



MS Barometer 2011

**Workshop C: MS Barometer and its photo
journalistic translation “Under Pressure”**

Elisabeth Kasilingam
EMSP Annual Congress, 19th May 2012, Barcelona

MS Barometer

- ❖ 2008: first MS Barometer launched in the framework of the MS-ID project, co-financed by the European Commission under the Public Health Programme.



- ❖ Main goal of this benchmarking tool: to obtain an accurate picture of the situation of PwMS across Europe through answers to key questions about obstacles and barriers faced by PwMS
- ❖ In 2011, 33 countries were represented versus 29 countries in 2009.



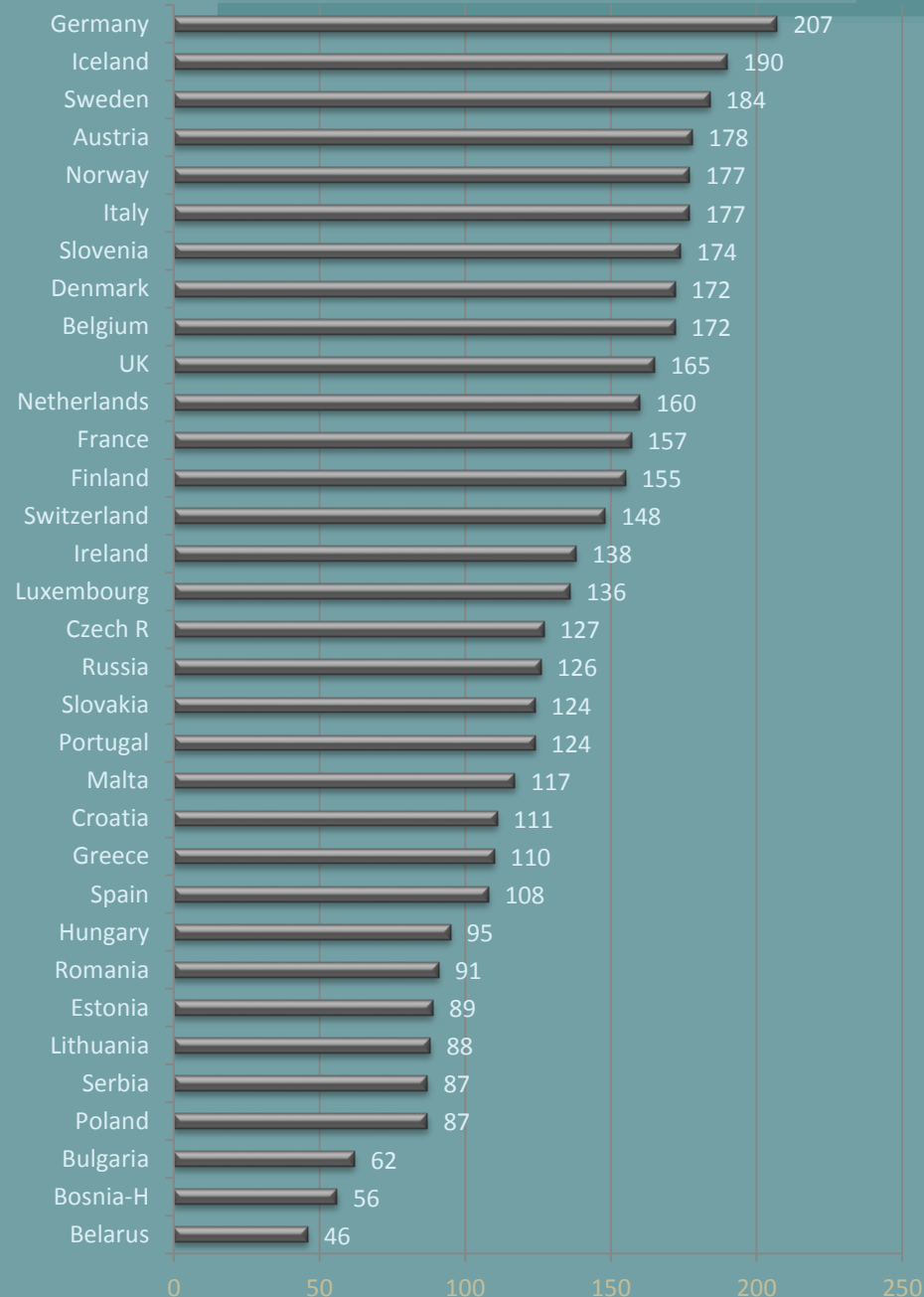
Structure of the MS Barometer

- Structure of the Barometer inspired by **European Code of Good Practice**
- Extensive transnational consultation with the medical and patient communities to review content in 2009
- **7 Areas:**
 1. Access to treatment & therapies (19 questions – 70 points)
 2. Research (3 questions – 15 points)
 3. Employment & Job retention(8 questions – 35 points)
 4. Empowerment (7 questions – 35 points)
 5. Reimbursement of Costs (6 questions – 30 points)
 6. Data Collection (5 questions – 25 points)
 7. Medication coming to the market (3 questions – 15 points)

