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## Economic Burden of Multiple Sclerosis in the United States: Estimate of Direct and Indirect Costs

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## Abstract

**Background and Objectives:** A recent report estimated that approximately one million adults were living with multiple sclerosis (MS) in the United States (US). While MS is rarely the direct cause of death, its debilitating effects on normal body functions can result in considerable disruption to daily living and life roles including work, physical independence, mobility, social interaction, and participation in leisure activities. This study estimated the total economic burden of MS in the US in 2019.

**Methods:** This study used a prevalence-based approach to estimate the national economic burden of MS. Claims from three sources (Medicare Current Beneficiary Survey, Medicare Standard Analytical File, and Optum de-identified Normative Health Information System) were used to obtain direct costs, while a survey was developed to collect indirect costs (e.g., labor market productivity losses, costs of paid and unpaid caregivers, home modification) from 946 patients with MS (PwMS). Direct medical costs reflected the difference in the total average annual amount paid for PwMS versus matched controls without MS. Future earnings loss due to premature death attributable to MS was calculated using Centers for Disease Control and Prevention mortality data and Medicare claims data.

**Results:** The estimated total economic burden was \$85.4 billion, with a direct medical cost of \$63.3 billion and indirect and non-medical costs of \$22.1 billion. Retail prescription medication (54%), clinic administered drugs (12%), medication and administration, and outpatient care (9%) were the three largest components of the direct costs. The average excess per person annual medical costs for PwMS was \$65,612; at \$35,154 per person, disease-modifying

therapies (DMTs) accounted for the largest proportion of this cost. The cost per DMT user ranged from \$57,202 to \$92,719, depending on gender-age strata.

The average indirect and non-medical costs were \$18,542 per PwMS and \$22,875 per PwMS if caregivers' costs were included. Lost earnings due to premature death, presenteeism, and absenteeism losses were the largest indirect cost components.

**Discussion:** MS is a very costly chronic disease, with direct costs of prescription drugs and indirect productivity loss being the significant cost drivers. Our findings suggested that the burden of MS in the US has been underestimated.

## Introduction

According to a new estimate in 2017, approximately one million adults lived with Multiple Sclerosis (MS) in the United States (US).<sup>1</sup> MS disease onset usually occurs between ages 20 and 40 years and often leads to disability. It affects nearly three times as many women as men and while it is prevalent in whites with northern European ancestry, it has become increasingly common among African Americans.<sup>2</sup> MS manifests with a multitude of symptoms<sup>3</sup> and they may intensify and subside over time, creating relapsing-remitting and progressive patterns of disease. Patients with MS (PwMS) also experience higher rates of comorbidities than the general population.<sup>4</sup>

MS is the leading progressive neurological condition of young working-age adults where nearly 30 percent of working-age individuals with MS across the US rely on Social Security Disability Insurance (SSDI).<sup>5</sup> MS has caused significant economic burden in the US.<sup>6</sup> PwMS have higher healthcare utilization compared to controls without MS.<sup>7</sup> While MS is rarely the direct cause of death, its debilitating effects result in considerable disruption to daily living and life roles including physical independence, mobility, social interaction, and participation in leisure activities.<sup>8</sup> Neurological disability can prevent PwMS from working or limit employment opportunities and reduce earnings.<sup>9</sup> Also, many family members need to leave their employment to be caregivers.<sup>10</sup>

Prior studies examining the economic burden of MS in the US are outdated due to recent changes in the prevalence estimates of MS and the development of new treatments in the last

two decades.<sup>6,11</sup> The objective of this study was to provide an estimate of the economic burden of MS in the US in 2019.

## **Methods**

We used a prevalence-based approach in estimating the economic burden of MS. The direct and indirect costs of MS were estimated based on the disease attributable cost approach and human capital approach, respectively.<sup>12</sup>

### ***Data sources***

We relied on a variety of primary and secondary data sources to estimate different components of the costs of MS, including existing national survey data, public and private claims data, national death records, and a self-administered survey (**Figure 1**). We relied on MS prevalence estimates for year 2010 that were published in the literature in 2019.<sup>1</sup> To obtain the 2019 MS estimates, we used the strategy described by the MS Prevalence Workgroup<sup>1</sup> and applied an annual growth rate of 2.3% to the 2010 estimates.

