Launching *Defeating MS Together*

The European Code of Good Practice in MS

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emsp

EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Defeating MS Together
The European Code of Good Practice in MS

Outline

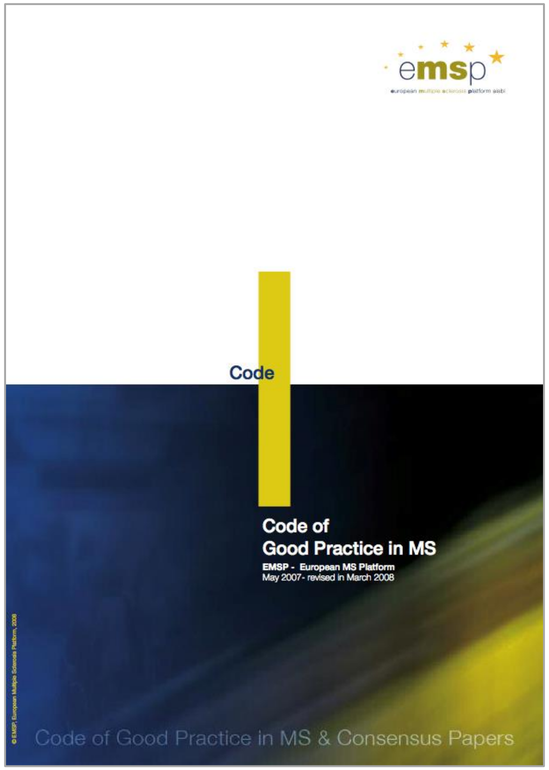
1. Background
2. Activity since the original Code
3. Revision process
4. Key features of *Defeating MS Together*
5. Next steps

Background

- Over 600,000 people living with MS - yet the treatment and support varies widely. Many people with MS are missing out on the vital care.
- The European Code of Good Practice in Multiple Sclerosis (Code) originally published in 2005 to highlight issues faced by people with MS and the measures needed to drive improvements. **A landmark publication and tool**.
- Since then, over nearly 10 years EMSP has worked with its members and European Parliament to create tools to transform the Code’s principles into national policy and standards of practice.

Activity since the original Code

- A number key initiatives have been devised to support implementation at national level across the EU, including:
  - Multiple Sclerosis Information Dividend (MS-ID) - MS Barometer
  - High-level roundtables on MS
  - European MS Register
- Pocket Guide



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Code

Code of Good Practice in MS

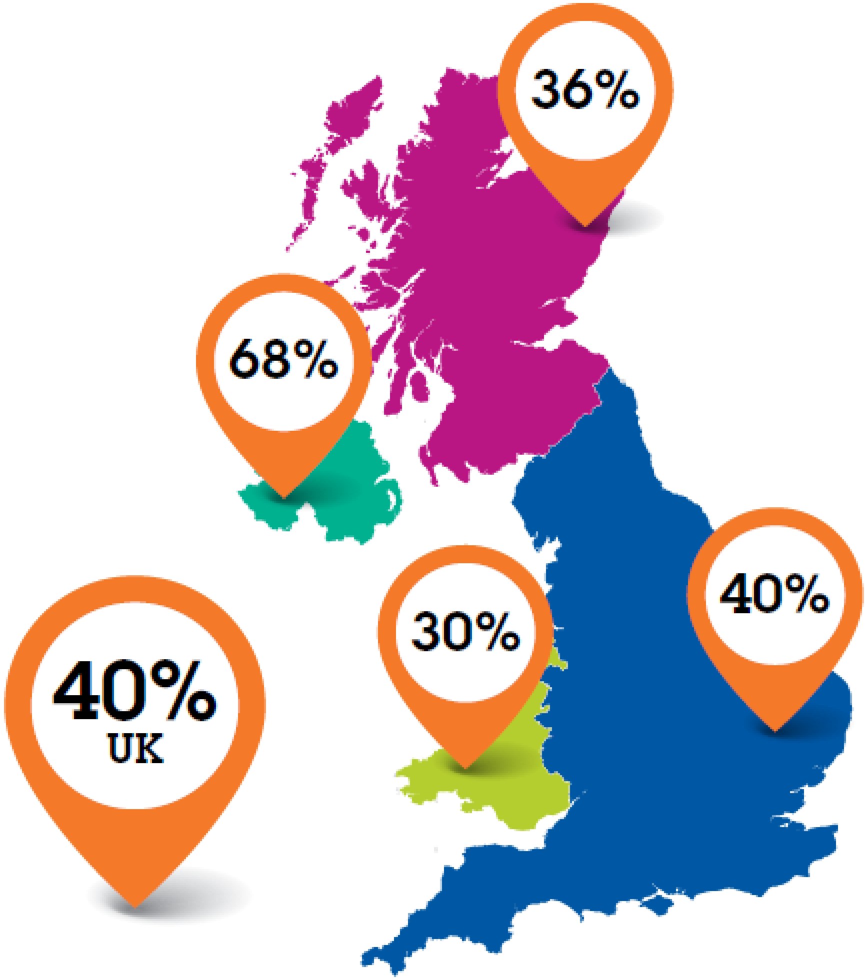
EMSP - European MS Platform
May 2007- revised in March 2008

Code of Good Practice in MS & Consensus Papers

Why is the Code still needed?