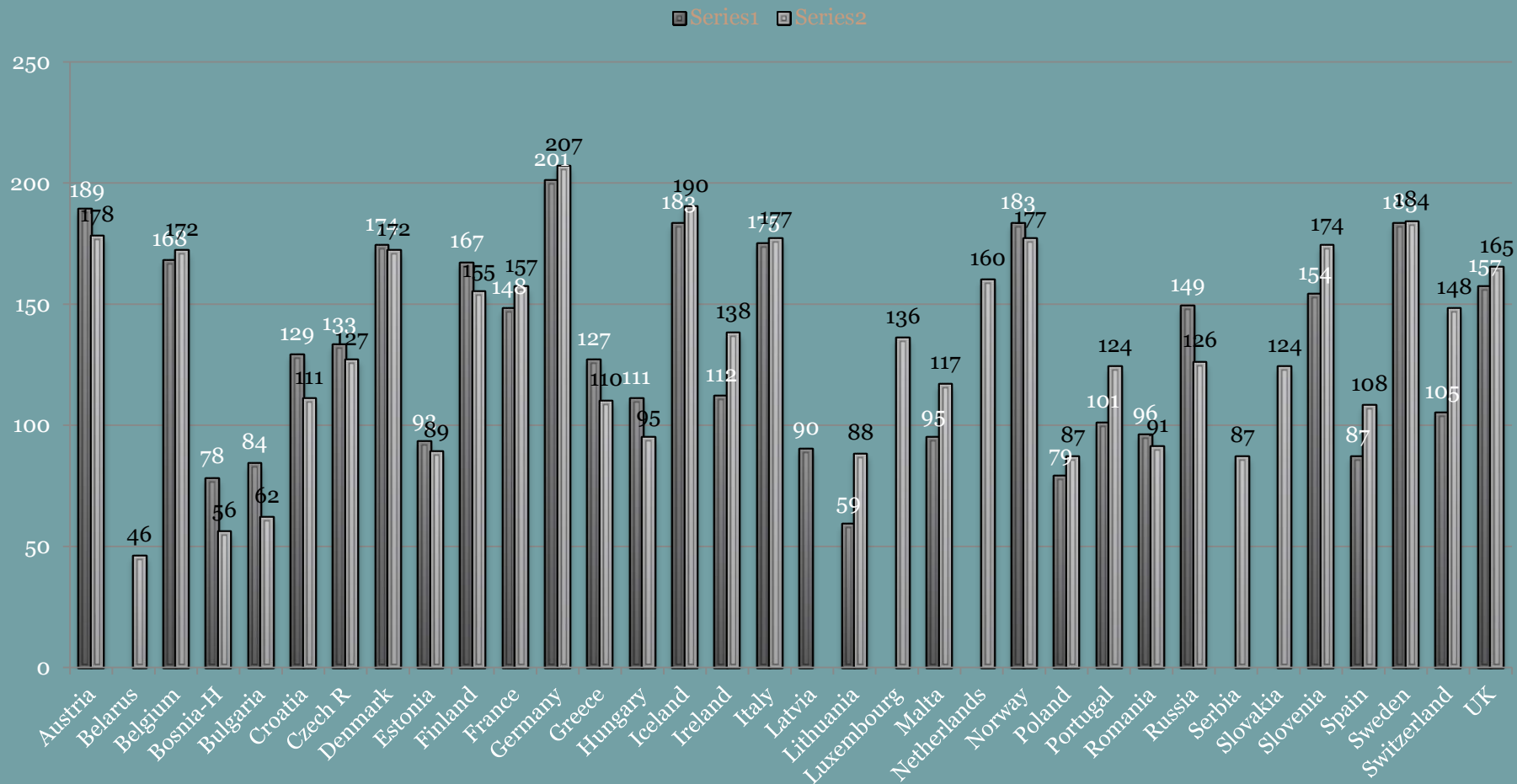
Barometer 2011: Overall results



- Max. score: 225 points
- 33 countries



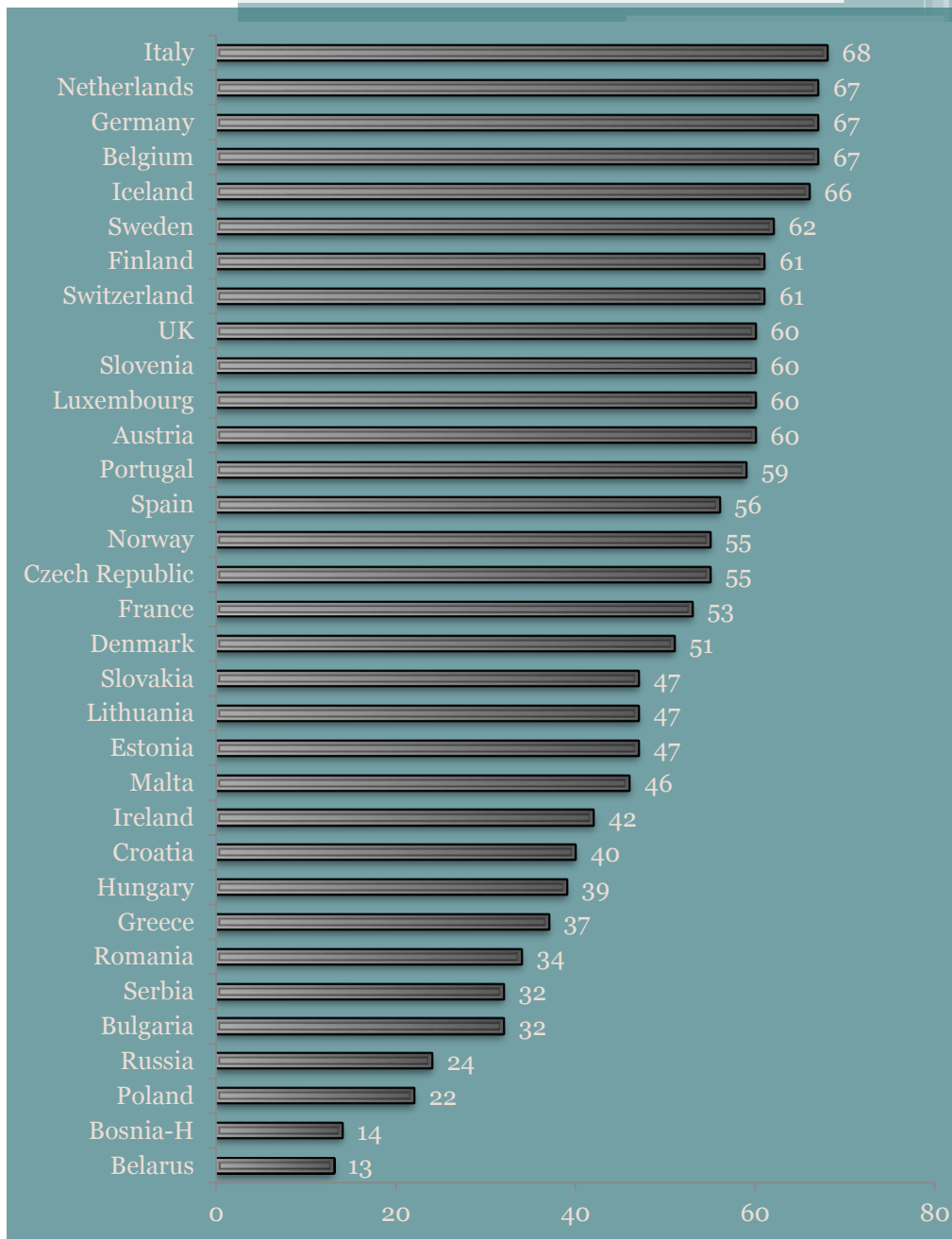
Comparison overall results 2009 (series1) / 2011 (series2)