To estimate the direct medical cost of MS, we used the 2017-2019 Medicare Standard Analytical File (Medicare 5%) and the 2017-2019 Optum de-identified Normative Health Information (dNHI) System.<sup>13,14</sup> The 2018 Medicare Current Beneficiary Survey (MCBS)<sup>15</sup> was used for the estimation of prescription drugs and long-term care costs for the Medicare population, as these costs were not reported in the Medicare 5%. Future earnings loss due to premature deaths attributable to MS was estimated using death certificates from the Centers for Disease Control and Prevention (CDC) Wide-ranging Online Data for Epidemiologic Research (WONDER) Detailed Mortality Database<sup>16</sup> for 2015-2017, 2018 Medicare 5% sample claims

data, Bureau of Labor Statistics (BLS) earnings data<sup>17</sup>, and CDC National Vital Statistics Report.<sup>18</sup> Finally, we implemented a web-based survey to estimate the caregiver burden utilizing a set of comprehensive measures of labor market consequences for PwMS and their caregivers. It also included cost of medical treatments that were not typically covered by insurance and hence, were paid out-of-pocket. For indirect cost estimates, we also utilized data from the American Community Survey (ACS) public use microdata,<sup>19</sup> Current Population Survey (CPS) Volunteer Supplement,<sup>20</sup> and data published by the Independent Sector.<sup>21</sup>

### ***Study samples***

For the dNHI and the Medicare files, PwMS were identified if they had continuous coverage for both medical and pharmacy benefits in the study year and MS diagnostic code (ICD-9 code 340 or ICD-10 code G35) at any time during the year at either the primary or the secondary diagnosis positions. Also, for the dNHI claims, they must have had  $\geq 3$  MS-related inpatient, outpatient visits, or prescription claims for an MS disease-modifying therapy (DMT) in any combination within a 1-year period. For Medicare 5% claims that did not include Medicare Part D drug claims, we required  $\geq 2$  MS-related inpatient or outpatient visits in any combination. For the 2018 MCBS file, we required  $\geq 2$  MS-related medical claims, any drug claim for a DMT, or one answer in the MCBS survey file indicating that he/she had MS. For the questionnaire (see Supplementary materials), a total of 946 PwMS completed the survey. **eTables 1–5** show the characteristics of our survey respondents.

A comparison of the characteristics of the total MS population as calculated from the prevalence estimates, and that of the survey respondents found that the survey sample is

slightly younger than the prevalent MS population<sup>1</sup> and have slightly more females. Therefore, we stratified the survey sample and the MS population into both age group and gender strata and applied weights for each survey respondent to represent the underlying population.

### ***Estimation of direct costs***

We used dNHI, Medicare claims, and the MCBS to estimate medical costs related to MS. Per person medical costs included primary payer paid amount, out-of-pocket expenses, and third party paid amounts. We calculated the per person direct medical costs for 2017, 2018, and 2019; then a 3-year average cost. The direct excess medical costs were calculated as the difference in the annual per-person costs between the MS samples and matched controls by age, gender, race/ethnicity, and insurance (10:1 control-to-case ratio). We also estimated the direct medical costs of MS by insurance types, age, gender, and types of healthcare services, including cost of hospital inpatient stays, physician office visits, prescription medications, administration of prescription medication in the outpatient setting, durable medical equipment, outpatient services, and non-acute institutional care (e.g., SNF, nursing home, or hospice). The prescription medication costs, identified from the pharmacy claims, included DMT costs. The administration of medication in the clinic setting was identified from outpatient/physician claims. All costs were expressed in 2019 dollars.

