

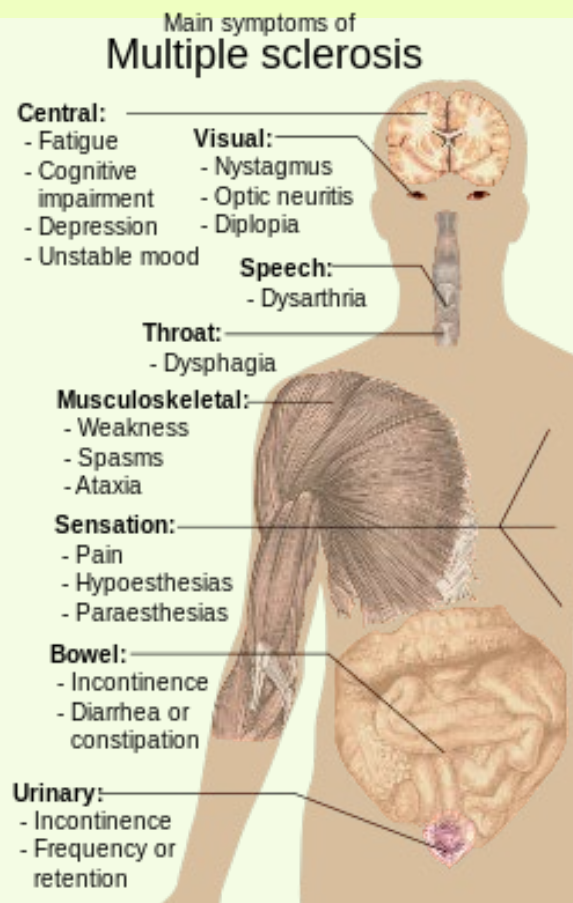


Early advocacy successes in neurology and future roadmap; putting MS persons at the centre

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What is Multiple Sclerosis?

- Multiple sclerosis (MS) is a neurological condition commonly diagnosed between the ages of 20 and 35. There is no cure, it is unpredictable and it lasts a lifetime.
- MS affects the Central Nervous System that is the eyes, the brain, the spinal cord & all connections.
- Common MS symptoms include: blurred vision, extreme fatigue, pain, numbness in legs and hands, loss of movement and speech problems.
- Management includes personal support, disease modifying therapies, health management, professional care and empowerment.



The European MS Platform

The European Multiple Sclerosis Platform (EMSP) represents National MS Societies in 34 European countries*

EMSP represent **600,000 persons with MS** and **1.5 million people daily affected by MS.**



* Austria, Belarus, Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France (x2), Germany, Greece, Hungary (x2), Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain (x2), Sweden, Switzerland, UK.



Major EMSP Projects

- **European CODE of Good Practice** in MS and the European Therapy Guidelines and Consensus Papers (EP request in 2003)
- **Multiple Sclerosis Information Dividend** – a feasibility study for European patient data collection (2007-2009)
- **European MS Barometer** - a bi-annual survey (2008, 2009, 2011) used in national roundtables for monitoring & comparison)
- **European Register for Multiple Sclerosis** (2011-2014)
- **UNDER PRESSURE** = European MS Photo campaign & photojournalistic translation of the Barometer (Phase I :2011-2012)
- **MS Nurse PROfessional** online training and campaign for their empowerment = better services for PwMS (2011 – 2013)

EU Code of Good Practice

The “CODE” is a political statement reflecting “state of the art” practice outlined in the following European Guidelines:

- Disease modifying therapies (e.g. Interferons)
- Symptomatic treatments (e.g. against bladder problems)
- Rehabilitation
- Palliative Care
- MS Nursing
- Principles of Quality of Life (developed by MSIF)

The MS Barometer

The Goal

• **Accurate picture of the situation of people with MS across Europe through answers to the key questions about obstacles and barriers faced by people with MS.**



Seven Areas

Section 1: Access to treatment & therapies (19 questions – 70 points)

Section 2: Research (3 questions – 15 points)