Access to treatments and therapies

Striking differences between 2009/2011

- Lithuania: 60 points to 47
- Ireland: 28 to 42

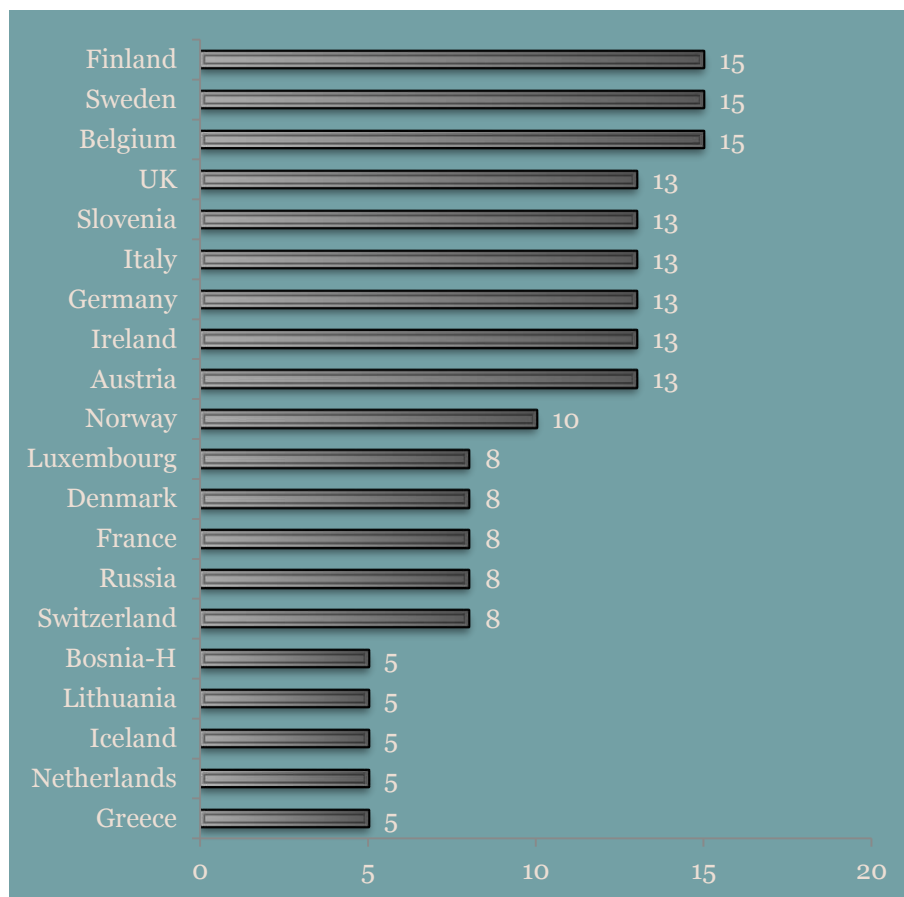


Research Agenda on MS

Striking difference between 2009/2011

Iceland: 15 points to 5

The MS societies in the following countries do not have access to grants/schemes for research and do not have any kind of influence on the national research agenda on MS: Belarus, Bulgaria, Croatia, Czech Republic, Estonia, Hungary, Malta, Poland, Portugal, Romania, Serbia, Slovakia and Spain.

