Policy proposals to improve access to multiple sclerosis treatments in Europe

Key findings and conclusions

Warsaw, 26 April 2016

Watch Health Care Foundation
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- Background - difference in access to treatment in 2013
- Project overview - objectives of the 2016 MS study
- Methodology
- Summary of key findings
- Challenges to access along the MS care pathway in Poland
- Challenges & example of good practices along the care pathway
- Policy implications for Poland
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 (%) \(^1\)

<table>
<thead>
<tr>
<th>Country</th>
<th>Proportion</th>
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</thead>
<tbody>
<tr>
<td>Germany</td>
<td>69%</td>
</tr>
<tr>
<td>Finland</td>
<td>62%</td>
</tr>
<tr>
<td>Belgium</td>
<td>59%</td>
</tr>
<tr>
<td>Slovenia</td>
<td>53%</td>
</tr>
<tr>
<td>Norway</td>
<td>52%</td>
</tr>
<tr>
<td>Austria</td>
<td>51%</td>
</tr>
<tr>
<td>Spain</td>
<td>50%</td>
</tr>
<tr>
<td>Italy</td>
<td>47%</td>
</tr>
<tr>
<td>Denmark</td>
<td>44%</td>
</tr>
<tr>
<td>France</td>
<td>40%</td>
</tr>
<tr>
<td>Romania</td>
<td>39%</td>
</tr>
<tr>
<td>Sweden</td>
<td>39%</td>
</tr>
<tr>
<td>Czech Rep</td>
<td>39%</td>
</tr>
<tr>
<td>UK</td>
<td>21%</td>
</tr>
<tr>
<td>Poland</td>
<td>13%</td>
</tr>
</tbody>
</table>

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
Differences in access are explained by a range of factors including healthcare infrastructure, restrictive reimbursement and affordability.

CRA found that differences in access can be explained by:

1. Considerable variation in **availability of specialised neurology centres** and qualified healthcare professionals (e.g. UK, Czech Rep)

2. Although in most countries clinical guidelines are similar, **restrictive guidelines do contribute to reduced access** in some cases (e.g. Czech Rep)

3. In most countries, all first line products are reimbursed, but **some restrictions are imposed on the use of the medicines**. (e.g. Romania)

4. Whilst recent HTA decisions are relatively similar across countries, the biggest impact appears to be in the **delay this causes to market access** (e.g. UK, Finland)

5. **Affordability remains a barrier to access** in some CEE countries (e.g. Romania, Poland, Slovenia, Czech Rep)
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Objectives of the 2016 MS study

The aim of this 2016 report is look beyond the access statistics and seek to characterize more precisely what barriers prevent access to good clinical care in MS along the entire patient care pathway

It focuses the public policy factors that restrict patient access to Multiple Sclerosis (MS) treatments in Europe and to develop credible practical proposals to improve access

This includes:

1. Identifying specific barriers that are restricting access to MS therapy in different European countries

2. Understanding what constitutes good practice from the perspective of MS patient community

3. Identify potential reforms and system improvements which will enable/facilitate better access to treatment and disease management for MS patients
Methodology

- CRA held discussions with MS patient groups (EMSP, EBC, EFNA) to identify some criteria to compare countries on their management of MS.

- Leveraged the existing comparative literature as starting point to identify local points for discussion.

- Selected 7 countries from the 15 countries in the 2014 CRA report, which offer variety in the diagnosis and management of MS across Europe and represent sufficient geographic and income diversity.

- Based on this input, CRA developed a set of tailored questionnaires (by country and by stakeholder) and asked respondents their perspective on the following elements:

  - Referral and diagnosis
    - PCP awareness, access to a neurologist/MRI, overall length of diagnostic process
  - Initiation of treatment
    - Treatment options and restrictions, clinical guidelines
  - Organisation of care and patient monitoring
    - Responsibly and coordination of care
  - Access to Non-clinical care
    - Availability of rehabilitation services, palliative care, disability support
  - Financial coverage
    - Overall funding of MS, Reimbursment coverage
CRA conducted an internal and external process to collect and validate input from experts at both national and European level.

