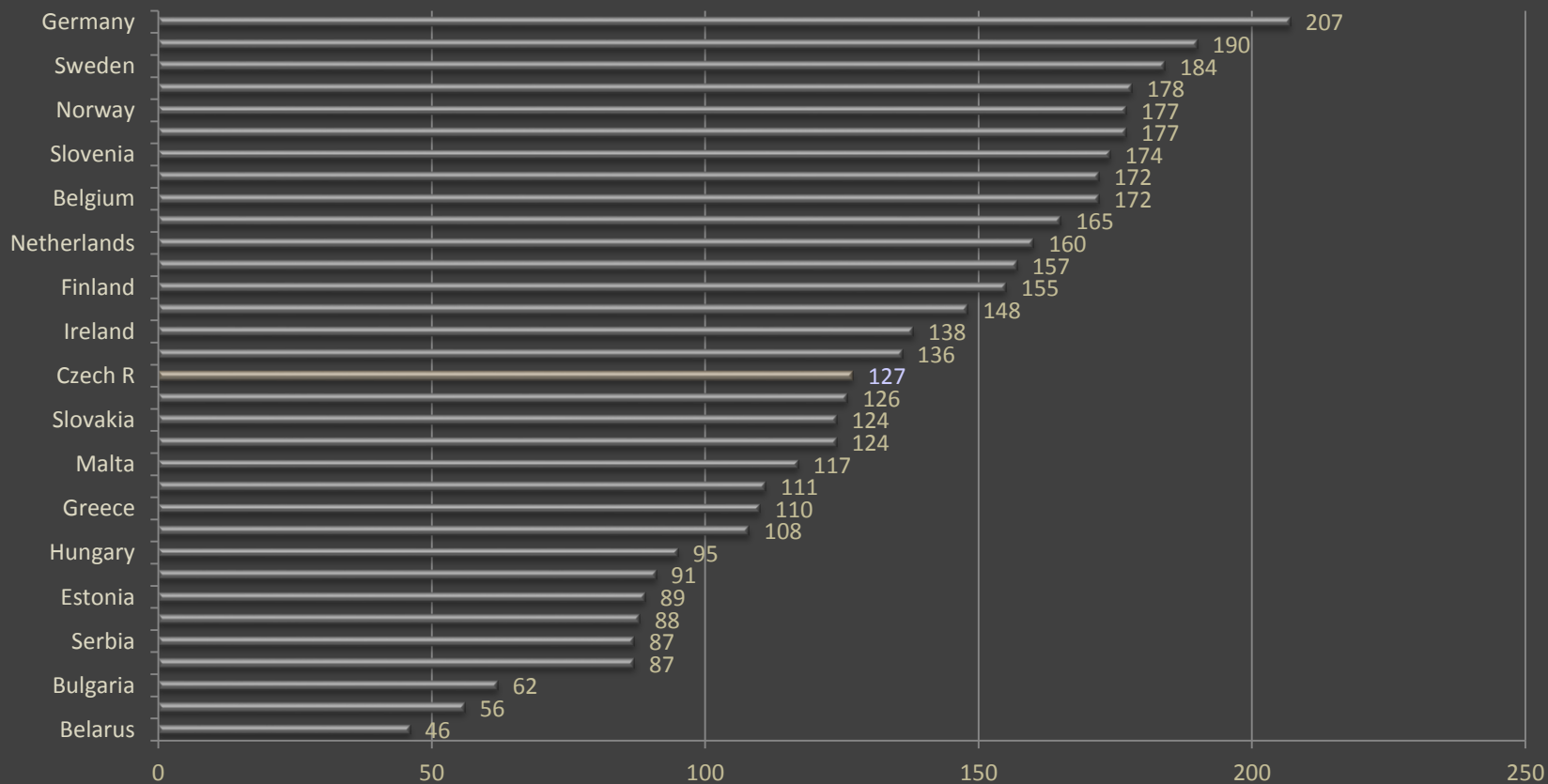
Objective: to obtain an **accurate picture of the situation of people with MS across Europe**

7 Areas:

- Access to treatment & therapies
- Research
- Employment & Job retention
- Empowerment
- Reimbursement of Costs
- Data collection
- Medication coming to the market

