Societal Cost of Multiple Sclerosis 2015

Ava Battles
Chief Executive, MS Ireland

#thinkms
MS Ireland’s Mission is:
‘to enable and empower people affected by MS
to live the life of their choice to their fullest potential’

Our Services:
- Individual and Family Support
- Living with MS programmes
- Exercise based programmes
- Information and Education
- MS Information Line 1850 233 233
- The MS Care Centre (respite)
- Research
- Advocacy
- Website www.ms-society.ie
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.
What this research provides

Large scale, comprehensive costing of MS in Ireland

- Comprehensive original research to describe the population of people with MS in Ireland in 2015
- 600 volunteer participants from across Ireland
- The report describes and quantifies the impact of MS on individuals, families and society.
- This will allow policy-makers consider a broader context when examining interventions in the health and social care community.
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 our bloggers >>

Together We Are Better

Thursday April 09 2015 11:02 AM

I often hear people say that all MSers are different. I know where they are coming from. This chronic illness has so many, seemingly random symptoms. The brain is supposed to be conducting the orchestra but due to inexplicable glitches, certain instruments go out of tune from time to time or stop playing altogether. It’s tempting to turn down the volume or stop the music completely. It’s true that all MSers are affected differently. Yet we are all the same. We ALL have MS. Just like organisations like the IFA or the GAA we have something massive in common, even though we are different.
Agenda

- Killian O’Rourke – **Overview and Study Development**
- Chris McGuigan – **Study Results & Key Findings**
- Joan Jordan – **Living with MS**
- Q & A and close
Societal Cost of Multiple Sclerosis 2015

Study Overview and Development

Kilian O'Rourke
Mater Misericordiae University Hospital & UCD

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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**

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MSIreland

Supported by NOVARTIS
Previous Cost of MS Research

*International estimates range from €22k to €84k per person per year*

Gaps in the Literature:

- Limited epidemiology
- Little attention to QoL
- Tend to focus on direct costs and rather than societal costs.
- Mostly clinic-based samples

Our Contribution:

- A large non-clinic based sample of people with MS in Ireland.
- Comprehensive questionnaire designed based on best practice in the literature
- Rich data without large respondent burden
Relationship between cost and disease severity

*Disability progression associated with increased costs*

**Workforce participation and disease progression**

**MS costs increases with disease severity**

Total mean cost per patient / year

- **Mild**
  - EDSS score 0–3.5
  - €21,434

- **Moderate**
  - EDSS score 4–6.5
  - €46,822

- **Severe**
  - EDSS score 7–9
  - €106,834

Costs inflated to €2015

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.

- A self-reported survey was hosted online for one month in February 2015
- Paper questionnaires were also available
- All respondents data was anonymised
Methodological Rigour

**Self-reported data and survey instruments**

<table>
<thead>
<tr>
<th>Client Services Receipt Inventory (CSRI)</th>
<th>Work Productivity &amp; Activity Impairment (WPAI)</th>
<th>EQ-5D-5L</th>
<th>Modified Fatigue Impact Scale (MFIS-5)</th>
<th>MOS Pain Effects Scale (PES)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The CSRI is a research instrument applied for the collection of information on costs.</td>
<td>The WPAI is a tool which quantifies the impact a specific condition has on the ability to work and on activities of daily life.</td>
<td>Measures health related quality of life on five dimensions (details on next slide)</td>
<td>Provides assessment of the effects of fatigue in terms of physical, cognitive, and psycho-social functioning.</td>
<td>Assesses the ways in which pain interferes with mood, ability to walk or move, sleep, work, recreation, and enjoyment.</td>
</tr>
</tbody>
</table>

**Direct Cost**

**Indirect Costs**

**Intangible Costs**

**Descriptive**

**Descriptive**

**Self-report methods may be subject to recall bias.** People tend to under-report their hospitalisations for longer recall periods and overstate for shorter.

But there is also evidence suggesting that self-reported resource utilisation data, is as reliable as other sources—including administrative records.
Self-Reporting Disease Information

Respondents provided information on disability severity, disease type and relapse history.

<table>
<thead>
<tr>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am independently mobile with minimal disability</td>
<td>I have a moderate level of disability. My mobility is somewhat restricted and sometimes I depend on others to perform day-to-day activities.</td>
<td>I require a high level of assistance for all activities of daily living</td>
</tr>
</tbody>
</table>

The statement below shows three levels of disablement (mild; moderate; severe). Please tick the category which most closely reflects your general level of disability these days.

