

# The increasing differences in MS care in Europe – and patient driven measures for improvement

ECTRIMS 2015

**Anne Winslow,**  
***President European Multiple Sclerosis Platform (EMSP)***

# EMSP – our vision and mission

## A WORLD WITHOUT MS

### ADVOCACY

- ✓ Ensure the voice and influence of people with MS is recognised
- ✓ Campaign for equitable access to high quality treatment, services and employment across Europe

### KNOWLEDGE and EXPERTISE

- ✓ Share and promote evidence-based best practice
- ✓ Foster effective cooperation between people affected by MS, health professionals, policy decision-makers and researchers

### RESEARCH

- ✓ Encourage and support high quality MS research and international MS research collaboration
- ✓ Support the collection, pooling and interrogation of essential MS data across Europe

## IMPROVING THE QUALITY OF LIFE OF MORE THAN 700,000 PEOPLE WITH MS ACROSS EUROPE

European MS data  
collection for  
research and  
better outcomes:  
**EUREMS**

Comparative  
survey of the  
national situation  
in 38 European  
countries:  
**MS Barometer**

Online education  
supporting the  
crucial role of  
European MS  
nurses:  
**MS Nurse PRO**

European Code of  
Good Practice in  
MS:  
**Defeating MS  
Together**

Multi-media  
campaign to raise  
awareness of the  
impact of MS:  
**Under  
Pressure**

Improving access  
to employment  
for young people  
with MS:  
**Believe and  
Achieve**

# DATA, Data, Data: MS BAROMETER 2013 and Voice of the MS Patients' survey 2015

**Objective:** provide a picture of the situation of people with MS across Europe.

## MS BAROMETER: 7 Priority areas

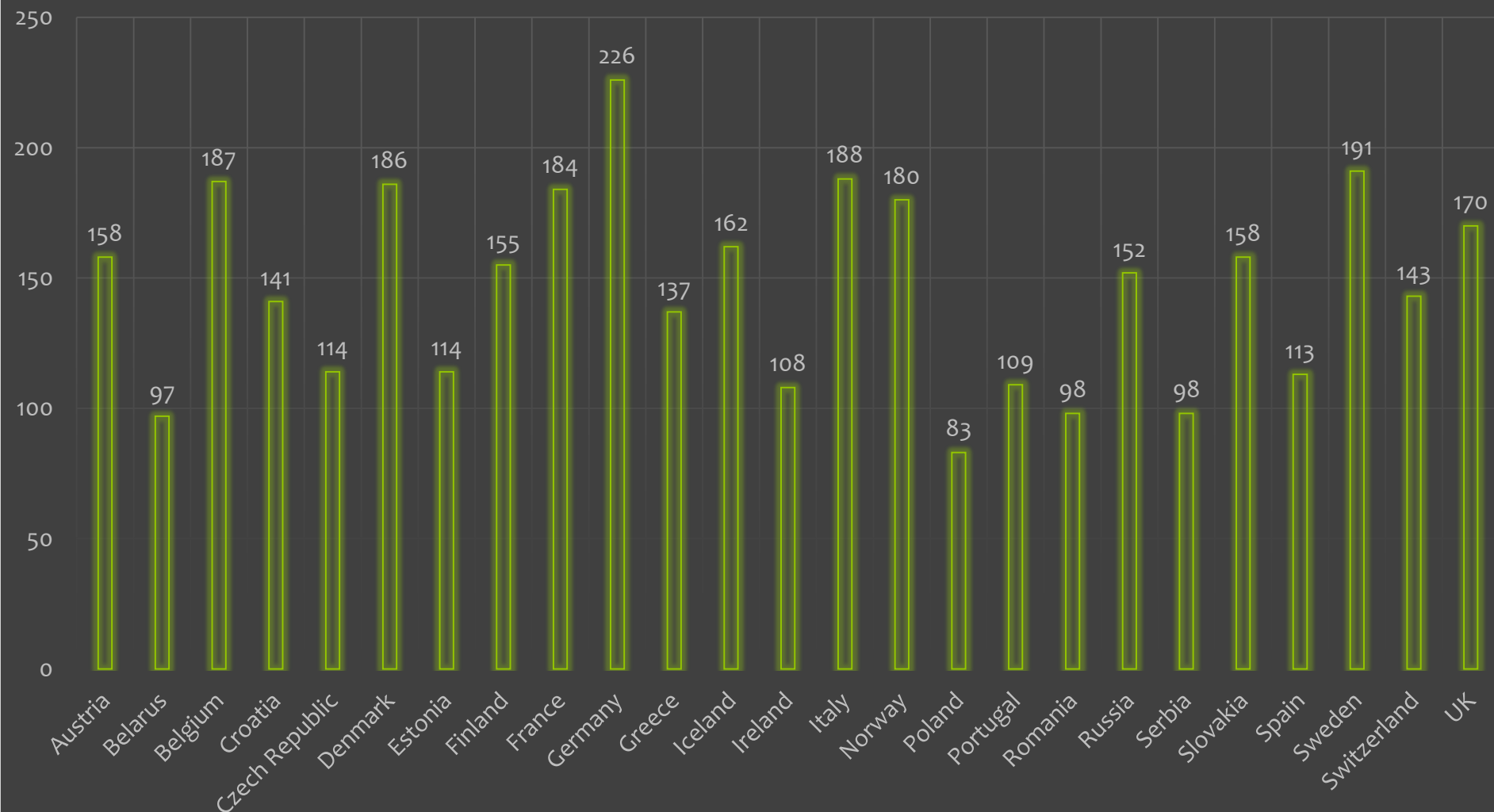
- ✓ Access to treatment & therapies
- ✓ MS Research
- ✓ Education, Employment & Job retention
- ✓ Empowerment of people with MS
- ✓ Reimbursement of Costs
- ✓ Accurate Data Collection
- ✓ Medication coming to the market