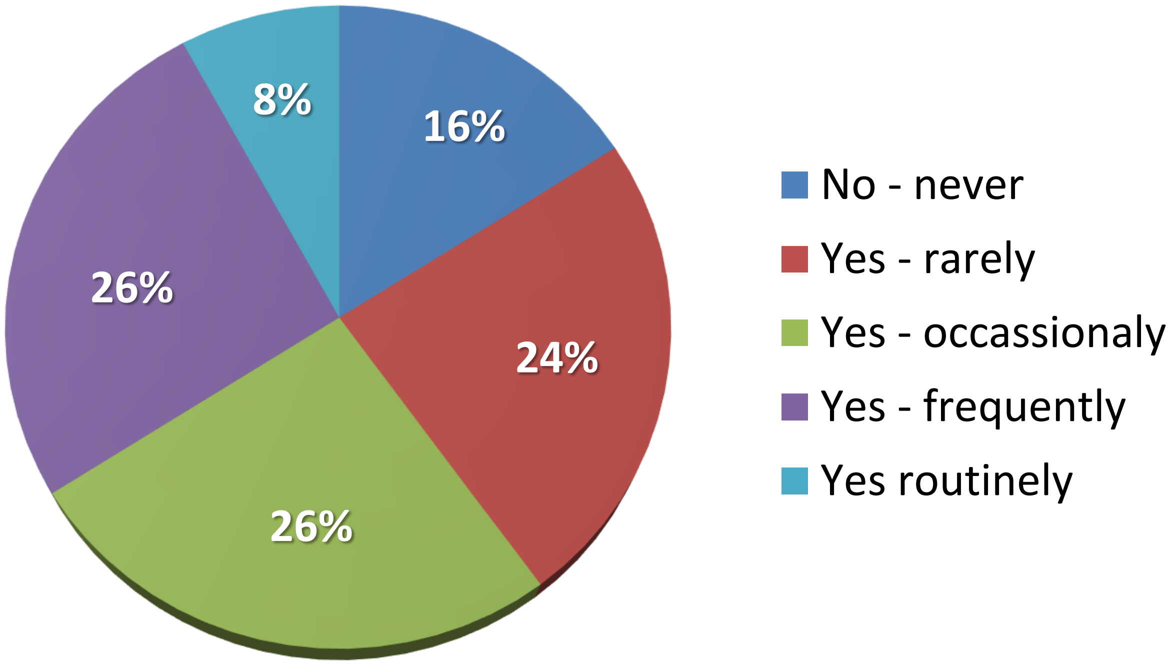
- Despite progress:
  - People with MS across EU **still face wide variation** in access to treatment and support as well as barriers to employment and benefits.
  - We **still need to better understand** the initiation and progress of MS, including in those diagnosed as children, and how to effectively treat it.
- Taking action makes social and economic sense – **and is essential**.
- The MS community across the EU alongside policy makers must work together in order to generate meaningful change.

Proportion of MSers eligible taking DMTs in the UK



“A lottery of treatment and care – MS services across the UK”; MS Society April 2013.

Proportion of MSologists in the UK who use MRI to monitor for a response, or non-response, to DMTs?



The Revision Process

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Revision process

1. Briefing – EMSP's broad vision
2. Consultation with EMSP stakeholders
3. Evidence review
4. *Defeating MS Together* developed

Defeating MS Together:

- Main focus on policy makers – action focused language, explanatory text, more quotes
- 12 Calls to Action, under 5 Action Areas and 1 Core Principle
- Timeline of Action

Defeating MS Together

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Defeating MS Together
The European Code of
Good Practice in MS

- In *Defeating MS Together:*
  - Current issues facing people with MS, and those who care for them, and set out clear calls to action aimed at improving their lives and reducing inequalities.
  - Detailed Consensus Statements developed on key areas to provide best practice advice for the care and treatment of people with MS.

Calls to Action: Themes

- **Core Principle:** *Empowering People with MS*
- **Action Area 1:** *Ensuring Access to MS Treatment, Therapies, Rehabilitation and Services*
- **Action Area 2:** *Better Understanding and Treatment of Pediatric MS*
- **Action Area 3:** *Focusing MS Research*
- **Action Area 4:** *Enabling Employment, Job Retention and Education*
- **Action Area 5:** *Supporting and Empowering MS Carers*

Core Principle: Empowering People with MS

- Underpinning all the action areas - core principle and requirement to support and encourage the participation and empowerment of people with MS.
- Essential all people with MS, and their carers, are given opportunity to be involved in decision making about their treatment and care and to feed into research and policies.
- Need better partnerships between people with MS, the organisations that represent them, healthcare professionals, researchers, and policy makers.

Core Principle: Empowering People with MS

- **Call 1:** All those who work with people with MS, and their carers, should positively encourage their involvement and provide appropriate information and support to enable them to take part in decision-making that ultimately affects their lives.

- **Call 2:** All healthcare professionals must recognise the information needs of people with MS, and their carers, and provide honest and useful information about their condition, prognosis and treatment, therapies, rehabilitation and support available to them.