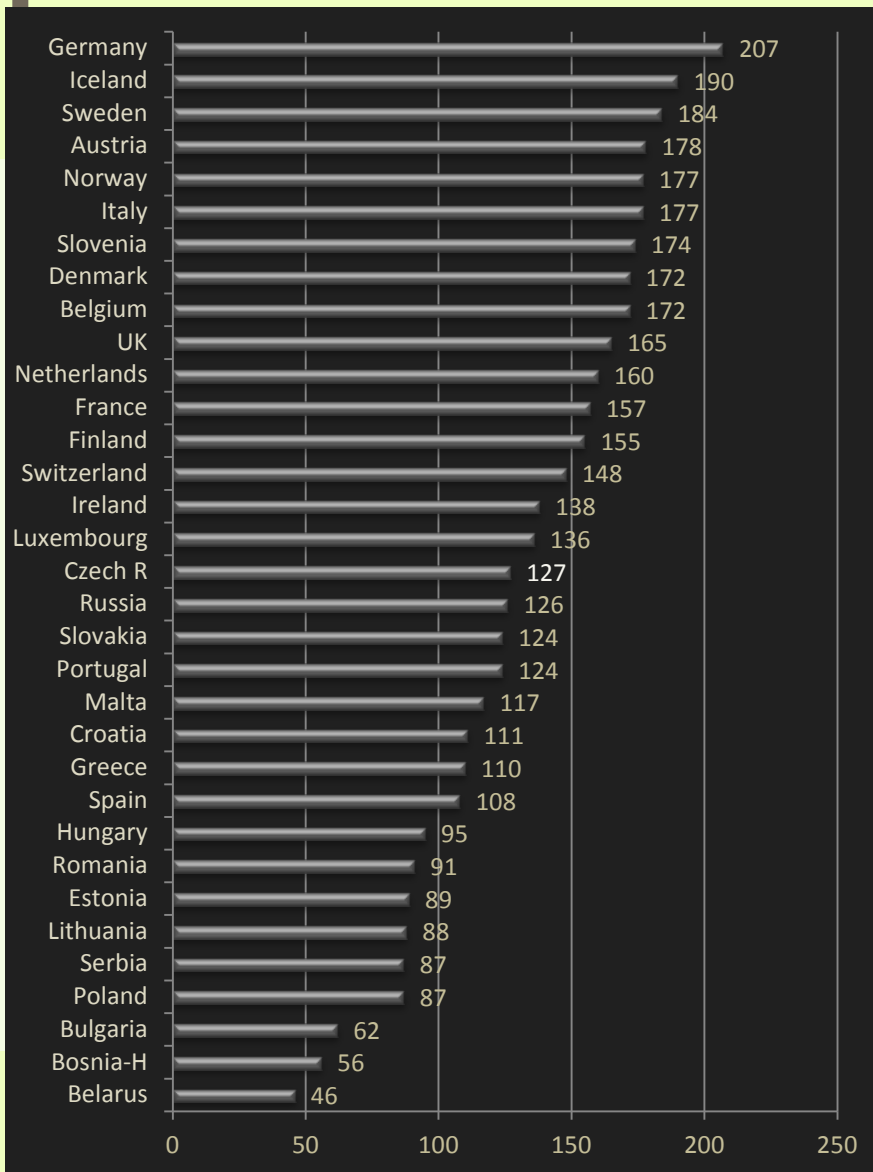
Section 3: Employment & Job retention (8 questions – 35 points)

Section 4: Empowerment (7 questions – 35 points)

Section 5: Reimbursement of Costs (6 questions – 30 points)

Section 6: Data collection (5 questions – 25 points)

Section 7: Medication coming to the market (3 questions – 15 points)



What does it Mean?

- A **high score** as you can see here, indicated there were fewer obstacles and challenges for people with.
- A **low score** indicates the countries with severe weaknesses in terms of disease management and support for MS patients.
- Max. score: 225 points
- 33 countries

Practical Use of Barometer

At the European level

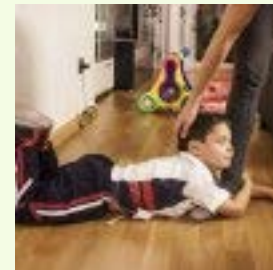
- ✓ Obtaining an accurate picture of the situation of people with MS across Europe and providing comparable data;
- ✓ Monitoring implementation of the European Code of Good Practice.

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.

Under Pressure





Thank you for your attention

Please stay in touch

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