### ***Estimations of indirect and non-medical costs***

Indirect costs included future earnings loss due to premature mortality, reduced labor market participation because of early retirement, productivity loss for those in the labor force, productivity loss from reduced participation in social activities, and non-medical costs of MS. To

estimate the loss in future earnings, we first estimated the number of premature deaths associated with MS and then multiplied that number by an estimate of average present value of future earnings (by age group). We computed the net present value of future earnings for men and women by age group to estimate the national productivity loss of early mortality associated with MS. We assumed zero loss in earnings from MS for those aged 75 and older. This approach incorporated information on average annual earnings, labor force participation rates and mortality rates for men and women in the US and assumed a productivity growth rate of 1% and a discount rate of 3%, a rate often used in public health studies.<sup>22,23,24</sup>

All other indirect and non-medical cost categories were estimated from the survey. Among working age (18-64) PwMS, 58.7% were in the labor market, compared to the US labor force participation rate of 63.1%. The labor market employment related earnings loss due to MS was calculated as the counts of PwMS who had retired or stopped working in the past 12 months and indicated that MS played a major role in their early retirement decision, multiplied with the median annual earnings by age-gender and job status obtained from the 2019 ACS public use microdata.<sup>19</sup> As the job status of PwMS before retirement was unknown, we used the allocation of full-time to part-time job status among currently working PwMS.

Based on the number of days in an average working month during 2019 that the PwMS and the caregivers missed work or felt less productive while at work because of MS and the average daily earnings calculated from the self-reported annual earnings, we calculated the annualized productivity loss due to absenteeism and presenteeism (with an adjustment factor applied to each day felt unproductive).

We evaluated the plausibility of reported hours by comparing the reported volunteering hours with the average national annual volunteering hours obtained from the CPS Volunteer Supplement (2017).<sup>20</sup> We took a conservative approach by calculating the percentage of people volunteered and average hours volunteered from CPS and multiplied it with the estimated percentage productivity loss from our survey (calculated as the difference between before and after hours divided by before hours). Productivity loss due to forgone volunteering activities was calculated as volunteering hours affected per year times \$27.20, the estimated dollar value per hour volunteering according to the Independent Sector.<sup>21</sup>

Non-medical costs included expenses for purchasing formal daily care, modification to homes, purchases of special motor vehicles, food, or dietary supplements, and increased travel costs for medical visits, as well as medical tourism. We estimated the costs of non-medical components and medical out-of-pocket costs by multiplying the weighted percentage of families who responded as having incurred such expenses and the median expense per-family per-year, with the total MS population in 2019, by age and gender.

Additionally, we asked whether the PwMS had received Supplemental Security Income (SSI), SSDI, or other types of disability income (e.g., income from state disability insurance, VA benefits, long-term disability benefits, etc.), in 2019.

Finally, we projected the number of people with MS and the economic burden over the next 20 years assuming current population growth and mortality trends. Specifically, we applied the estimated age-gender specific MS prevalence rate to US Census population projections for

years 2020-2039.<sup>25</sup> We assumed that MS incidence increased 2.3% annually, while mortality rates and per person burden remained constant during this period.

### ***Standard protocol approvals, registrations, and patient consents***

The study was reviewed and exempted by the New England Institutional Review Board. Standard contracts and data use agreements were obtained for the analysis of all datasets.

### ***Data availability***

The private and Medicare claims datasets for this study are proprietary to Optum and CMS and therefore cannot be shared without a data use agreement. Parties interested in the survey data should contact the National Multiple Sclerosis Society (NMSS).

### **Results**

**Table 1** presents the estimated prevalence of MS by population characteristics for this study. Approximately 1 million individuals in the US had MS in 2019. The prevalence of MS increased with age. The 45-65 age group represented the largest share (50%) of the MS population. While the prevalence among those younger than 45 years was low (0.22%), this age group represented the second largest group in the MS population (nearly 30%). Females had a higher prevalence than males, 0.55% and 0.20% respectively (549 females and 199 males per 100,000 people, respectively); females also represent 74% of the total MS population in 2019.

### ***Economic Burden***

**Figure 2** shows the cost components of the burden. The estimated total economic burden of MS in 2019 was \$85.4 billion, including direct medical costs of \$63.3 billion and an additional

nearly \$21.0 billion in indirect costs and \$1.1 billion in non-medical costs and cost of healthcare services not covered by insurance.