## Voice of the MS Patients' survey:

- ✓ Demographics
- ✓ Empowerment of people with MS
- ✓ Access to medicines and therapies
- ✓ Availability of therapies/services
- ✓ Quality of life
- ✓ Accurate Data Collection
- ✓ Education and employment

# MS Barometer 2013 - overall results

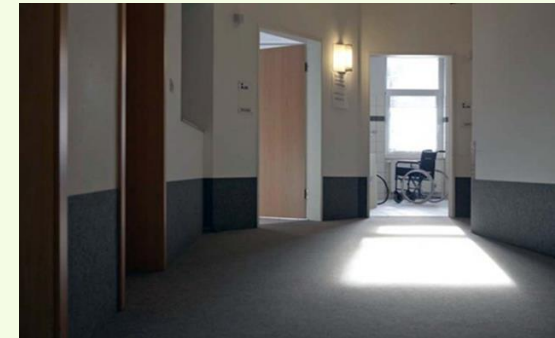
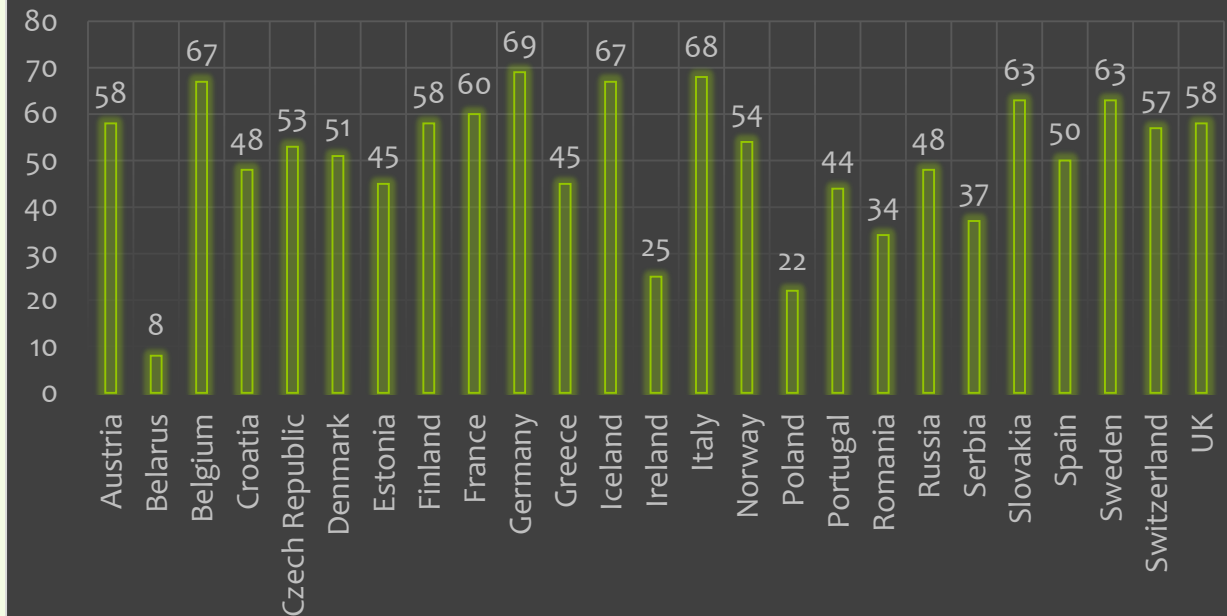
■ Max. score for the overall Barometer: 245 points



