Policy proposals to improve access to multiple sclerosis treatments in Europe

Key findings and conclusions

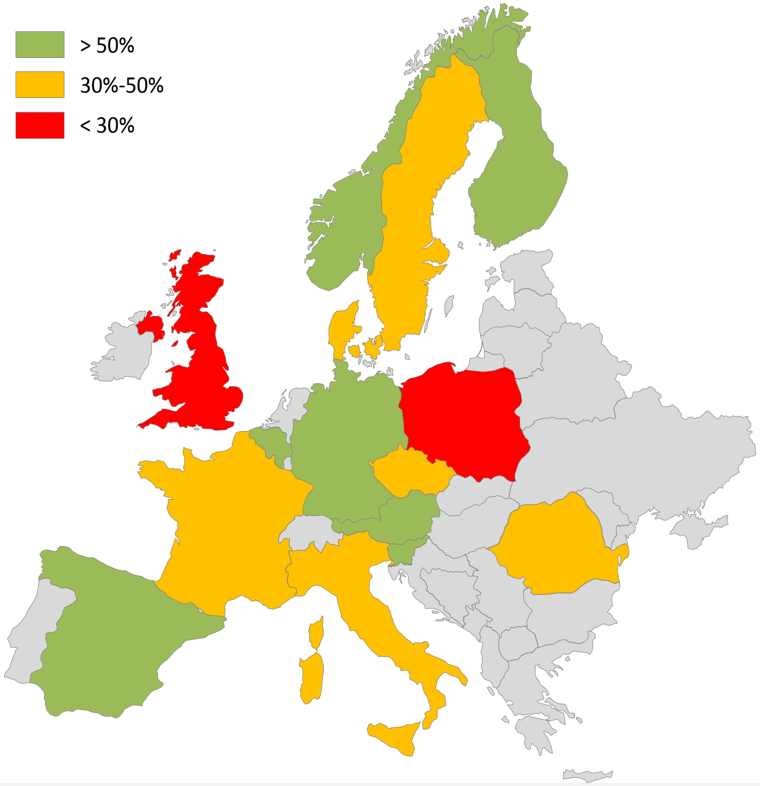
EMSP Conference

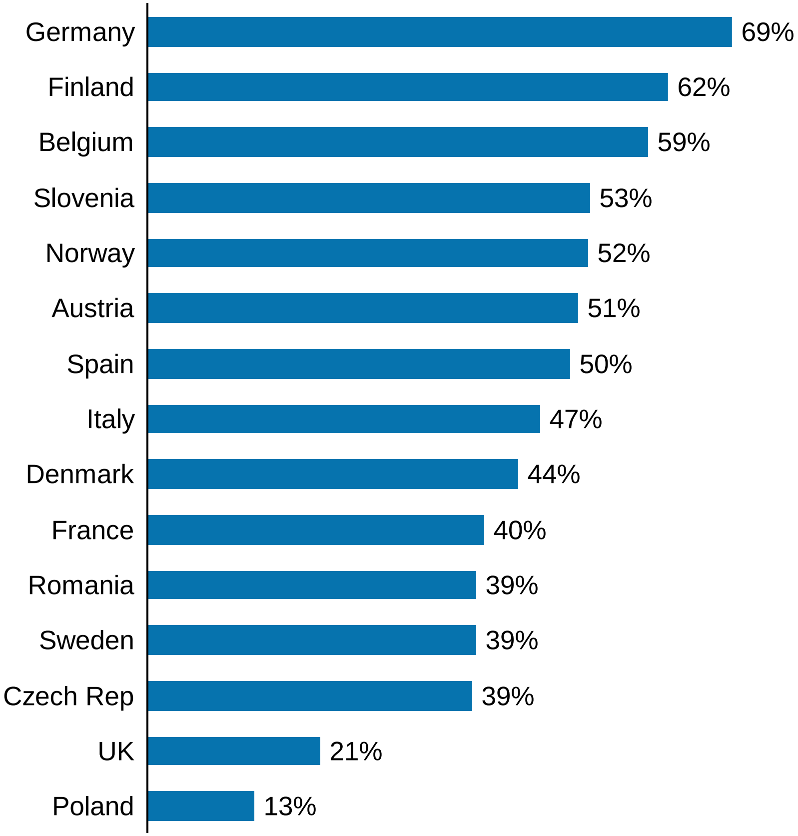
Oslo, 17 May 2016

This research builds on a study conducted by CRA in 2014

There are considerable variation in access to treatment for MS patients

Proportion of all MS patients receiving DMDs in 2013 (%) [1]





Best performers have seen increased access along with catch up from poor performers such as the UK and Eastern European countries.

---

[1] CRA (2014) Access to medicines for multiple sclerosis: Challenges and opportunities

This report seek to characterize more precisely what barriers prevent access to good clinical care in MS along the entire patient care pathway

emsp EUROPEAN MULTIPLE SCLEROSIS PLATFORM

EBC European Brain Council

EFNA European Federation of Neurological Associations

Multiple Sclerosis Trust MS

MS National Multiple Sclerosis Society

UNIE ROSKA Česká multiple sclerosis společnost

Ligue française contre la sclérose en plaque Ensemble

DMSG DEUTSCHE MULTIPLE SKLEROSE GESELLSCHAFT LANDESVERBAND HESSEN E.V.