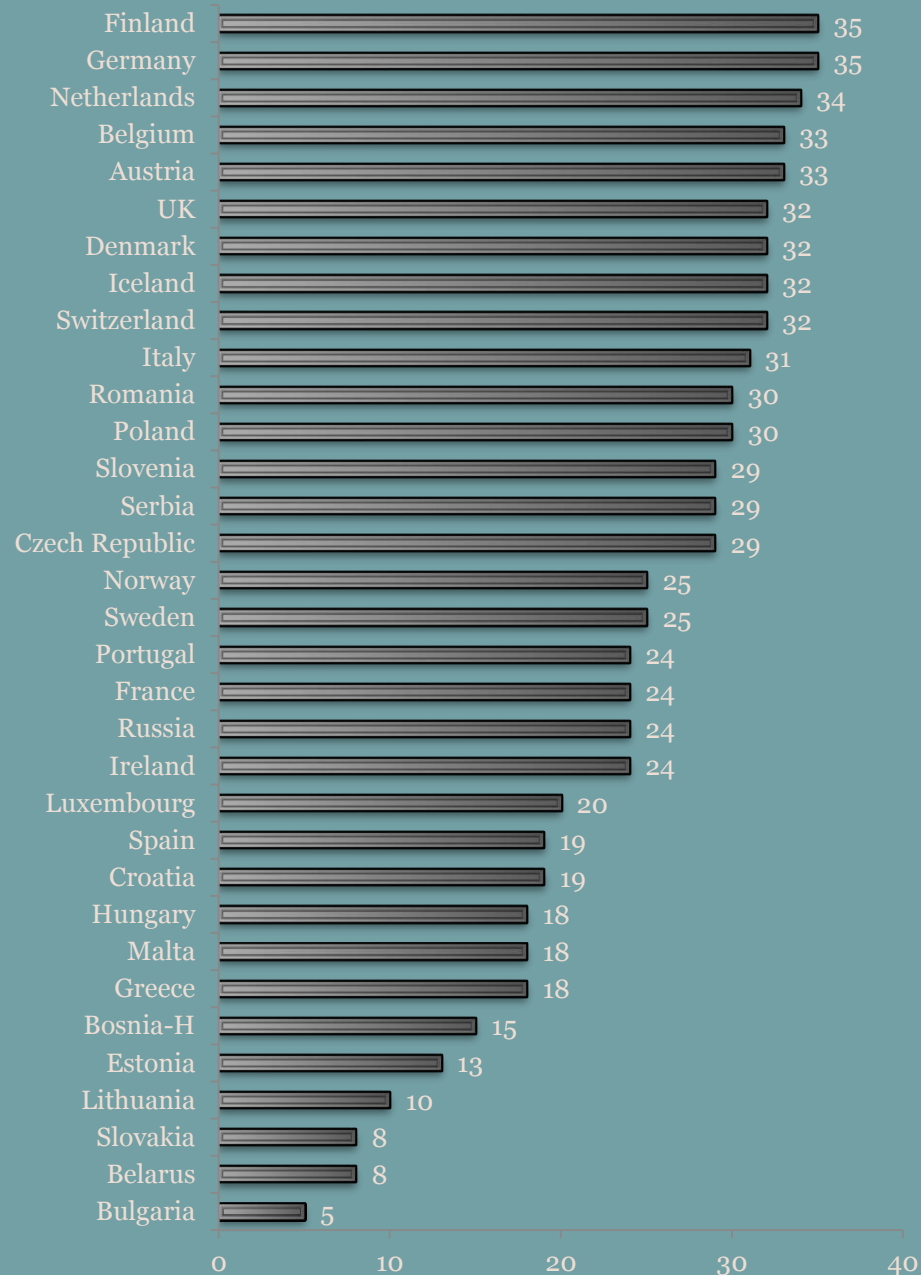


Employment

- ❖ **Access to employment** for Persons with disabilities: **a challenge** in European Countries
- ❖ Percentages of PwMS in active work remain low
- ❖ **Lack of adequate income** affects the quality of life of PwMS

Striking differences between 2009/2011

- Switzerland: 13 points to 32
- Portugal: 11 to 24
- Spain: 4 to 19
- Bulgaria: 19 to 5

