Societal Cost of Multiple Sclerosis 2015

Study Results

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Motivation for Study

The life of their choice to their fullest potential

The Need:

- Limited research into the costs of MS in Ireland.
- Existing work focuses on direct healthcare costs with less attention given to the wider societal impact of MS.

The Aim:

- Take a snapshot of lives of people with MS in Ireland in 2015 to allow future benchmarking.
- To show the impact of MS on society at the national level—in a context relevant to policy makers.
- To adopt a more person centred approach—without a large burden of response.
- A study with scientific rigour that would meet international peer standards.
Research Contributors

- + 600 people with MS
- Dr Chris McGuigan, Consultant Neurologists, SVUH and UCD
- Dr Killian O’Rourke, Consultant Neurologist, MMUH and UCD
- Aidan Larkin, Service Development Manager, MS Ireland
- Derek O’Boyle, Health Economist, NUIG
- Peter Carney, Health Economist, Novartis
- As well as MS Ireland bloggers >>
Why Examine the Societal Cost of MS?

To provide a framework for considering the **scale of MS in Ireland**

To show the **distribution of costs** in society

To inform health and social care **planning and spending decisions**

- A **prevalence-based** approach
- Survey based – **online & postal**
- **Patient’s perspective**
- Self-reports with **validated instruments**
Survey Design

We included the best aspects of previous cost-of-illness research

- Based on best mix of frequently used methodologies in several earlier studies
- Compiled of a mix of health and economic instruments
- Insights from Irish clinical practice and community knowledge.

Respondents were asked to provide information on the following areas:
- Their disease
- Healthcare resource use
- Experience of relapses
- Productivity impacts,
- Care needs
- Health-related quality of life.

MS Ireland invited their membership base to participate (N= 6,098) in this self reported study in February 2015
- by email for members with email address
- by mail if no email address (paper questionnaires available)

The recruitment of other people with MS in Ireland was sought through notification of the survey in the national press, and through active non-traditional media channels (i.e., blogs, Twitter, and Facebook).
- All data anonymised
Societal Cost of Illness

Economic costs from a societal perspective --

**Market**

**DIRECT COSTS**
- Medical
  - Physicians
  - Tests
  - Imaging
  - Prescriptions
  - Hospital
  - Assistive devices (e.g. wheelchair)
  - Physiotherapy
  - Cognitive therapy
  - Long term care
- Non-medical
  - Home / car modifications
  - Transport
  - Formal Care

**INDIRECT COSTS**
- Increased morbidity
- Work loss
- Reduced productivity
- Work change
- Loss of earnings
- Economic Impact on family and friends
- Employment changes
- Health effects

**Non-Market**

**INTANGIBLE COSTS**
- Pain & Suffering
- Decreased QoL
- Psychological Impact on families and friends

**QoL Value**
Final Sample & Key Characteristics

Eligibility Criteria

- Age ≥ 18
- Diagnosed with MS (or CIS)
- Consent to involvement

Online respondents = 805
Postal respondents = 20
Total respondents = 825
Eligible = 792
Excluded = 198 (incomplete)
Final = 595

1 / 15 of all people with MS in Ireland included

<table>
<thead>
<tr>
<th>Age characteristics</th>
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<tbody>
<tr>
<td>Mean (SE) (years)</td>
<td>47.03 (SE 12.16)</td>
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<tr>
<td>Proportion ≥65 years</td>
<td>8.1</td>
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<tr>
<td>18–29 years</td>
<td>6.57</td>
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<tr>
<td>30–39 years</td>
<td>23.95</td>
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<tr>
<td>40–49 years</td>
<td>26.47</td>
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<tr>
<td>50–59 years</td>
<td>27.82</td>
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<tr>
<td>60–69 years</td>
<td>11.97</td>
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<tr>
<td>70–79 years</td>
<td>2.7</td>
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<tr>
<td>≥80 years</td>
<td>0.51</td>
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<table>
<thead>
<tr>
<th>Sex</th>
<th></th>
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<tbody>
<tr>
<td>Female n (%)</td>
<td>424 (71.38)</td>
</tr>
<tr>
<td>Male n (%)</td>
<td>170 (28.62)</td>
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<table>
<thead>
<tr>
<th>Marital status n (%)</th>
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<tbody>
<tr>
<td>Single</td>
<td>156 (26.31)</td>
</tr>
<tr>
<td>Married/Cohabitating</td>
<td>388 (65.32)</td>
</tr>
<tr>
<td>Widowed</td>
<td>11 (1.85)</td>
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<tr>
<td>Separated/Divorced</td>
<td>38 (6.41)</td>
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<tr>
<th>Habituation, n (%)</th>
<th></th>
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<tbody>
<tr>
<td>Live alone</td>
<td>116 (19.83)</td>
</tr>
<tr>
<td>Live with others</td>
<td>464 (79.32)</td>
</tr>
<tr>
<td>Live in a care home</td>
<td>5 (0.85)</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Children, n (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>224 (37.77)</td>
</tr>
<tr>
<td>1</td>
<td>95 (15.97)</td>
</tr>
<tr>
<td>&gt; 1</td>
<td>276 (46.26)</td>
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Epidemiology