MS Barometer

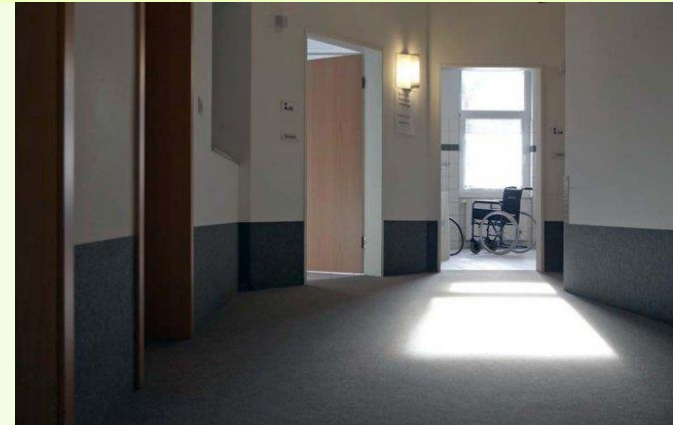
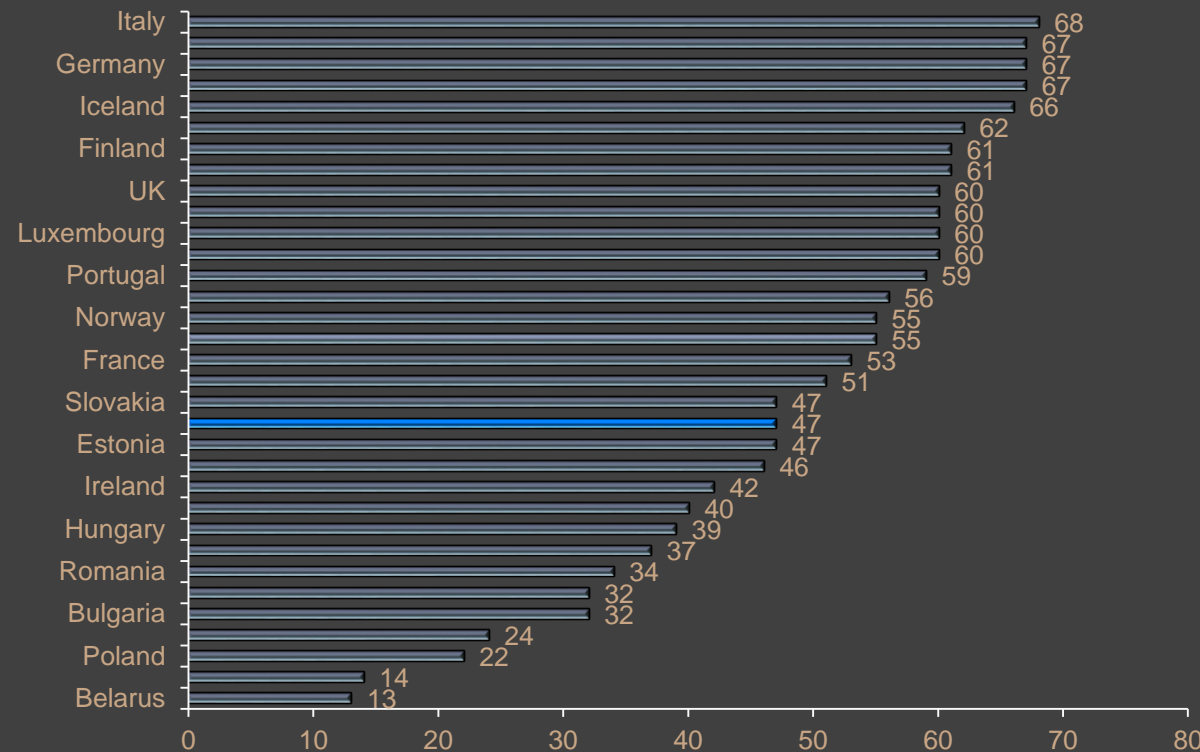
Overall results



Access to treatments and therapies

max. score for this section: 70 points

Access to treatments and therapies
(max. score for this section: 70 points)



Practical uses of the Barometer

At the European level

- Obtaining an accurate picture of the situation of people with MS across Europe and providing comparable data;
- Monitoring implementation of the European Code of Good Practice.



