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**W**e would like to welcome you to the latest edition of *European Neurological Review*. This Issue covers several major and topical areas, diseases which demand the attention of policymakers and politicians throughout Europe, particularly the neurodegenerative conditions and stroke. Between them they contribute much to the total cost and burden to patients and the payers. The total cost of brain disorders in Europe was recently shown by a European Brain Council study (utilising the most up to date epidemiological and health economic data) to be €798 billion, more than the cost of cancer, cardiovascular disorders and diabetes combined.<sup>1</sup>

In part this is related to the chronic nature of brain disorders, in part through the huge advances made in the treatment of these other conditions, more patients surviving cancer and cardiovascular diseases. Surviving to then develop long term, progressive and disabling brain disorders. These data focus the mind on the challenges all of us must face, but, just as importantly, we need to be part of the solution.

With this in mind, the European Brain Council launched a call for 2014 to be made the European Year of the Brain. We have created a coalition of nearly 200 organisations, the European institutions are listening and we are hopeful that they will have the courage to join us in making this a European Year like never seen before.

We have created a very ambitious programme to celebrate the wonder of the brain but also to demonstrate to the public the best way to nurture, protect and preserve our most vital asset, our brains. We plan to have a mobile brain exhibit visiting more than 900 cities and towns across Europe, a comprehensive schools and university programme, a digital and social media campaign and cultural, sporting and scientific events with hundreds of brain ambassadors.<sup>2</sup>

Science and research and the efforts of healthcare professionals and researchers are vital to make the progress needed with the conditions discussed in this edition. But this alone will not be enough. Much needs to be done to improve the quality of life for all those who have a brain disorder and their families and carers, this can only truly be achieved by prevention wherever possible, earlier and accurate diagnosis, faster and more appropriate use of treatment, better regulatory processes that are truly fit for purpose and health technology assessment that also recognises outcomes of relevance to patients. We also need to encourage greater responsibility by all Europeans for their health and the health of their families. This will need considerable education and much more targeted information and engagement. The time for action is now. ■

1. Gustavsson A, Svensson M, Jacobic F, et al., Cost of disorders of the brain in Europe 2010, *Eur Neuropsychopharmacol*, 2011; in press. Available at: [www.europeanbraincouncil.org/pdfs/Publications\\_/Cost%20of%20Disorders%20of%20the%20Brain%20in%20Europe%20-%20EurNeuro2011.pdf](http://www.europeanbraincouncil.org/pdfs/Publications_/Cost%20of%20Disorders%20of%20the%20Brain%20in%20Europe%20-%20EurNeuro2011.pdf) (accessed 20 December 2011).

2. European Brain Council (EBC), European Year of the Brain 2014, European Year of the Brain Materials. Available at: [www.europeanbraincouncil.org/projects/eyob/materials.asp](http://www.europeanbraincouncil.org/projects/eyob/materials.asp) (accessed 20 December 2011).

# First Major European-Wide Nurse Survey Shows Disparity in Nursing of MS Patients

## Multiple Sclerosis in Europe: Current Practice and Future Needs

Multiple sclerosis (MS) affects nearly half a million people in the European Union (Figure 1). MS nurses play a pivotal role in delivering MS patient care.

Currently there are significant national and regional disparities in the provision and quality of services and support for people affected by MS across the European Union.<sup>1</sup>

There is a need for greater understanding and awareness of the role of MS nurses and to identify best practice in order to improve patient access to care and optimise quality of life.

**The Multiple Sclerosis-Nurse Empowering Education (MS-NEED): European Survey** led by the European Multiple Sclerosis Platform (EMSP) in cooperation with the International Organization of Multiple Sclerosis Nurses (IOMSN) and Rehabilitation in MS (RIMS) centres, was conducted to understand and raise awareness of the roles of nurses in MS and the provision of care across Europe.

## Key aims of the survey

The survey aims to identify areas for improvement and best practice, and to promote the need for comprehensive nurse services across Europe.