Excess medical costs represent 74% of overall economic burden of MS. **Table 2** presents the direct medical costs of MS by age, gender, and types of service. Overall, the average excess per-person medical cost was \$65,612. When compared to a matched comparison group, the direct costs for PwMS differed by age, gender, and insurance coverage. Per person cost was slightly higher for PwMS <65 years of age (\$66,356) than for those ≥65 (\$63,175). Males, although incurring slightly higher per-person costs than females with MS (\$63,896 vs \$70,603 per person), had a lower overall direct medical cost, due to the lower prevalence of MS among males.

Outpatient retail prescription medications (including DMT and non-DMT) were the largest cost component (\$37.9 billion or about 60% of the direct medical costs) when compared to other components. DMT costs accounted for 89% of the total outpatient medication expenditure. As a consequence, per-person costs were lower if DMT costs were excluded: \$29,258 for those <65 years and \$34,392 for those ≥65. The usage of DMT varied substantially by age group with about 50% of adults with MS age 18-64 regardless of gender and 21% of males and 40% of females of those aged ≥65 treated with DMT (**eTable 6** in Supplementary materials). Therefore, the cost per PwMS who used DMT was high and ranged from \$57,202 to \$92,719, depending on gender or age strata.

Clinic administered medications (including infused DMTs), and outpatient facilities were the next two largest direct medical cost categories (\$6.7 billion and \$5.5 billion, respectively).

**Table 3** shows the estimated indirect and non-medical cost of MS. The estimated total indirect costs of MS were \$21.0 billion in 2019 (or 25% of the total burden), with nearly \$16.8 billion to PwMS and \$4.2 billion to unpaid caregivers. Premature death accounted for the largest share (\$8.0 billion; 38%) of indirect costs, followed by presenteeism (\$5.9 billion; 28%), and absenteeism (\$5.6 billion; 26%). The costs of absenteeism and presenteeism for the caregivers were about half of those for PwMS. The average indirect per capita cost was \$17,407 for PwMS only and \$21,741 for PwMS and caregivers. The total non-medical costs were \$752 million with the paid non-medical daily care being the largest share (\$247 million; 33%), followed by purchase of special equipment for home or vehicle (\$202 million; 27%). The average non-medical cost per capita was \$780. Finally, the medical costs associated with experimental, alternative, and non-traditional treatments, which were not covered by insurance, represented \$342 million. The average per capita cost for healthcare not covered by insurance was \$355. The overall burden was even higher when the government supplemental income programs based on disability eligibility were considered. Transfer payments to PwMS represented an additional \$6.7 billion, which we did not include in the total burden as transfer payments are often used to pay for both medical and non-medical services which would double count costs.

## **Discussion**

To determine the total economic burden associated with MS in the U.S, this study used large claims databases to estimate the direct medical cost of MS by types of healthcare services and used a survey to collect indirect and non-medical costs for PwMS, caregivers, and families. We found that, in 2019, MS was associated with an overall cost of \$85.4 billion. We estimated that

by 2039, there will be nearly 1.2 million PwMS in the US and the economic burden will increase to \$108.1 billion. The main driver of the burden was direct medical costs, especially prescription drugs, such as DMT (54% of the total medical costs per PwMS), which became available in the past several decades.

Although DMTs were found to make up more than 50% of the total medical costs per PwMS, these therapies provide value to patients. Studies have shown DMTs to reduce relapses, decrease disability, and improve health-related quality of life.<sup>26</sup> Additionally, when patients are treated early, DMTs can delay the progression of disease and reduce the number of new lesions;<sup>27</sup> and could lead to lower treatment costs,<sup>28</sup> reduced healthcare utilization, fewer days of work loss, and lower direct and indirect costs.<sup>29</sup> It is important to note that as the cost of DMTs rises and the affordability decreases, patients may be deterred to start DMTs or be forced to interrupt their therapy.<sup>30</sup>

The total economic burden of MS estimated in this study was higher than estimates in prior US based studies. For example, based on data from 1994, the total annual cost of MS was estimated at \$34,103 per person.<sup>6</sup> A more recent study in 2006 based on a survey estimated that the average total cost of MS was about \$47,215 per-patient per-year (2004 dollars).<sup>Error!</sup>