# ACCESS TO TREATMENT AND THERAPIES

## Section 1: access to treatments and therapies

□ Max. score for section 1: 70 pts



# Case study: Patients do have a say about their treatments!

EMA says  
“NO”  
to  
FAMPYRA

People  
with MS  
raise their  
voice

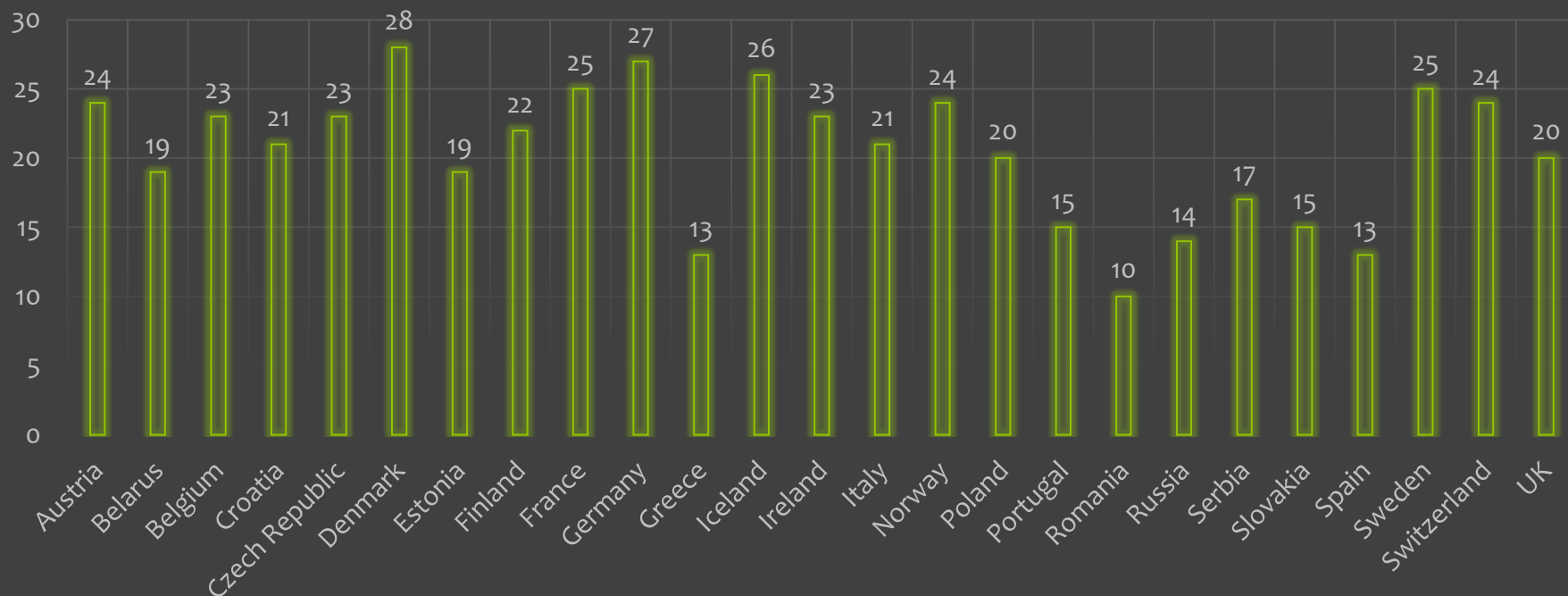
Building  
up a  
strong  
coalition  
via EMSP