Action Area 1: Ensuring Access to MS Treatment, Therapies, Rehabilitation and Services

- Lack of access to treatment, therapies, rehabilitation and services severely diminishes quality of life, and can lead to missed opportunities to more effectively manage the progression of the disease. But - wide variation in access to optimal treatment and care across the EU.
- Role of MS nurse is diverse and varies across EU, leading to inequalities in patient access to care and advice.

Action Area 1: Ensuring Access to MS Treatment, Therapies, Rehabilitation and Services

- **Call 3:** All people with MS across the EU must be able to access the recommended treatments, therapies, rehabilitation and skilled, professional support.

- **Call 4:** Healthcare commissioners and providers across the EU must fully recognise the importance and value of MS nurses and ensure there are adequate numbers employed.

Action Area 2: Better Understanding and Treatment of Paediatric MS

- Approx 3–5% of MS patients experience first MS attack during childhood.
- There is a lack of research studies in paediatric MS.
- Paediatric MS displays different disease progression from adult onset MS - more research needed to better understand prognosis, treatment options and support needs for children and adolescents.
- Diagnosis of MS has a major impact on young patients and their families, so psychological and social support needed to assist them in facing the physical and psychological limitations in family, school and social activities.

Action Area 2: Better Understanding and Treatment of Paediatric MS

- **Call 5:** All children and adolescents with MS across the EU, and their families, must be able to access the recommended treatments and therapies and skilled, professional support.

- **Call 6:** Research funders must provide increased resources for, and researchers must design, more targeted clinical trials to identify the most effective treatments for children and adolescents with MS.

Action Area 3: Focusing MS Research

- Significant investment needed to find a cure, or identify effective symptomatic treatments or prevention mechanisms.
- A number of research priorities identified, incl: the epidemiology, genetics, and clinical pathology of MS, types of therapy, biomarkers and the better understanding of progressive forms of MS.
- At present no effective disease-modifying treatment available for progressive MS and no way to accurately and consistently predict progression or prevent it from happening.
- Overall impact of research efforts can be undermined by a lack of co-ordination between European countries.

Action Area 3: Focusing MS Research

- **Call 7:** The EU and other research funders must allocate particular attention and resources to research into progressive MS.

- **Call 8:** Researchers, research funders and MS organisations across Europe must collaboratively develop a series of shared research and data management strategies.

Action Area 4: Enabling Employment, Job Retention and Education

- Extent to which people with MS are disabled by their condition varies and extent to which individuals may wish and be able to work also varies.
- Many employers not experienced in managing fluctuating and unpredictable changes in the functioning of employees with MS.
- People with chronic diseases, such as MS, can face difficulties in accessing and taking part in education.

Action Area 4: Enabling Employment, Job Retention and Education

- **Call 9:** All employers and education providers must be aware of legislation and policies requiring the need to provide support for people with chronic conditions, such as MS, and take steps to ensure this provision for all those who need it.

- **Call 10:** All policy-makers and employers must recognise the need for greater flexibility within social, disability and workplace benefits to account for the fluctuating needs of people with relapsing remitting MS.

Action Area 5: Supporting and Empowering Carers

- Estimated that more than one million people are affected through their role as carers and family members of people with MS.
- Essential that carers are adequately supported in their role.
- The isolation of carers also needs recognition.

Action Area 5: Supporting and Empowering Carers

- **Call 11:** All those who work with people with MS and their carers must take the particular needs of carers into account and offer support where appropriate.

- **Call 12:** The MS community should develop and promote a resource (such as an online hub) enabling MS carers from across the EU to communicate with each other, share their experiences and develop a voice.

Timeline for Action

CALL 1
Empowering people with MS

CALL 11
Supporting and Empowering Carers

CALL 3
Ensuring Access to MS Treatment, Therapies, Rehabilitation and Services

CALL 9
Enabling Employment, Job Retention and Education

CALL 4
Ensuring Access to MS Treatment Therapies, Rehabilitation and Services

CALL 10
Enabling Employment, Job Retention and Education

2015 **2016** 2017 **2018** 2019 **2020** 2021 **2022** 2023 **2024**

CALL 2
Empowering people with MS

CALL 12
Supporting and Empowering Carers

CALL 5
Better Understanding and Treatment of Paediatric MS

CALL 6
Better Understanding and Treatment of Paediatric MS

CALL 7
Focusing MS Research

CALL 8
Focusing MS Research

Next steps

- Hot of the press! Launch today
- Looking to all of you to help take the new Code to your countries and policy makers to spread the word and start taking action
- Distribution strategy
- Monitoring plan – EMSP Annual Progress Check

- Let us all encourage people to:

COMMIT. SUPPORT. ADVOCATE. ACT.

With thanks to…

- The invaluable contribution of the people with MS, carers, health professionals, policy specialists, member societies and Advisory Group members that generously provided their ideas, expert opinion and advice on *Defeating MS Together*.

- The financial contribution, in the form of unconditional grants, from EMSP’s corporate supporters that have enabled us to undertake the detailed research, consultation, development and production of *Defeating MS Together*.