

multiple sclerosis
nurse empowering
education

ms-need

In cooperation with:



References

1. Multiple Sclerosis International Federation website. http://www.msif.org/en/about_ms/index.html. Accessed March 2010.
2. European MS Platform website <http://www.ms-in-europe.org/multiple-sclerosis/index.php?kategorie=whatisms&cnr=6&anr=127>. Accessed March 2010.
3. Multiple Sclerosis International Federation website <http://www.msif.org/docs/MSinFocusIssue1EN1.pdf>. Accessed March 2010.
4. Isaksson A. et al. Quality of life and impairment in patients with multiple sclerosis. *J Neurol Neurosurg Psychiatry*. 2005;76:64-69.
5. European MS Platform data on file.

MS-NEED

First major European survey that highlights significant disparities in MS nursing across Europe.

Directive on Recognition of Professional Qualifications

Revision of Directive should be considered in order to recognise MS nurses as specialists.

EU Council Recommendation

Need for Council Recommendation on quality of healthcare to unify, define and benchmark care provision, including MS nursing, to avoid inequalities.

“Up to half a million people in the European Union have MS, a progressive auto-immune disease of the central nervous system.”^{1,2}

Multiple Sclerosis (MS): The key challenges

- Around 70% of newly diagnosed patients with MS are in the prime of their lives (20 and 40 years), which has a significant impact on their careers and families.^{1,2}
- Nearly 85% of people with MS are affected by fatigue, which interferes significantly with their quality of life³. About 50% of people with MS need a wheelchair within 20 years of developing MS.⁴
- People with MS are keen to remain in employment, however due to the progressive, degenerative or fluctuating nature of their disease, they often need to reduce or adapt their hours and working environment to accommodate their changing needs.²

MS-NEED: Understanding the role of MS nurses

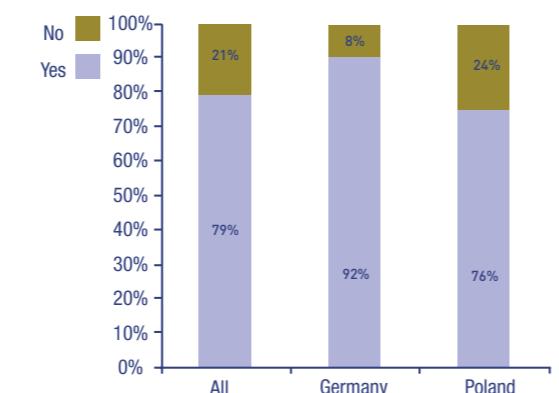
- MS nurses provide information, support and advice to patients and their families at the time of diagnosis and throughout the course of the disease, adopting a holistic, collaborative and co-ordinated approach to treatment.¹⁻³
- The first major European survey of 280 MS nurses across Czech Republic, Finland, Germany, Italy, Poland and the UK was conducted to better understand the changing role of the MS nurse and the link to service provisions in MS across Europe.⁵

MS-NEED: Turning recommendations into action

- EMSP, IOMSN and RIMS consider it necessary to form a European Network of MS nurses with the aim of facilitating:
 - cooperation and sharing of best practice between countries, to improve equality of healthcare in MS
 - promoting comparative research and data gathering
- The European Network of MS nurses will create educational tools and resources to increase health literacy skills and define a standard of healthcare quality in MS across Europe.

The need to harmonise education, training and recognition as specialists

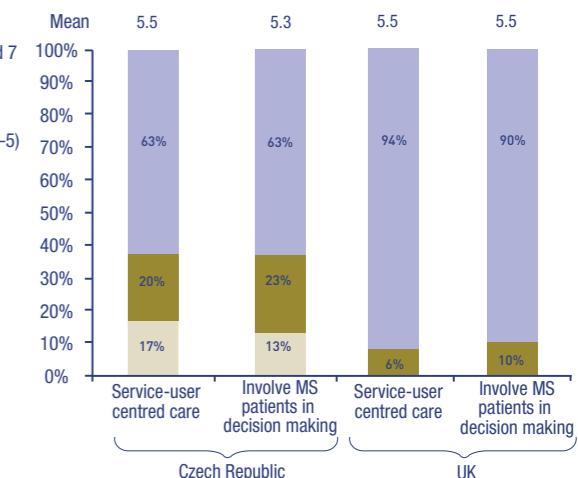
- The availability of specialised training and education across Europe varies considerably. For example, 21% of all surveyed nurses and 24% of nurses in Poland feel that they have not received adequate training and education to support them in their day-to-day role.⁵ However this was significantly less in Germany (8%).⁵



The importance of empowering patients

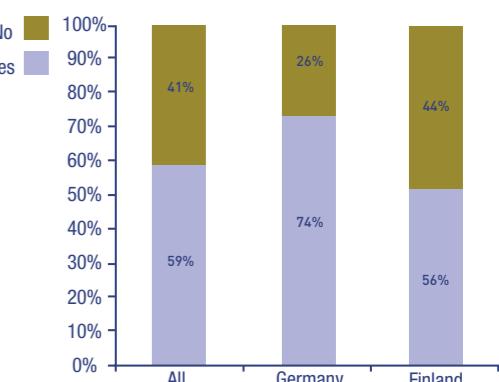
Where 1 is not at all important and 7 is very important:
 Unimportant (1-2)
 Important nor unimportant (3-5)
 Important (6-7)

- Service-user centred care and involving patients in decision-making was perceived to be an important method of empowering patients, especially in the UK. However, a higher proportion of MS nurses in the Czech Republic felt that this was unimportant.⁵



Improving patient access to treatment

- The extent to which nurses help patients with MS gain access to new treatments varies across Europe, with 74% of nurses in Germany helping patients with this compared to 56% in Finland.⁵



Recognition of MS nurses as specialists is needed to support the evolution of their role.

Training and certification of MS nurses across Europe is critical to ensure health equality and to improve the quality-of-life of MS patients and their families.

A European Network of MS Nurses will help provide valuable insights for the upcoming progress report on the EU *Communication on Health Inequalities*, due in 2012.

- MS-NEED: European survey is endorsed by: