



Accelerating research towards a cure for multiple sclerosis

## The Cost and Burden of MS in Europe 2015: A Patient-Reported Outcomes Approach

*By Farren Briggs PhD, ScM*

Commentary on access to and cost of healthcare is currently the center of most Capitol Hill conversations. These conversations touch every American, and understanding the healthcare cost relevant to subgroups of individuals is necessary for fruitful discussions. In the US, the direct healthcare cost for a person with MS (PwMS) is \$39,000; but when lost wages are considered, the annual cost rises to \$69,000<sup>1</sup>. Of course the annual cost of healthcare varies by disability level<sup>1</sup>: \$30,000 for those with mild disability and upwards of \$100,000 for those with severe disability<sup>2</sup>. Other considerations include drugs used – in 2011, for PwMS using disease modifying therapies (DMTs) to manage their MS, 75% of their total MS healthcare costs was for DMT monotherapy<sup>2</sup>. Healthcare costs change over time, due to changes in the rate of disability accrual, therapeutic options, and clinical care; therefore it is important to update estimates across multiple populations to appropriately inform policy and to allow easier comparisons across health systems and countries.



This month the *Multiple Sclerosis Journal* (MSJ) dedicated an entire issue to updating the information on the annual costs incurred by persons with MS (PwMS) in Europe<sup>1</sup>. What is unique about this issue is it presents MS-related healthcare costs across 16 countries, in 16 articles, allowing direct comparisons of costs across these European nations. The authors undertook a non-traditional ‘bottom-up’ approach to evaluating the costs related to MS, by directly asking PwMS about their health and healthcare utilization, versus a ‘top-down’ approach of extracting information from registries and administrative data (i.e. healthcare billing). A total of 16,808 PwMS were recruited from national MS societies in 16 countries, including: Austria, Belgium, Denmark, Czech Republic, France, Germany, Hungary, Italy, the Netherlands, Poland, Portugal, Russia, Spain, Sweden, Switzerland and the United Kingdom. Participants completed a detailed questionnaire that included questions on MS-related resource consumption, employment, MS symptoms and disease activity, and health-related quality of life. This ‘bottom-up’ approach allowed for assessing costs related to symptomatology and disease activity—something that would be extremely challenging from a ‘top-down’ approach.

A publication earlier this year summarized the results for the 16 countries, and noted many similarities and differences between these countries<sup>4</sup>. For example, perceived quality of life (as measured by EQ-5D) decreased with disease severity (as measured by the Expanded Disability Status Scale [EDSS]) across all countries (Figure 1). However, there were dramatic differences in the annual costs by EDSS (Figure 2). For mild to moderate disability (EDSS<5), healthcare costs were under ≤50,000€ EUR across all countries, but for EDSS>5, healthcare cost varied greatly. In 2015, for a PwMS with severe disease (EDSS=9; PwMS is bed-ridden but can communicate and eat) the annual cost of care in: Portugal=35,000€; Spain=50,000€; Italy=80,000€; Switzerland=100,000€; and Sweden=135,000€ (1€ was worth approximately \$1.10 USD in 2015). These differences in cost relate to the cost of living in each country, but more importantly these costs are influenced by healthcare systems organization, the availability of services, and the ease of access to these services to PwMS. Also, 95% and 70% of participants reported fatigue and cognitive difficulties as major issues irrespective of disease severity and country of origin, which argues for more focus on management of these areas of MS in Europe. The overall goal of the special MSJ issue and these evaluations is to contribute to more effective approaches to disease management to result in better outcomes for PwMS.

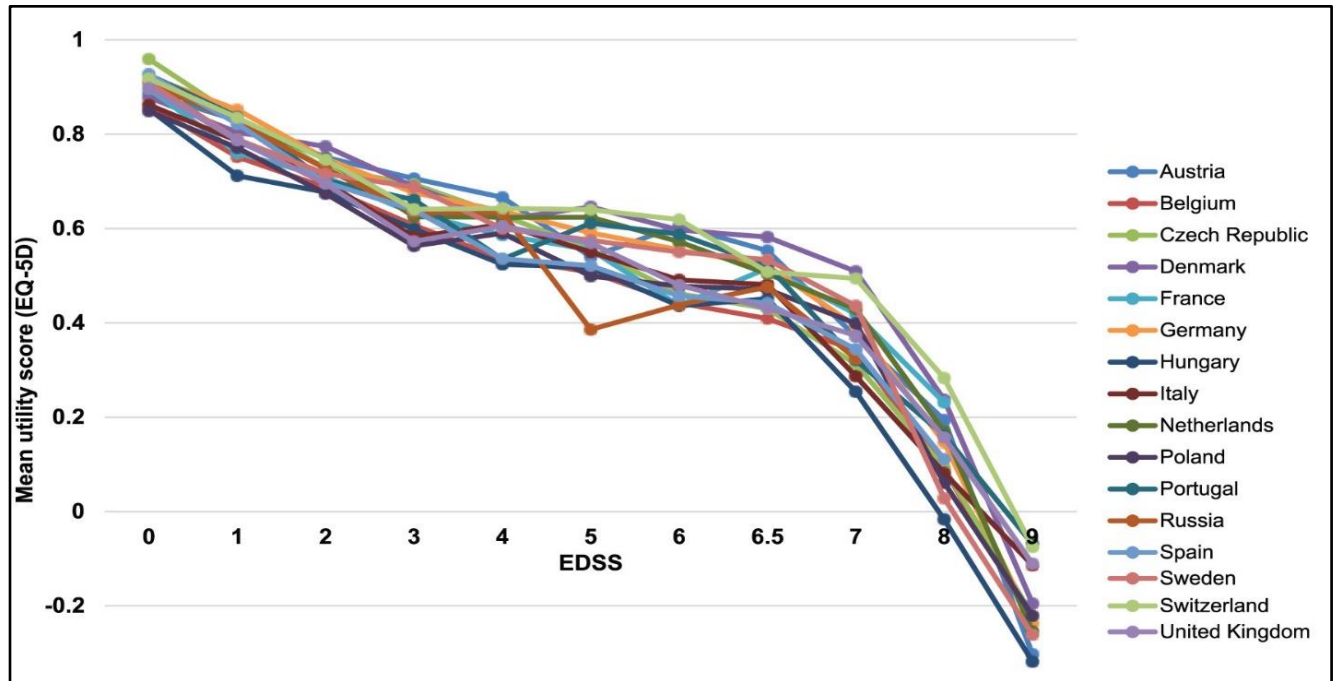
1. <https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Documents/Health-Policy-Fact-Sheet-2-Costs.pdf>