**Bookmark not defined.** Our direct medical cost PwMS of \$65,612 was substantially higher than in these previous studies even when those cost estimates were inflated to 2019 dollars. The largest cost component within our medical costs was DMT that were not included in other recent cost estimates. If the average DMT cost was added to the per person direct cost estimated by Whetten-Goldstein et al.,<sup>6,11</sup> it would be over \$60,000. A more recent study from US, estimated

medical costs of MS to be \$13.9 billion in 2016 dollars,<sup>31</sup> substantially smaller than our estimate (\$63.3 billion). However, all these studies had significantly different data sources, methods, and included different cost components, and are therefore, not directly comparable to our estimates.

The total per person cost estimate from our study is similar to some other chronic, disabling diseases in the US. For example, a per-person cost (including direct medical, indirect, and non-medical costs) estimate for amyotrophic lateral sclerosis is \$63,693 and \$50,952 for Duchenne muscular dystrophy (in 2010 dollars).<sup>32</sup> While the per-person burden of Parkinson's disease is smaller than our estimate for MS (\$49,997 in 2017 dollars vs \$88,132 in 2019 dollars), the indirect and non-medical costs of Parkinson's are comparable to that of the MS (\$20,969 vs \$22,520).<sup>33</sup>

This study has several limitations. First, we used MCBS data for long-term care costs and prescription drug costs for the Medicare population. While we aggregated the analysis to larger subgroups when sample sizes were too small, certain strata-specific estimates might still be subject to small sample size and outlier issues. Second, because MS is likely to affect the overall health, we did not want to over-control in estimating the direct medical costs and therefore only included age, gender, race/ethnicity, and insurance in matching PwMS to people without MS. Third, due to lack of MS-specific mortality data for those younger than 65, we relied on imputed rates. Fourth, the indirect and non-medical costs were estimated using a self-administered survey, which may be subject to non-representativeness, non-response, or recall biases. We compared demographic characteristics of survey respondents to claims data and

found the survey respondents slightly younger, although we applied weights to adjust for this. Lastly, we did not include the Medicaid and veteran populations in the cost estimates.

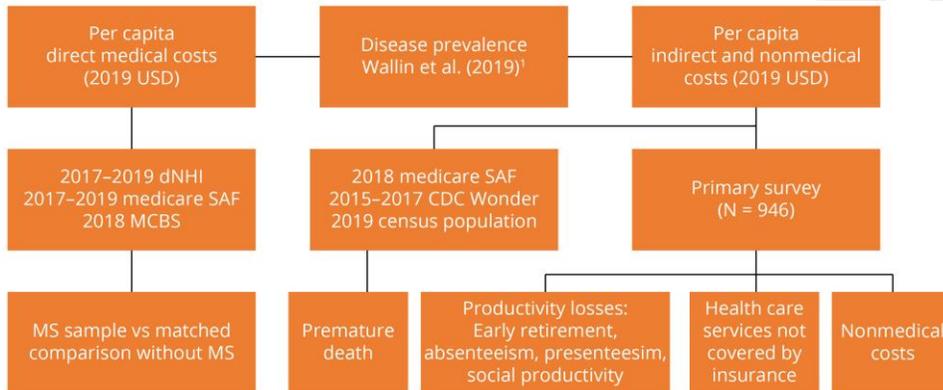
It is important to address why we used the human capital approach to estimate indirect costs and its implications. Although the human capital approach is frequently used in cost-of-illness analyses, it does have limitations<sup>12</sup> It assumes a worker is irreplaceable and that the loss of productivity will not be made up. Using the friction cost method would account for this; however, this method is limited to the effects of a short-term period and has its own set of limitations.<sup>34</sup> Additionally, although the human capital approach may overestimate the economic burden of an illness it is important to understand not only the cost due to loss of productivity but also the potential cost for employers to hire replacements.