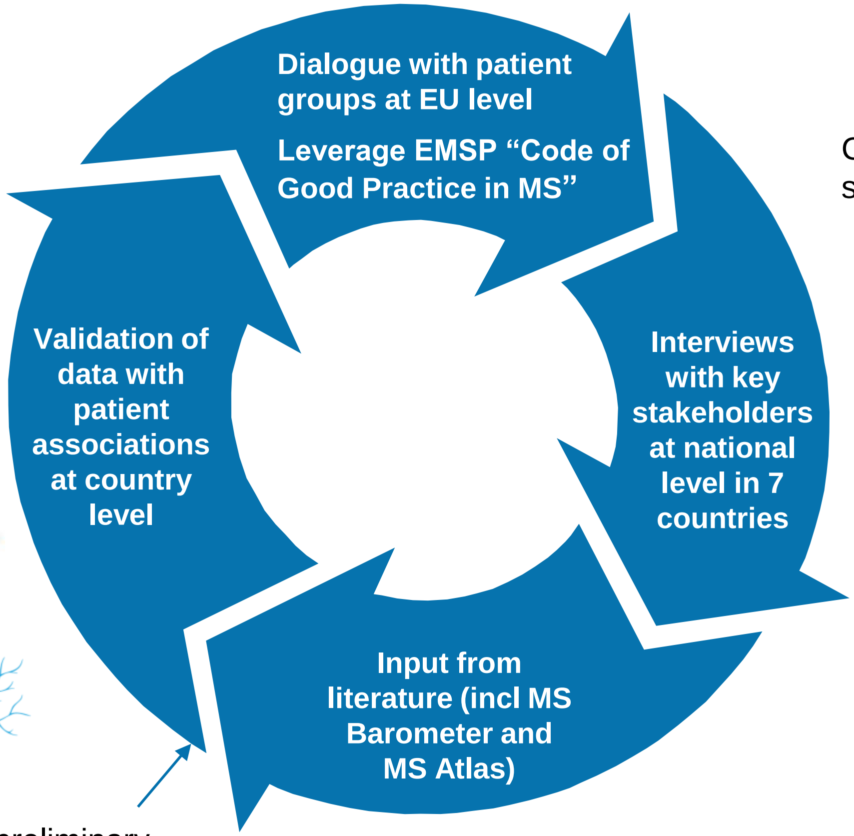
POLSKIE TOWARZYSTWO STWARDNIENIA ROZSIANEGO

NEURO

unisep

M Esclerosis Múltiple España

NeuroPozytywni



Dialogue with patient groups at EU level

Leverage EMSP "Code of Good Practice in MS"

Interviews with key stakeholders at national level in 7 countries

Input from literature (incl MS Barometer and MS Atlas)

Validation of data with patient associations at country level

CRA completed 51 interviews in has 7 selected European countries

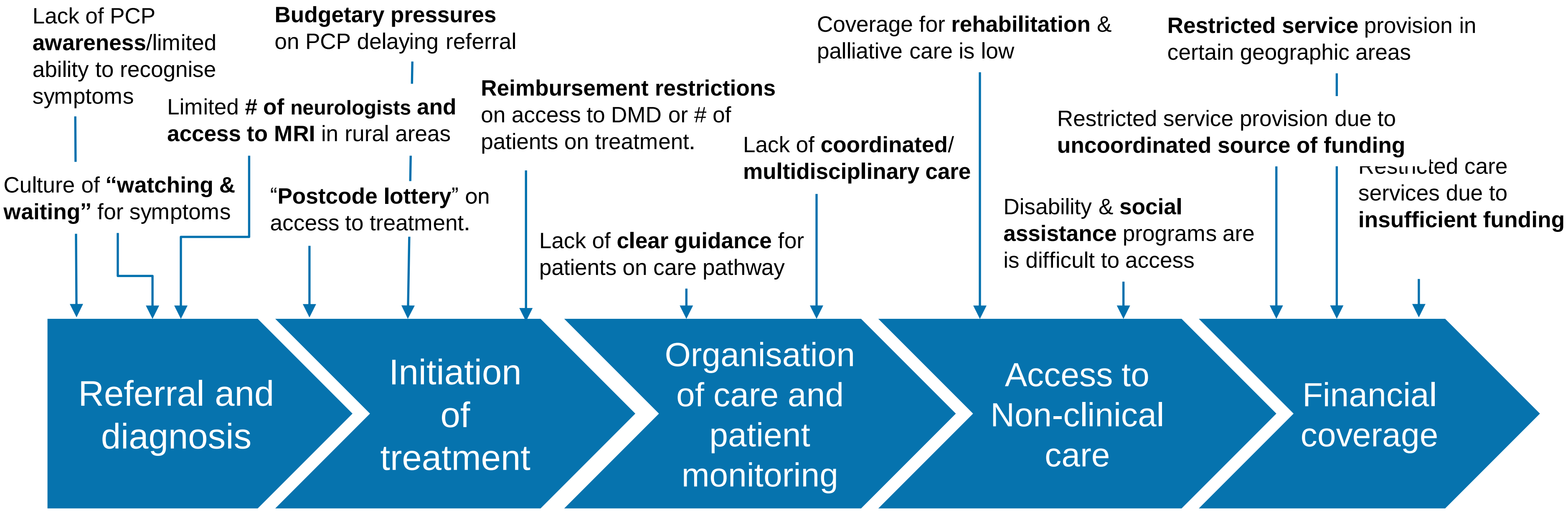
- Patient groups
- Neurologists
- General Practitioner
- MS Nurses
- Occupational Therapist
- Physiotherapist
- Policy makers
- Fund holders/payers