EMA  
approves  
the drug

# REIMBURSEMENT OF COSTS

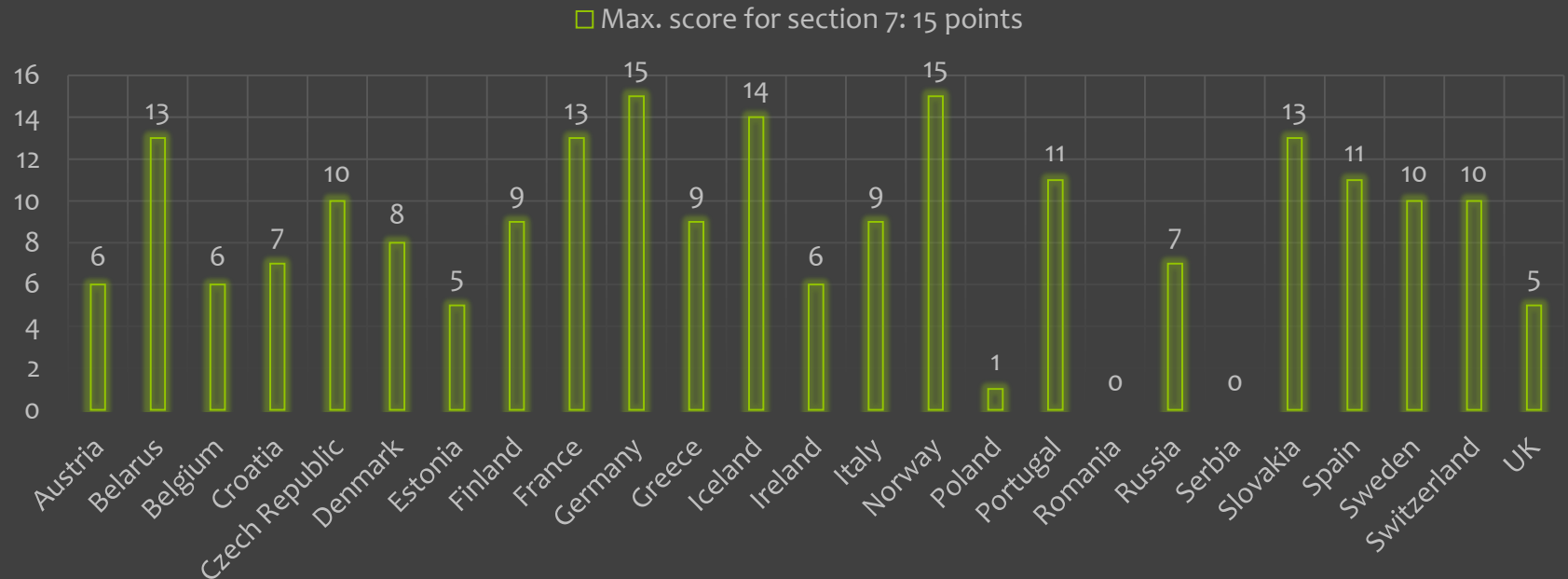
## Section 5: Reimbursement of costs related to MS