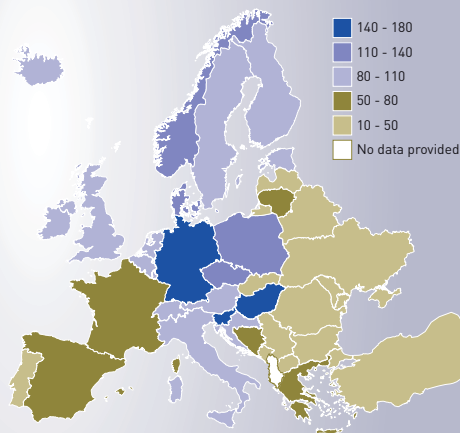
## How the survey was conducted

Respondents were recruited from six countries within the European Union.\* The survey comprised of a 35-minute telephone questionnaire focusing on four key areas:

- Clinical practice
- Advocacy
- Training and education
- Research and publication

\*Respondents were recruited from six countries in the European Union: UK, Germany, Italy, Poland, Finland and the Czech Republic. Respondents were either specialist nurses or nurses who regularly treated patients with MS.

Fig 1. Prevalence of MS in Europe



Source: [www.europeanmapofms.org](http://www.europeanmapofms.org)

Fig 2. Taking Leadership – Multidisciplinary team perception

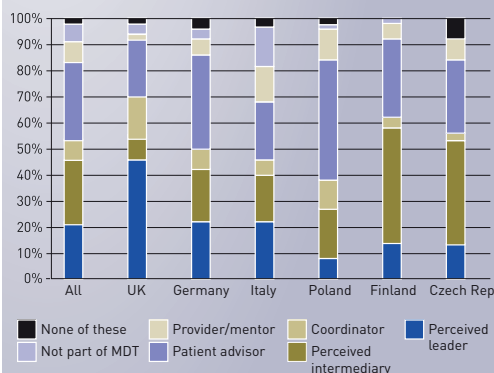
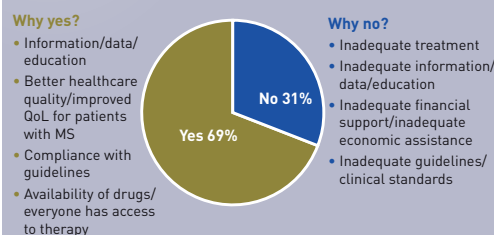


Fig 3. Do you feel that standards of care are well-maintained in your country?



## Key findings:

### The role of the MS nurse is varied

- Many MS nurses are currently involved in activities that reach beyond traditional responsibilities
- Over one-fifth of MS nurses believe they are viewed as leaders within a multi-disciplinary team (MDT), while approximately one-third of nurses believe they are a 'day-to-day patient advisor' (Figure 2)
- There is disparity in role perception between countries; most countries have a number of nurses who do not feel part of a wider MDT

### There are many remaining opportunities to take leadership

- Specialist MS nurses currently take the lead in major areas of care including the professional development of other MS nurses
- Opportunities to lead in measuring and auditing care standards is a key area of growth potential in nearly every country

### There is a need for additional training and certification

- Over half of nurses feel 'very qualified and informed' to provide specialist advice and education to patients on symptom management with practical solutions
- One-fifth of nurses do not feel they have adequate training and education to support them in their day-to-day role
- One-third of MS nurses do not feel that standards of care are well maintained in their country (Figure 3). Many see this as a result of inadequate information, data or education

## Giving people with MS the best possible outcome – the recommendations

- Recognise nursing in MS as a specialty within Europe
- Facilitate the sharing of knowledge, best practice and build collaborative expertise between countries
- Standardise, benchmark and certify MS nurse training across Europe

**The MS-NEED study group has begun development of a European consensus framework to define the role and responsibilities of the MS nurse. This will aid consistency of care across all countries and facilitate the best possible outcome for people with MS in Europe.**

In cooperation with:

## References:

1. European Multiple Sclerosis Platform (EMSP) website. <http://www.ms-in-europe.org/multiple-sclerosis/index.php?kategorie=multiplesclerosis>. Accessed October 2010.

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