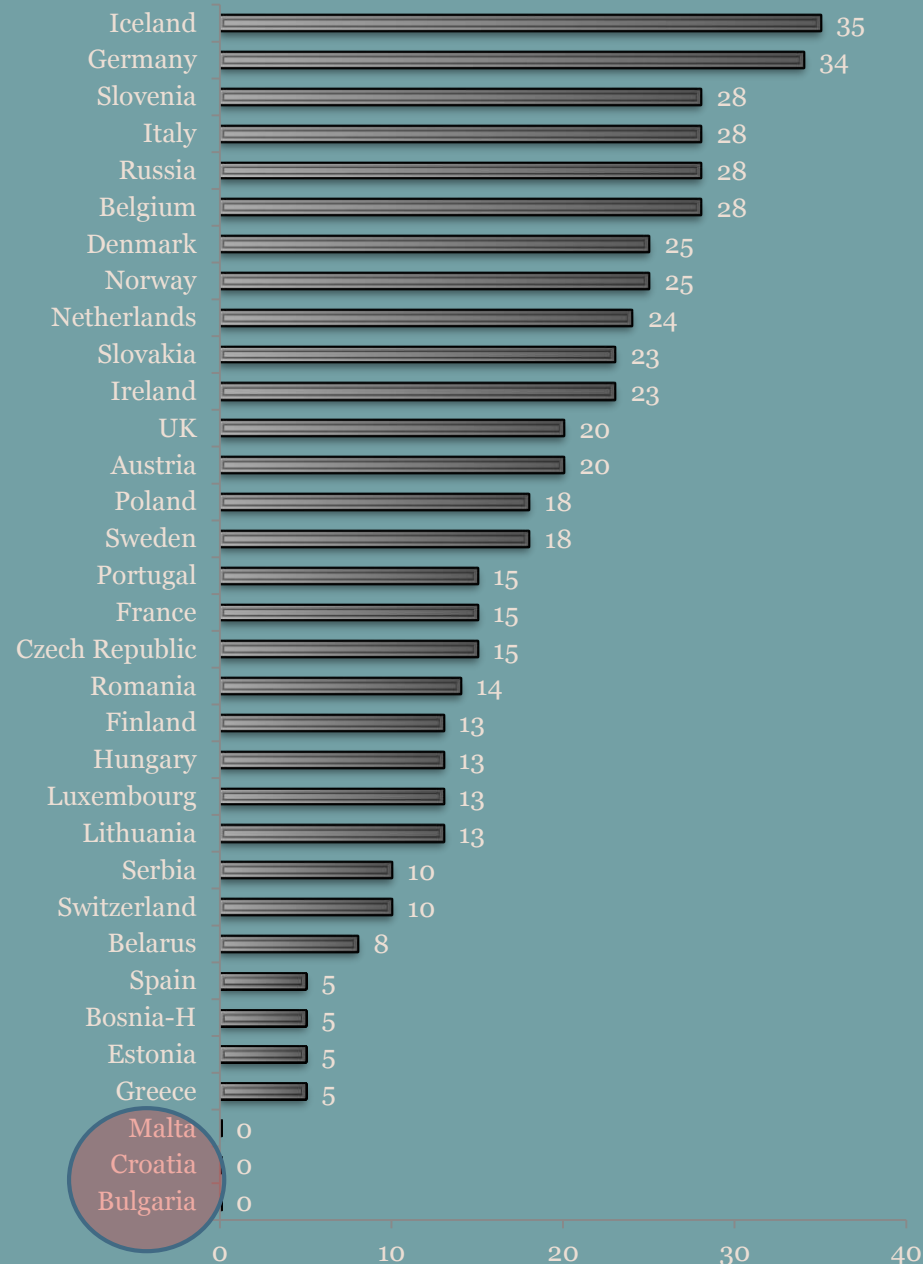


Empowerment of PwMS

- ❖ **Lack of consultation** with MS societies or group by political decision makers
- ❖ Added value of the **input of PwMS in the decision making process** for new MS therapy