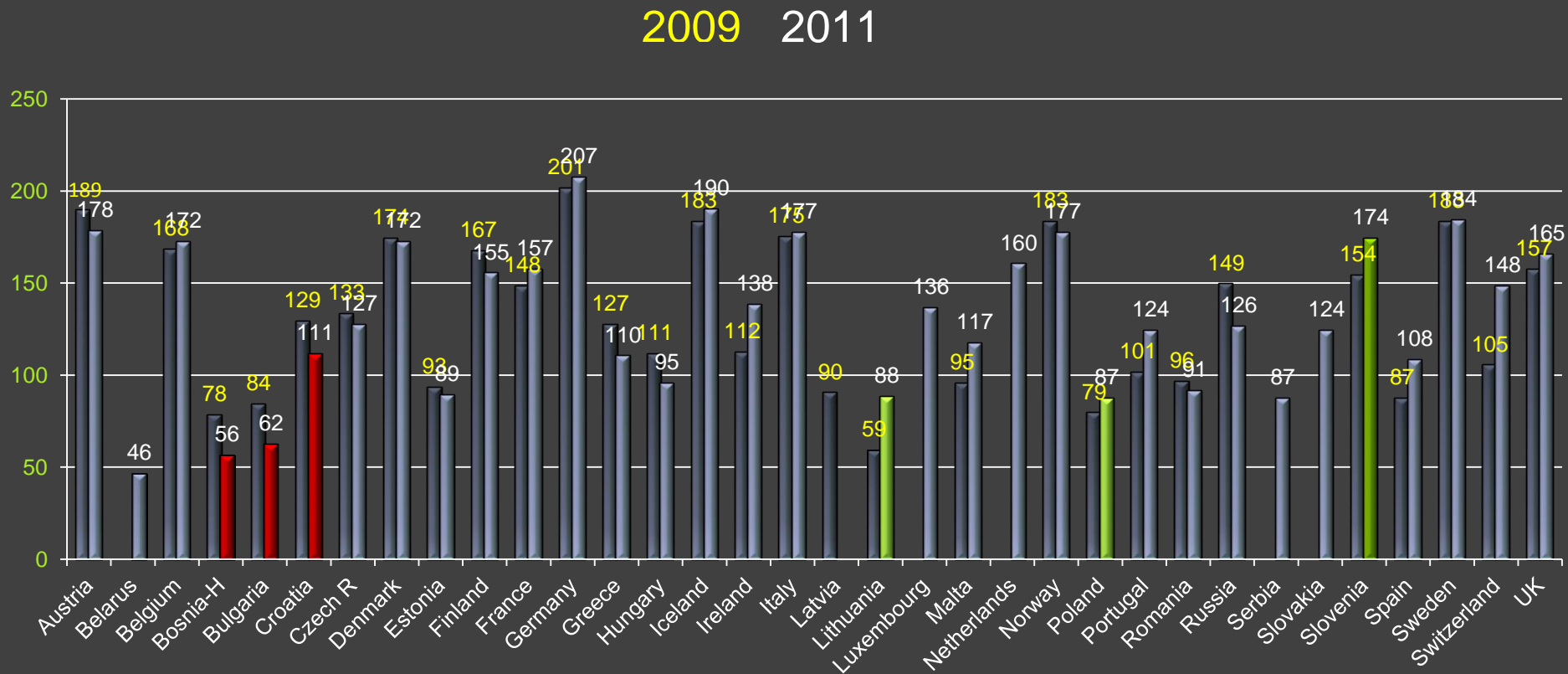
Identification of **Best Practice** between countries with **similar socio-economic situations**.

At national level: High level national Roundtables

Identification of aspects of the condition which are well-managed and areas where administrations need to improve their policies and practices.

Comparison overall results

2009 / 2011



Outcomes of national high level roundtable in Estonia

- **Successful awareness-raising**
- **Specific actions:**
 - From 1 January 2013 (where patients meet the criteria), the Health Insurance Fund will provide 100% compensation for treatment with TYSABRI
 - Pharmaceutical committee has opened discussions on Gilenya

Requests of PwMS being addressed at HLNRT in Lithuania (1)

1 – The costs of EMA authorised MS drugs should be reimbursed

- Higher efficacy treatments are not available and not reimbursed by the state for people with active MS
- MS sufferers experience significant discrepancies in access to the most effective and new disease-modifying treatments compared to people living in other EU countries

2 – Improve access to the highest quality professional rehabilitation services

3 – Improve the system for disability level assessment

Requests of PwMS being addressed at HLNRT in Lithuania (2)

4 – Establishing and implementing EUREMS, the European Register of Multiple Sclerosis patient data