□ Max. score for section 5: 30 points



# MEDICATION COMING TO THE MARKET

## Section 7: Medication coming to the market



# MEDICATION COMING TO THE MARKET

- All drugs being authorised by EMA or NCAs should be reimbursed
- Administrative and legal delays should be reduced to allow better access to the drugs for all medically entitled patients

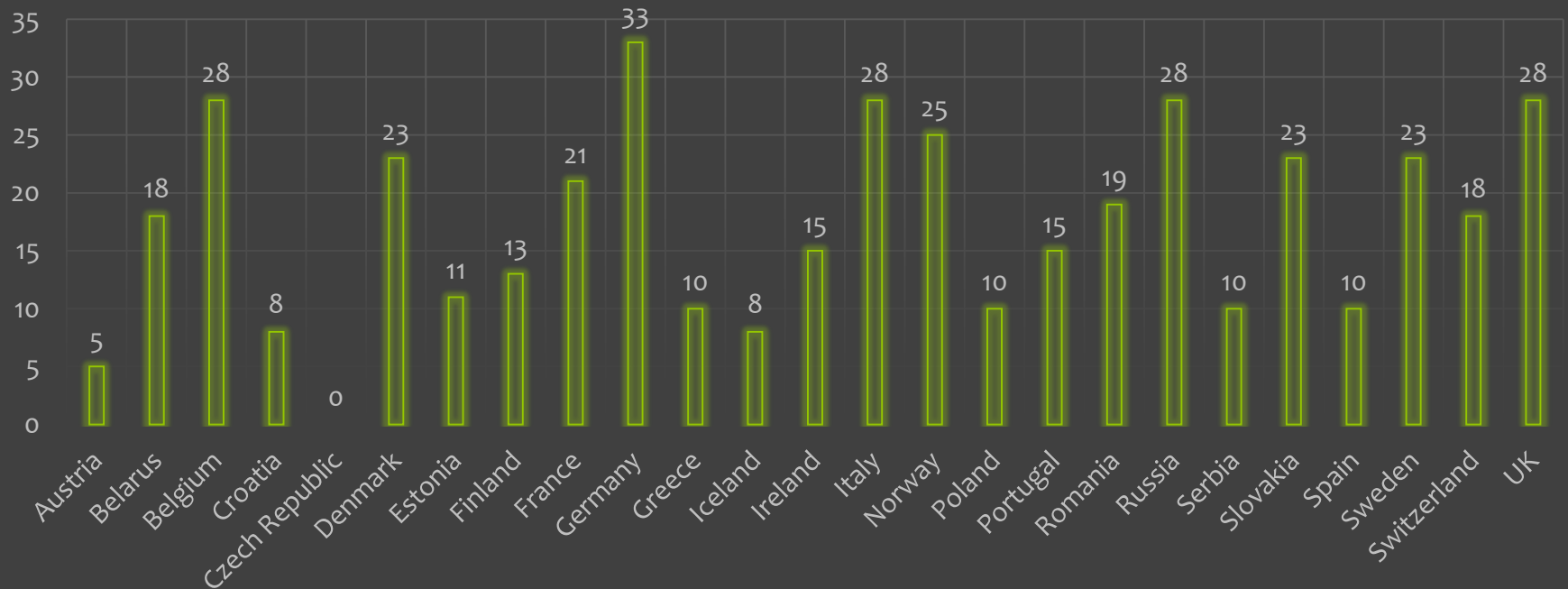
*(see TIME MATTERS poster here at ECTRIMS!)*



# INVOLVEMENT AND EMPOWERMENT OF PEOPLE WITH MS

## Section 4: Involvement and empowerment of people with MS

□ Max. score for section 4: 35 points



# EMPOWERMENT OF PEOPLE WITH MS

## How to improve empowerment?

- ✓ Encourage representation of people with MS in consultative political bodies
- ✓ Initiate and promote self-management course
- ✓ Participation in health literacy courses being offered in many countries