Respondents reported their form of MS:
- RRMS, PPMS, SPMS, benign disease, CIS or whether they did not know

Respondents reported if they experienced a relapse in the past 12 months.
A global definition of MS relapse was provided in the survey.

“The appearance of new symptoms related to your MS or very definite worsening of old symptoms, which lasted for at least 24 hours and occurred after you had been stable for at least a month and when you did not have a temperature, an infection or any other health trouble”
Recruitment

Achieving a nationally representative sample of people with MS

- MS Ireland invited their membership base to participate (N=6,098)
  - by email for members with email address
  - by mail if no email address
- 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).
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

**Non-Market**

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

**QoL Value**

Economic Impact on family and friends
- Employment changes
- Health effects

Increased morbidity
- Work loss
- Reduced productivity
- Work change
- Loss of earnings

**Increased morbidity**
- Work loss
- Reduced productivity
- Work change
- Loss of earnings

**Economic Impact on family and friends**
- Employment changes
- Health effects

**QoL Value**
Overview of Instrument for measuring QoL and estimating Intangible Costs

**EQ-5D-5L**

5 Dimensions

- Usual activities
- Pain / Discomfort
- Mobility
- Self-care
- Anxiety / Depression

5 Levels

1. I have no problems in walking about
2. I have slight problems in walking about
3. I have moderate problems in walking about
4. I have severe problems in walking about
5. I am unable to walk about

EQ-5D (Index) 0.587

Compared to the general population, the people in our sample report 32% lower QoL

Intangible Cost Estimates

General Population Value Preferences

^Time trade off method – Dolan (1994) UK

Societal Cost of Multiple Sclerosis 2015
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
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

Societal Cost of Multiple Sclerosis 2015

Study Results

Chris McGuigan

St. Vincent’s University Hospital & UCD

#thinkms
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.

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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.)
The majority of the sample have RRMS and mild disability

Sample characteristics by MS severity and disease course

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

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

*People with MS have substantial healthcare needs*

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Resource Description</th>
</tr>
</thead>
<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>
</tr>
</tbody>
</table>

29% had no visit to a neurologist in the previous 6 months

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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

21,800 Neurology visits per year

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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:** €23,75
- 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 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.
MS Relapses: Total cost €16.9 million

Total annual cost of relapse: €16.9 million

- Inpatient care 44%
- Medication 4%
- Tests/investigation 9%
- Travel etc 1%
- Formal care 1%
- Informal care 15%
- Productivity losses 13%
- Outpatient/Primary care 13%
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**: No standardized method for assessing the progression of MS.
- **1970**: Average time between a person’s first symptom and a definitive diagnosis of MS - 7 years.
- **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.
- **2000**: MRI integrated into best practice for diagnosing MS.
- **2008**: First disease modifying therapy (DMT) approved for people with MS.
- **2010**: 6 DMTs available 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.

*Note: Details are based on historical and scientific references and may vary.
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.

- Estimated savings from relapses avoided: up to €10 million
- Estimated savings from delayed disability: over €19 million
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

**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
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.
Meet Joan

Wednesday December 11 2013 11:00 AM

In her introductory blog for MS Ireland, Joan diagnosed with MS four years ago, has a 'can-do' attitude and a weakness for coffee and chocolate.

Hello! My name is Joan Jordan and this is my M.S. story. Please go easy on me readers as this is my first attempt at blogging. I was a very average English student in school but maybe I have a bit more to say about living life with MS than I ever had to say about Shakespeare’s Sonnets!

2010 was not a good year for me and my family. I was hospitalised in May, having lost the power in my hand and foot. I got my diagnosis of relapsing remitting MS “Lightning Bolt No One...” Within a few days, my three year old was diagnosed with a severe form of epilepsy, called Doose Syndrome. “Lightning Bolt No Two...!”

Normally, I am a positive person. I have a “can-do” attitude and I can roll with the punches. I had been juggling a demanding job in IT, a husband, a Celtic-tiger mortgage and two kids. This wasn’t normal though. Over the next few days / months / years I have come to know and love a new kind of normal. MS has taken so much but it has also given some unexpected things.

The small stuff has gone. I don’t worry about what other people think of me. I don’t worry if the dishes aren’t washed. I don’t look into other people’s lives and wish they were mine.
Societal Cost of Multiple Sclerosis in Ireland 2015
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

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