- ❖ Empowerment of PwMS can be developed through **State support** (e.g. Iceland, Norway, Germany)

Striking differences between 2009/2011

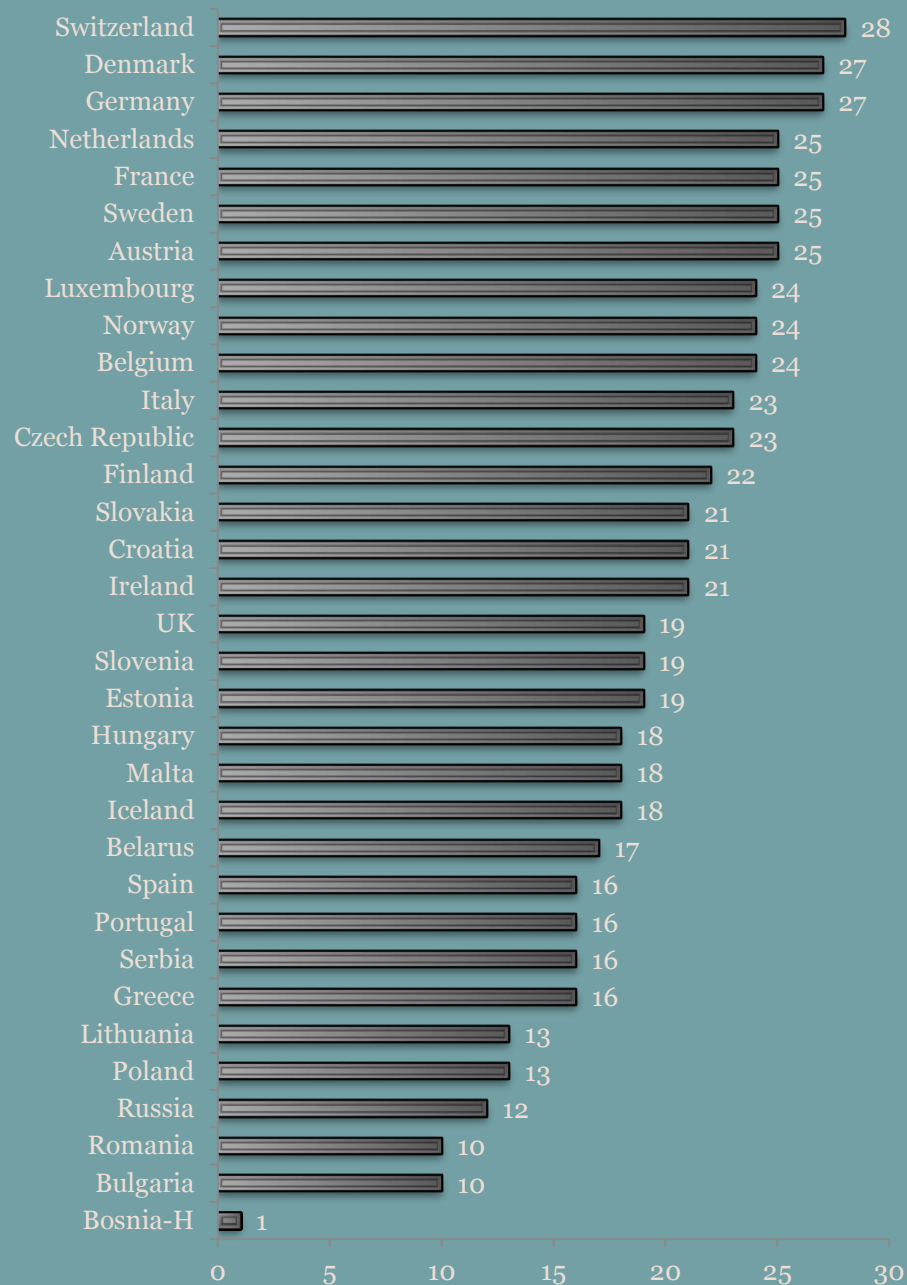
- Poland: 8 points to 18
- Lithuania: 0 to 13
- Switzerland: 0 to 10
- Estonia: 13 to 5
- Croatia: 8 to 0