# Case study II: Patients propose new ways towards improved drug safety !

Very rare cases of PML appear for two newer drugs

EMA discusses possible solutions with the two MAHs separately for many months without final conclusion

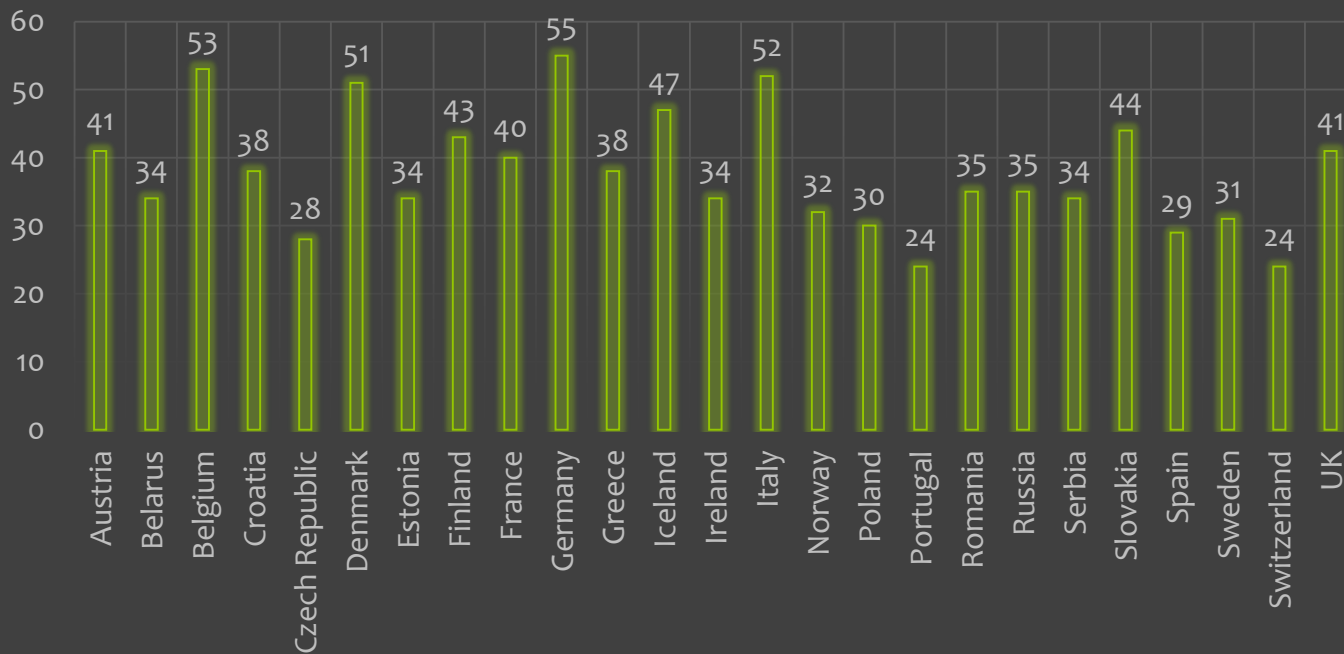
EMSP as European voice of patients suggests “roundtable” talk with both MAHs and EMA experts

Two MAHs + EMA discussing severe safety issue TOGETHER – the way forward to obtain faster solutions?