CRA completed 51 interviews in 7 selected European countries:
- Patient groups
- Neurologists
- General Practitioner
- MS Nurses
- Occupational Therapist
- Physiotherapist
- Policy makers
- Fund holders/payers

Validation of data with patient associations at country level
Interviews with key stakeholders at national level in 7 countries
Input from Biogen national affiliates
Dialogue with patient groups at EU level
Leverage EMSP “Code of Good Practice in MS”
Presentation of preliminary findings to patient groups at Patient Advocacy Summit ECTRIMS – October 2015
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Key findings on patient referral and diagnosis

<table>
<thead>
<tr>
<th>Findings</th>
<th>Countries</th>
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</thead>
<tbody>
<tr>
<td>Some countries experience <strong>delays in referral of patients</strong> with</td>
<td>Poland, Sweden, Czech Rep,</td>
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<tr>
<td>suspected MS to a neurologist/MS centre due to lack of awareness of</td>
<td>UK</td>
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<td>MS symptoms and insufficient training for primary care professionals</td>
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<td></td>
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<tr>
<td>There is a <strong>culture of “watching and waiting” for symptoms to formalise</strong></td>
<td>Poland, UK</td>
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<tr>
<td>which creates reluctance to refer patients to a neurologist</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>There is a difficulty in accessing specialised care due to a <strong>shortage of neurologists</strong></td>
<td>Poland, Sweden, Czech Rep, UK</td>
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<tr>
<td></td>
<td></td>
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<tr>
<td>There are <strong>delays in accessing an MRI scan</strong></td>
<td>Poland, UK, Sweden</td>
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</table>
Key findings on treatment initiation & access to innovative therapies

<table>
<thead>
<tr>
<th>Findings</th>
<th>Countries</th>
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<tbody>
<tr>
<td>Some countries postpone treatment initiation due to clinical pre-conditions – patient must demonstrate active MS, relapsing onset. i.e. only patients with RRMS, CIS, or the first phase of SPMS.</td>
<td>Poland, Czech Rep, UK</td>
</tr>
<tr>
<td>There are strict conditions or other limitations on access to treatment, e.g. restrictions on the number of MS patients; geographical conditions; and clinical restrictions</td>
<td>Poland, Czech Rep.</td>
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<tr>
<td>There are limits on the types of medications MS patients have access to i.e. innovative medicines, off label use of treatments</td>
<td>Poland, Czech Rep, UK</td>
</tr>
<tr>
<td>There are delays in accessing innovative treatment due to formal reimbursement procedures</td>
<td>Poland</td>
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Key findings on ongoing management of MS

<table>
<thead>
<tr>
<th>Finding</th>
<th>Countries</th>
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</thead>
<tbody>
<tr>
<td>Neurologists are heavily involved in guiding treatment choices</td>
<td>Czech Rep, Spain, France</td>
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<tr>
<td>and managing patient care</td>
<td></td>
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<tr>
<td>Specialised MS nurses take a leading role and are instrumental in</td>
<td>UK, Sweden, Germany</td>
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<tr>
<td>coordinating and organising patient care</td>
<td></td>
</tr>
<tr>
<td>Some countries provide care within specialised MS care centres, which</td>
<td>Germany, Czech Rep, UK</td>
</tr>
<tr>
<td>integrate all medical services</td>
<td></td>
</tr>
<tr>
<td>In other countries, care is being provided within both hospital and</td>
<td>Spain, Poland, Sweden, France</td>
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<td>ambulatory settings, but coordination of care remains a significant</td>
<td></td>
</tr>
<tr>
<td>issue</td>
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<tr>
<td>Some countries still lack fully fledged MS patient registry</td>
<td>Germany, UK, Poland, Spain</td>
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<tr>
<td>In some countries, physiotherapy and rehabilitative care is</td>
<td>Spain, Poland, Sweden, France</td>
</tr>
<tr>
<td>difficult to access and is either under-prescribed by neurologists or</td>
<td></td>
</tr>
<tr>
<td>geographically restricted</td>
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</table>
### Key findings on resources and financial coverage

<table>
<thead>
<tr>
<th>Finding</th>
<th>Countries</th>
</tr>
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<tbody>
<tr>
<td>The <em>budget allocated to MS was seen as insufficient</em> resulting in a high number of untreated patients</td>
<td>Czech Rep, Poland</td>
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<tr>
<td>There are important <strong>differences in resources and funding between regions</strong>, leading to important differences in coverage within a country</td>
<td>Poland, Spain, Sweden</td>
</tr>
<tr>
<td>Some countries have <strong>little or no co-payment</strong> to access clinical MS care</td>
<td>Germany, UK, Poland, Czech Rep</td>
</tr>
<tr>
<td>Other countries have <strong>some levels of co-pay but this remains relatively low</strong> and is not seen as a significant barrier to access</td>
<td>Sweden, Spain, France</td>
</tr>
</tbody>
</table>
Key conclusion on barriers to access to MS Treatment