Reimbursement of costs

Striking differences between 2009/2011

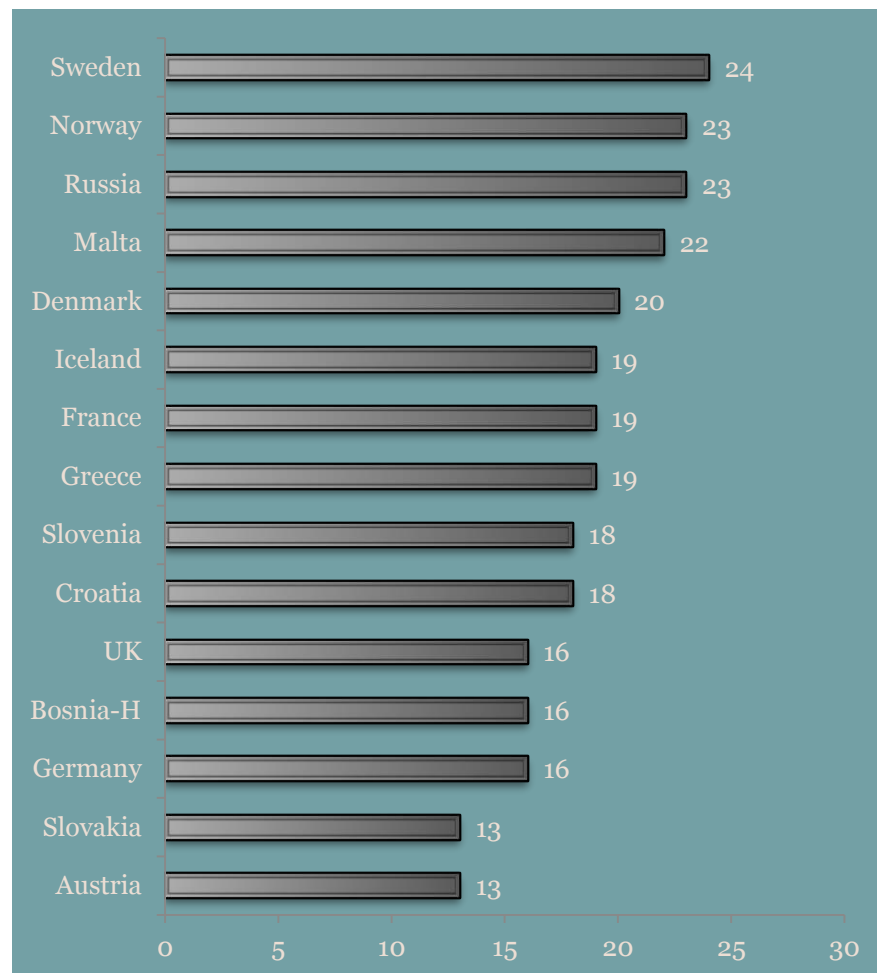
- Estonia: 13 points to 19
- Bulgaria: 17 to 10
- Bosnia: 9 to 1



Data collection

Only 15 countries have stated having national MS registers: Austria, Bosnia-H, Croatia, Denmark, France, Germany, Greece, Iceland, Malta, Norway, Russia, Slovakia, Slovenia, Sweden and UK.