Presentation of preliminary findings to patient groups at **Patient Advocacy Summit ECTRIMS** – October 2015

CRA Charles River Associates

Key barriers & suggested good practices along the care pathway

Challenges



Lack of PCP **awareness**/limited ability to recognise symptoms

Culture of **“watching & waiting”** for symptoms

Limited **# of neurologists and access to MRI** in rural areas

Budgetary pressures on PCP delaying referral

“Postcode lottery” on access to treatment.

Reimbursement restrictions on access to DMD or # of patients on treatment.

Lack of **clear guidance** for patients on care pathway

Lack of **coordinated/ multidisciplinary care**

Coverage for **rehabilitation** & palliative care is low

Disability & **social assistance** programs are is difficult to access

Restricted service provision in certain geographic areas

Restricted service provision due to **uncoordinated source of funding**

Restricted care services due to **insufficient funding**

Referral and diagnosis

Initiation of treatment

Organisation of care and patient monitoring

Access to Non-clinical care

Financial coverage

Example of good practices

🇫🇷 Introduce training programme for HCPs

🇩🇪 Improve the degree of referrals.

🇩🇪 **Improve access to specialised neurologists** and **invest in MRI** machines

🇬🇧 🇫🇷 🇩🇪 Develop appropriate clinical guidelines

🇩🇪 🇫🇷 🇪🇸 Promote & monitor **appropriate use of medicines**

🇩🇪 🇫🇷 Develop scheme **to provide temporary access to new treatments**

🇨🇿 🇸🇪 🇩🇪 **Designate a clear point of contact** responsible for the patient care.

🇬🇧 🇸🇪 **Leverage specialised MS nurses** to ensure adequate coordination of care

🇨🇿 🇩🇪 🇫🇷 **Develop specialised MS care centres** or develop **multidimensional team (network)**

🇵🇱 **Develop complementary sources of funding** for disability support

🇫🇷 Introduce **special coverage protocol for chronic conditions** that require ongoing long-term care.

🏴󠁧󠁢󠁳󠁣󠁴󠁿 🇸🇪 Integrate **health & social care** services

🇫🇷 🇸🇪 Collect patient data through **registries & databases**

CRA Charles River Associates

Policy recommendations at national level

Western European countries with social health insurance system

- Accentuate effort on coordinated approach to care
- Ensure greater availability of neurological rehabilitation in rural areas
- Support the expansion of the MS nurse network to overcome workload issues
- Increase funding for non-clinical care such as physiotherapy/rehabilitation

Northern European countries

- Supporting the development of infrastructure to enable patients in rural settings to be diagnosed earlier
- Raise the profile of MS, with the longer-term goal of increasing access to PCPs and neurologists
- Investigate ways to clearly define the scope of healthcare and social care
- Support and encourage contributions from MS care providers to the MS registry

Southern European countries

- Support development of infrastructure to enable patients in rural settings to access neurologists in a timely manner
- Continue to promote the development of MS network and or specialised MS centres
- Raise general awareness of MS in the population and amongst healthcare professionals to raise the quality of MS care

Central and Eastern European countries

- Increase health care spending in line with economic growth and increase funding for MS
- Raise physician awareness of the need to diagnose and treat MS early
- Lower restrictions in access to treatment and expand treatment criteria to include all patients at early stage.
- Investigate ways to support the development of the patient databases
- Continue to promote the development of MS network and or specialised MS centres

Key Policy Recommendations at EU level

- Raise the profile of MS at European level, including disease awareness in the population and amongst healthcare professionals to raise the quality of MS care
- Encourage the developments of schemes to provide fast access to new treatments (e.g. early access schemes, EU fast-track procedures)
- Accentuate efforts across the EU on ensuring a coordinated approach to care and continue to promote the development of specialised MS care centres or MS network to ensure coordinated multidisciplinary care
- Support the expansion of the MS nurse network to overcome workload issues and improve holistic care for all patients
- Increase focus on rehabilitative care and ensure greater availability of neurological rehabilitation in rural areas
- Encourage the development of an EU-wide database of MS patient, building on the progress of European Register for Multiple Sclerosis (EUReMS)