2. <http://www.ajmc.com/journals/supplement/2016/cost-effectiveness-multiple-sclerosis/cost-effectiveness-multiple-sclerosis-economic-burden>

3. [http://journals.sagepub.com/toc/msja/23/2\\_suppl](http://journals.sagepub.com/toc/msja/23/2_suppl)

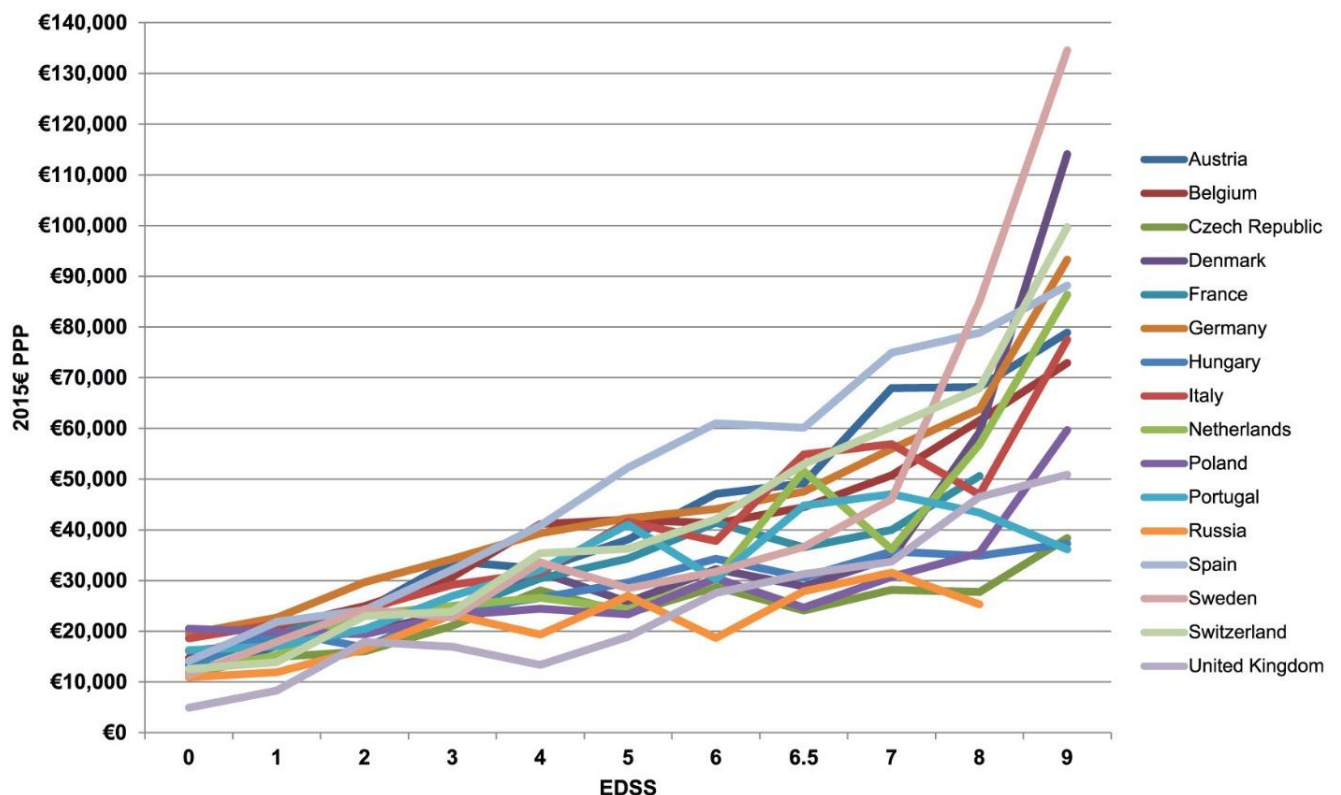
4. <http://journals.sagepub.com/doi/10.1177/1352458517694432>

**Figure 1: Relationship between disease severity and health-related quality of life in 16 European countries (2015).**



Published in: Gisela Kobelt; Alan Thompson; Jenny Berg; Mia Gannedahl; Jennifer Eriksson; *Mult Scler* 23, 1123-1136.  
 DOI: 10.1177/1352458517694432. Copyright © 2017 SAGE Publications

**Figure 2: Mean annual cost (EUR €) per PwMS by MS severity (EDSS) in 2015 (1 EUR ~ 1.1 USD in 2015).**



Published in: Gisela Kobelt; Alan Thompson; Jenny Berg; Mia Gannedahl; Jennifer Eriksson; *Mult Scler* 23, 1123-1136.  
 DOI: 10.1177/1352458517694432. Copyright © 2017 SAGE Publications