*Estimated number of people with MS in Ireland*

No formal disease registry of MS in Ireland so prevalence requires estimation

- On the basis of our research we concluded there are approx. 9,000 people living with MS in Ireland in 2015
Breakdown of the sample by province

*Generalisability – our sample is nationally representative*

**Our Sample:**
% of Population by Province

- Ulster 5.4%
- Connacht 10.3%
- Leinster 59.2%
- Munster 24.3%

**Rep. of Ireland (Census):**
% of Population by Province

- Ulster 6.4%
- Connacht 11.8%
- Leinster 54.6%
- Munster 27.2%
Sample Characteristics

The majority of the sample are women; reflecting the international prevalence of MS generally.

- **47 years old** Average age of study respondents
- **70:30** Ratio of women to men in sample
- **65%** Are married or cohabiting
- **62%** Have children
- **20%** Live alone

1. All data from: Bevan et al., The Work Foundation Report, Ready to Work: Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, Main Findings, Executive Summary, p. 3-4 (Supported by Novartis with an educational grant.)
Sample Characteristics – Disease information

MS is a chronic disease affecting people in the prime of life

- 32 years old: Average age of disease onset
- 63%: Relapsing-remitting MS
- 36%: Restricted mobility and sometimes depend on others to perform day-to-day activities
- 42%: Report having experienced a relapse in the past year.

1. All data from: Bevan et al., The Work Foundation Report, Ready to Work: Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, Main Findings, Executive Summary, p. 3-4 (Supported by Novartis with an educational grant.)
Sample characteristics by MS severity and disease course

The majority of the sample have RRMS and mild disability

Disease severity
- Mild: 36%
- Moderate: 57%
- Severe: 7%

Disease course
- Relapsing remitting: 63%
- Secondary progressive: 11%
- Primary progressive: 6%
- Benign: 17%
- Clinically Isolated Syndrome: 1%
- I do not know: 2%
### Direct Healthcare Resource Use

*People with MS have substantial healthcare needs*

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Resource Details</th>
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<tbody>
<tr>
<td>84%</td>
<td>7 GP visits</td>
</tr>
<tr>
<td>21%</td>
<td>9 nights in hospital</td>
</tr>
<tr>
<td>7%</td>
<td>3 ED visits (not admitted)</td>
</tr>
<tr>
<td>71%</td>
<td>3 Neurology visits</td>
</tr>
<tr>
<td>16%</td>
<td>5 MS Ireland case workers visits</td>
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#### People with MS require a lot of care

- 54,000 GP visits/year
- 16,450 nights in hospital
- 1,544 emergency department visits (not admitted)
- 7,600 visits from MS Ireland caseworkers

#### Notes

1. All data from: Bevan et al., The Work Foundation Report, Ready to Work: Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, Main Findings, Executive Summary, p. 3-4 (Supported by Novartis with an educational grant.)
Societal Cost of MS: €429 million

The largest proportion of costs to society occur outside the healthcare system

Annual societal cost per person

€47,683

Direct costs: €14,895
e.g. hospitals, doctors, medication

Indirect costs: €23,750
e.g. time off work, carers

Intangible costs: €9,038
e.g. quality of life

MS costs Ireland €429 million per year

1. All data from: Bevan et al., The Work Foundation Report, Ready to Work: Meeting the Employment and Career Aspirations of People with Multiple Sclerosis, Main Findings, Executive Summary, p. 3-4 (Supported by Novartis with an educational grant.)
Total annual societal costs: €429 million

The largest contributor to overall societal costs is productivity loss

Total annual societal costs: €429.15 million

- 19% Intangible costs
- 3% Hospital/rehabilitation
- 0.4% Nursing home/respite care
- 2% Diagnostics
- 14% Medication
- 8% Outpatient care
- 1% Aids and adaptations
- 3% Professional help at home
- 32% Total productivity costs
- 18% Total informal care costs
- 0.1% Cost of Depression

Societal Cost of Multiple Sclerosis 2015
Total Annual Direct Costs: €134m

Treatment makes up the majority of direct costs

Total direct costs: €134.1 million

- Medication 45%
- Outpatient care 25%
- Aids and adaptations 5%
- Professional help at home 9%
- Hospital/rehabilitation 10%
- Nursing Home/respite care 1%
- Diagnostics 5%
Total Indirect costs €213.8 million

The majority of indirect costs are made of those having to “permanently withdraw from the workforce due to MS” and costs attributable to informal care.