• There are significant differences in management of care of MS between countries, and the policies that different countries have implemented
  – There are significant variation in the speed of diagnosis which are associated with a range of different barriers.
  – Once patients are adequately diagnosed, timely access to appropriate treatment also varies widely across the selected countries.
  – There are important differences in the organisation of care, and the level of coordination of different MS specialists across countries
  – Access to complementary healthcare services varies widely within countries across regions.
  – There are important variations in the level of resources dedicated to MS

Improving access to treatments for patients with MS requires a holistic view of:
• how patients are diagnosed
• how treatment is initiated
• how the disease is managed on an ongoing basis
• the required resources and the level of coverage of care
Challenges to access along the care pathway in Poland

Present at PCP

Referral

Neurologist Consultation
Up to 6 months for MRI

Total time to diagnosis: mean time from first symptoms to diagnosis is 2.6 years

PCP have a limited knowledge around MS, including the role of DMTs and communication with specialist is poor

Not all neurologist have a contract with the social health insurance which limits access to specialist care

Waiting time to access MRI in Poland is about six months to a year in the outpatient setting

There are restrictions on the number of patients with MS eligible to receive DMD treatment

For some 2nd line treatment, patients can be treated with a DMD only for a maximum of 5 years and in only 34 treatment centres

Lack of specialised outpatient clinics that offer multidisciplinary care for MS

1-2 years to access treatment

Diagnosis

Treatment Initiation

Continued Care

Complementary care services

Patients must meet certain criteria in order to qualify for reimbursement of DMDs

Clinical professionals have no way to share information regarding the patient

Palliative care is not well organized and is often reserved for other types of disorders and diseases

Total time to access treatment is around 3-4 years (2.6 year to diagnosis + 6 months for MRI + ~ 1-2 years to get on treatment once diagnosed)
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Challenges & suggested good practices along the care pathway – Part 1

**Challenges**

- Lack of PCP awareness/limited ability to recognise symptoms
- Culture of “watching and waiting” for symptoms lead to delay in referral times
- Budgetary pressures on PCP delaying referral
- Limited number of neurologists in rural areas
- Waiting times for specialised centres/MRI

**Example of good practices**

- Introduce an educational component (training programme)
- Increase disease awareness and improve the degree of referrals.
- Improve access to specialised neurologists and invest in MRI machines, particularly in rural areas.
Challenges & suggested good practices along the care pathway – Part 2

**Challenges**

“Postcode lottery” on access to treatment.

Reimbursement Restrictions on access to DMD or number of patients on treatment.

Lack of clear guidance for patients on care pathway/options

Lack of coordinated/multidisciplinary care

Coverage for rehabilitation & palliative care is low

**Example of good practices**

Develop appropriate clinical guidelines

Promoting and monitoring 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

Further **develop specialised MS care centres** specialised in MS or develop **multidimensional team (network)** to organise multidisciplinary care
Challenges & suggested good practices along the care pathway – Part 3

**Challenges**

- Restricted care services due to insufficient funding
- Restricted service provision in certain geographic areas
- Restricted service provision due to uncoordinated source of funding
- Disability benefits and social assistance programmes are difficult to access for certain patients

**Example of good practices**

- Collect patient data through registries & databases
- Develop complementary sources of funding for rehabilitation and disability support
- Introduce special coverage protocol for chronic conditions that require ongoing long-term care.
- Integrate health and social care services and funding
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Policy initiatives could improve patient access in Poland (Part 1)

1. Raise patient and physician awareness of the need to diagnose and treat MS early

2. Support development of infrastructure to enable rural/public insurance patients to access neurologists more quickly

3. Increase funding for MS and eliminate restrictions on the number of patients with MS eligible to receive DMD treatment

4. Reduce geographic barriers to second-line treatment by increasing the number of sites eligible to prescribe second-line DMD therapies

5. Remove 5-year restriction on DMD therapies for second-line therapies

6. Grant reimbursement to newer, more effective and comfortable treatments, e.g. orals, less frequently applied injections

7. Develop clinically appropriate and up-to-date guidelines with flexibility to address specific patient needs
8. Remove indication limitation on DMDs and focus on promoting and monitoring appropriate use of medicines

9. Encourage multidimensional teams with fluid communication by formalising professional networks

10. Increase funding for non-clinical care such as physiotherapy/rehabilitation

11. Investigate ways to support the development of the patient registry and include measures of relative effectiveness of MS treatments
THANK YOU!

QUESTIONS?