- 3 year project (2011-2014) co-funded by the European Union under the Health Programme and co-sponsors, led by EMSP with 11 associated partners
- **Aim:** to develop a European Register data collection system aimed at improving the quality of life of people with MS, minimising regional inequalities in MS management and serving as tool for epidemiological surveillance of MS in Europe

Using the Barometer

- Did your country use the Barometer, how and to what effect?
- New suggestions on how to use the Barometer
- EMSP Toolkit for Roundtables

European Register for Multiple Sclerosis



- Involve and combines the expertise of clinicians, researchers and patient organisations;
- Address questions by patients, scientists, regulators and industry through clustering of nationally collected patient data at an international level;
- Contribute to continuous fight of patient advocates for improved access for PwMS across Europe to evidence-based health care services;
- Offer a cutting-edge research tool to gain further insights into various aspects of MS, e.g. including long-term effects of the services offered to PwMS and post marketing assessment of new therapies for conditional HTA decisions

By mid 2014, EUREMS will ...

Clinical

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

Political

- Have an agreed set of **core socio-economic data on MS patients** - **partly coming via a new Patient Reported Outcome system**

Scientific

- Involve and partner with broader MS scientific community in EUREMS on **research projects and in long term development**

Outlook

- Utilise EU funds for **studies on MS being used by patient advocates, regulators, HTA bodies and others**
- **Expand the EUREMS network across Europe**

As of July 2014: Coordination Centre of EUREMS

- Partnership agreed in principle between EMSP, ECTRIMS, RIMS
- Coordinates and enlarges the Network of MS Registries (at least 10 Registries should already sign a contract with EMSP by June 2014)
- Initiates, coordinates and supports EUREMS based studies
- Disseminates the results of the studies to users and stakeholders

EUReMS

- Is there room for the new countries with their registries to join?
- Can countries, not involved or without a register, benefit from EUReMS?

UNDER PRESSURE

- A photojournalistic translation of the **MS Barometer** findings on inequalities in healthcare and social support in Europe
- A means of **allowing persons with MS to tell their own stories** of how the disease impacts their lives.



Reportage in 12 countries

- Belarus
- Estonia
- Germany
- Greece
- Iceland
- Ireland
- Italy
- Poland
- Romania
- Spain
- United Kingdom
- France

Objectives

- To **humanise the data** collected through the MS Barometer.
- To **provide a high-impact means of comparing** (across 12 countries) how health and social policies either alleviate or relieve the burden of MS.
- To **show policy makers** what it feels like to have MS – *right here, right now*.

What is available to be used?

NOW:

- 600 photographs (selected from ca. 10.000)
- 38 exhibition panels (75cm x 100) with some of those photos
- UP Multimedia website as of today (May 4th, 2013) incl. videos
- UP Brochure

LATER

- more videos of 5 – 7 minutes
- 30+ patient interviews (video)
- 20+ expert interviews (video)

Exhibition



Under Pressure: top event of MS week

The purpose of the exhibition, which is strictly free, is also to include the event in a larger schedule of international events in order to raise awareness (as it was done at the European Parliament in April 2012, and in Barcelona in May 2012) building around the show a detailed communication plan that aims to involve a large target audience, from middle school students to the institutions.

Street exhibition in Rome and Milan

Targets to be reached: institutions, media, large audience - especially young people

The exhibition, with its challenging themes and its artistic and cultural values, is organized in Italy as a street exhibition. It is designed as a value for all, today, tomorrow, always. It is also transmitted as a treasure to make our own and to bring on as inheritance. Young people, who this year are the protagonists of the international WMSday campaign, and students are the main recipients.

Exhibition

The exhibition, dealing with a social theme, finds its privileged location in a metropolitan context in which the photographs can get in touch with audience from all over the world. The choice of the location in Milan is one of the most interesting and central street (Via Dante), while in Rome it is still to be defined at the time of writing.



Via Dante, Milano

Schedule of the Street Exhibition

3rd-16th May: Milan

20th May-2nd June: Rome

- Do you have a suggestions on how you could use the Under Pressure materials?
 - For public relations
 - Awareness
 - Lobbying + Influencing

www.emsp.org

Contact us:

European Multiple Sclerosis Platform

christoph.thalheim@emsp.org

Rue Auguste Lambiotte 144,

B-1030 Brussels

+32 2 305 80 15

Thank you