**Total indirect costs: €213.8 MILLION**

- Retired due to MS 39%
- Presenteeism 11%
- Informal care 36%
- Cost of depression 0.2%
- Reduced working week 8%
- Extra hours missed per week 6%
MS Relapses: Total cost €16.9 million
Disability Progression sharply increase cost

The total cost associated with moderate MS was 70% higher than that for mild MS while costs associated with severe MS was approximately 3 times that associated with mild MS.

Disability progression associated with increased costs:

- Mild: €35,000
- Moderate: €58,000
- Severe: €100,000
Ways to Reduce Impact of MS

Managing MS helps avoid costs

- Reducing relapses and disability progression helps to lessen the burden of MS on the individual and their family, and reduce the impact of MS to society over time.

Cost of relapses in Ireland: €16.9 million

- Increase access to neurologists and achieve best practice monitoring and managing disease activity

- Enhance cognitive and psychological services

- Develop legislation and supports to encourage employers to provide more flexible working conditions.

- Access to best medicines
Innovative MS treatments have evolved over time

- **1948**
  - Median life expectancy 1948~17 years after MS disease onset

- **1960**
  - Average time between a person’s first symptom and a definitive diagnosis of MS - 7 years

- **1970**
  - No standardized method for assessing the progression of MS

- **1983-84**
  - The Expanded Disability Status Scale* was developed to assess disability in MS. Only ~20% of people with MS were employed

- **1990**
  - Treatments available for MS could only target disease symptoms

- **1993**
  - First disease modifying therapy (DMT) approved for people with MS

- **2000**
  - MRI integrated into best practice for diagnosing MS

- **2008**
  - 6 DMTs available for people with MS

- **2010**
  - First oral DMT approved for people with MS

- **NOW**
  - Average time between a person’s first symptom and a definitive diagnosis of MS - 6 months, thanks to advancements in science and technology

*Range of effective treatments available for people with MS

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9. Range of effective treatments available for people with MS
10. Average time between a person’s first symptom and a definitive diagnosis of MS - 6 months, thanks to advancements in science and technology
Reducing relapses and disability progression

Managing MS helps avoid costs

- Many of the efforts to reduce the impact of MS are difficult to measure in terms of their quantitative effect.

- Medication however has well-documented effectiveness from clinical trials.

- This allowed us to examine their impact in terms of reducing the impact of MS and avoiding disease related costs to society.

Example

MS drug therapy (DMTs) aim to reduce relapses (ARR; 30–60%) and delay disability progression (EDSS; 20 -40%).

Costs avoided due to lesser disease activity in this context is estimated at up to €29m per annum.
Employment Retention

Treatment & disease management can improve the ability of people to remain employed

- 7 out of 10 employees say MS has limited their career potential
- 34% of employees had to REDUCE working hours
- 900,000 days lost due to stopping work, absenteeism and presenteeism

- Since the average age of onset is between 20-40 years, MS impacts people at the prime of their working life.
- Furthermore, for those who experience relapses, or who experience extreme fatigue, or are unable to walk, it can be more difficult to sustain standard working arrangements.
MS has a significant impact on family life

MS is a disease of ADULTS but CHILDREN are affected

61% feel they can’t financially provide for their children

73% of children worry about parents’ health

Quality of Life is rated 32% less than for the general population and is lower in men than women

Societal Cost of Multiple Sclerosis 2015
Summary

Key Learnings

• MS is associated with high costs (€429m) and substantial healthcare needs.

• A larger proportion of the costs of MS to society are outside the healthcare system – productivity loss and informal care costs.

• Disability progression in MS is associated with sharp increases in costs and decreases quality of life.

• Depression is a very common co-morbidity associated with disease activity.

• Retaining employment is important for people living with MS – supports to enable this could reduce societal cost.

• Reducing disease activity and helping people continue to work helps to lower healthcare and societal costs
Conclusion

- **MS affects 9,000 people in Ireland in the prime of their life**
- **Healthy & productive people**: Vital for economic growth and societal prosperity
- **MS has high costs** with most outside the healthcare system, and productivity losses are high
- **Support policy solutions** taking a multi-pronged approach balancing health, social affairs and finance:
  - Access to best care and treatments
  - Flexible working practices

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**Need to:**

- Ensure **better health and social outcomes**
- **Inclusive participation** in society and the **workforce**
- **Stakeholders** working together in partnership
Thank you

www.ms-society.ie
Methodology References


- European Multiple Sclerosis Platform MS Barometer 2013., section on Multiple Sclerosis ; UK MS Society What is MS http://www.mssociety.org.uk/what-is-ms/treatments-and-therapies/disease-modifying-drugs-dmds Accessed 10 October 2014