# EDUCATION, EMPLOYMENT AND JOB RETENTION

## Section 3: Education, employment and job retention

□ Max. score for section 3: 55 points



# Improving access to employment

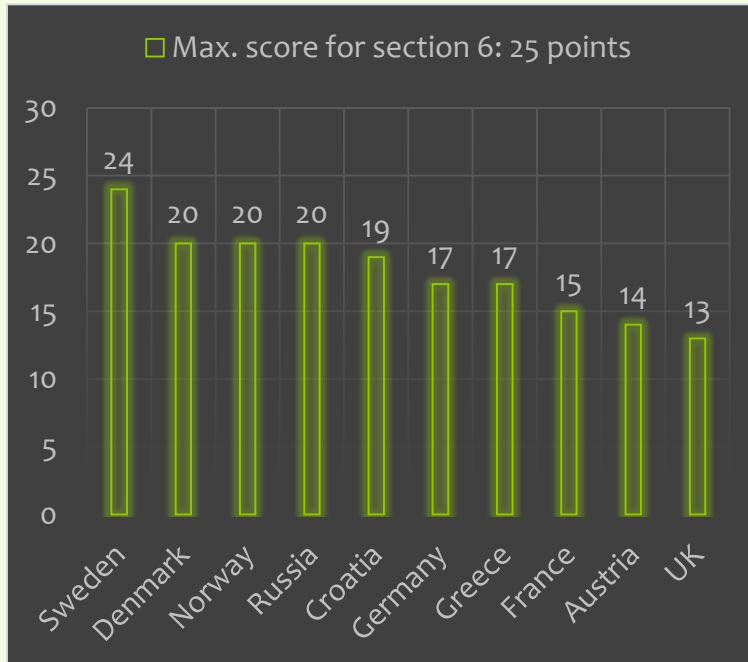
Addressing all stakeholders:

- **Believe & Achieve** training programme for young people
- **Paving the Path to participation** project (co-funded by the European Commission) : development of a European Employers' Charter and a toolkit for the employers
- **Ready to work** project – in collaboration with the Work Foundation and Novartis

# MS RESEARCH

- Need for more public funding to support research in the field of MS in most of EU countries
- Better collaboration between MS societies, national authorities and scientific committees would increase influence on the national research agendas and enhance the outcomes (e.g. via EU projects)
- Added value of involving patients in the scientific process: they bring real-life experience of the disease and its current therapeutic environment - Example: patient relevant endpoints for clinical trials...

# ACCURATE MS DATA COLLECTION



europa  
european register  
**eurems**  
project of european multiple sclerosis platform

# European Register for MS: a successful EU co-funded project 2011-2015

- Collaborative and geographically representative **Network of MS data providers in Europe**;
- Inspiration for creation of new national registries: Poland, Czech Republic, Switzerland and the UK
- Validated procedures and methodology for MS data merging;
- IT infrastructure for pooling and analysis of (pooled) MS data at UMG;
- Ethical and legal framework for cross-border MS data analysis on the base of temporary data pooling.

# European Network of MS registries to develop “SINGLE EUROPEAN PLATFORM FOR PATIENT RELEVANT OUTCOMES” ?

- Medical data alone from traditional clinical trials are no longer “golden standard”
- Both clinical research and patient advocacy is longing for stronger real life evidence
- Patient Reported and Patient Relevant Outcome Data are expected to grow into a major role as second criteria for future regulatory and pricing /reimbursement decisions together with clinical data from registries and clinical trials.

# Under Pressure trailer



# Under Pressure trailer



# EMSP Strategic Plan 2015 - 2020

- Five priorities
  1. Access to treatment, therapies, rehabilitation and services
  2. Employment, job retention and education
  3. Understanding Paediatric MS
  4. MS research
  5. Empowerment of MS carers

EMSP will work collaboratively with its members, its industry partners and the scientific community to move forward this agenda

# ....and Finally

- Persons with MS are the real experts on their conditions
- We must find ways to appropriately include people with MS in the decision-making process in areas affecting their quality of life
- It is not just an option but a must

# THANK YOU !

## CONTACT:

[christoph.thalheim@emsp.org](mailto:christoph.thalheim@emsp.org)

or

[elisabeth.kasilingam@emsp.org](mailto:elisabeth.kasilingam@emsp.org)

[www.emsp.org](http://www.emsp.org)

The European Multiple Sclerosis Platform

Rue Auguste Lambiotte 144, B-1030 Brussels

+32 2 304 50 13