In 2009, **13 countries** stated having national MS registers: Austria, Bosnia-H, Croatia, Denmark, France, Germany, Greece, Latvia, Malta, Norway, Russia, Slovenia and Sweden.

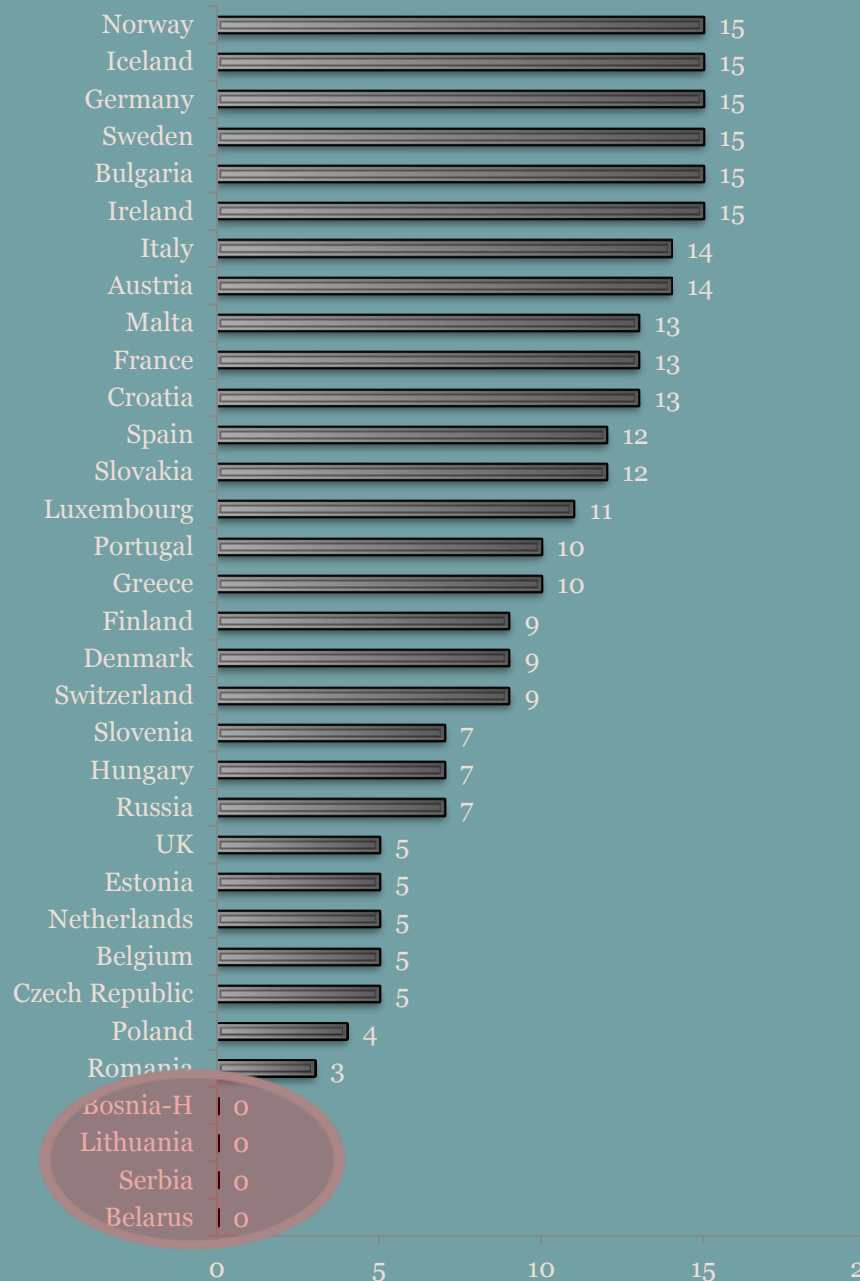


Medication on the Market

- ❖ Even **drugs approved** by EMA or National Drug regulatory body are **not accessible**:
 - Administrative delays (e.g. Tysabri)
 - Reimbursement costs not approved
- ❖ **The situation is particularly alarming** in Bosnia-Herzegovina, Lithuania, Serbia and Belarus.

Striking differences between 2009/2011

- Bulgaria: 9 points to 15
- Malta: 7 to 13
- **Russia: 15 to 7**
- **Czech Republic: 10 to 5**



THANK YOU !!!

For further information, please contact:

Elisabeth Kasilingam

Elisabeth.kasilingam@emsp.org

The European Multiple Sclerosis Platform

Rue Auguste Lambiotte 144/8

B-1030 Bruxelles

www.emsp.org