The findings of this study help underscore the burden of MS in the U.S. and potential impact of policy or treatment interventions. The results suggested a possible role for additional policy initiatives to better support individuals and families affected, in terms of providing treatment and long-term care, work-site support, employment, and occupational training. The findings will inform decision-making regarding MS related health resource investment and prioritization. For example, high caregiver losses could be alleviated by support at the state and national levels; employment and productivity related losses can be reduced by providing necessary accommodations and adding flexibility for PwMS in their current jobs such that they continue to be productive. These measures could reduce economic burden of MS and help improve the lives of those living with MS and their family caregivers.

## List of titles and legends

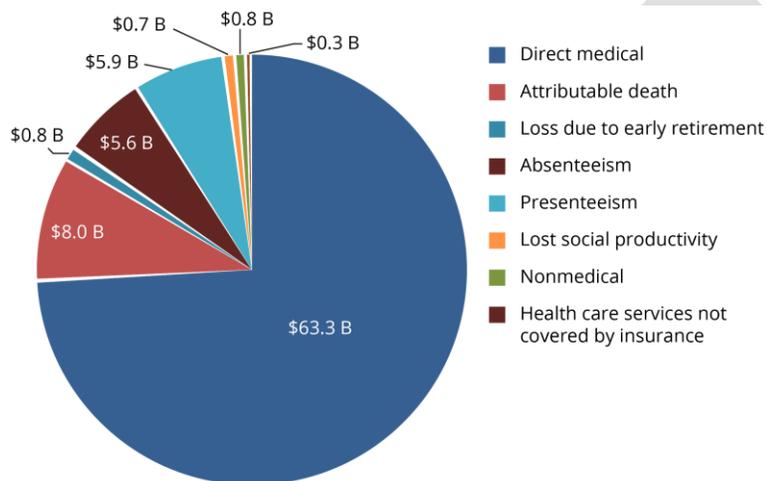
**Figure 1.** Flow chart of cost calculation and data sources

Abbreviations: dNHI: Optum de-identified Normative Health Information system;<sup>14</sup> Medicare SAF: Medicare Standard Analytical File 5% sample;<sup>13</sup> MCBS: Medicare Current Beneficiary Survey;<sup>15</sup> Error! Bookmark not defined. CDC: Centers for Disease Control and Prevention.<sup>16</sup>



**Figure 2.** Total economic burden of MS in the U.S. in 2019: \$85.4 Billion

Source: Lewin analyses of MS prevalence using published prevalence rates and Census population projection for 2019; combined with direct medical cost estimates using 2017-2019 Optum de-identified Normative Health Information system claims,<sup>14</sup> 2017-2019 Medicare Standard Analytical File 5% sample claims,<sup>13</sup> and 2018 Medicare Current Beneficiary Survey,<sup>Error!</sup> **Bookmark not defined.** indirect and non-medical cost estimates are from the MS Impact Survey.



**Table 1.** MS prevalence by population characteristics

	<b>No. of Persons Estimated to Have MS</b>	<b>Percent of Total MS population</b>	<b>Population</b>	<b>Prevalence</b>	<b>Prevalence per 100,000 people</b>
<b>Age</b>					
18-44	255,841	26.5%	117,818,671	0.22%	217
45-64	483,596	50.1%	83,323,439	0.58%	580
65-74	177,359	18.4%	31,483,433	0.56%	563
≥75	48,389	5.0%	22,574,830	0.21%	214
<b>Gender</b>					
Male	246,990	25.6%	124,348,656	0.20%	199
Female	718,195	74.4%	130,851,717	0.55%	549
<b>Total</b>	<b>965,185</b>	<b>100%</b>	<b>255,200,373</b>	<b>0.38%</b>	<b>378</b>

Source: Wallin et al (2019).<sup>1</sup> We applied the annual growth factor of 2.3% to the 2010 estimates to calculate prevalence in 2019.

**Table 2.** Direct medical cost of MS by age and gender

	<b>Total Excess Medical Cost due to MS</b>		<b>Per person (\$)</b>
	(in Million \$s)	Percentage of the Total	
<b>Age</b>			
18-44	\$16,554	26.1%	\$64,705
45-64	\$32,512	51.3%	\$67,230
≥65	\$14,262	22.5%	\$63,175
<b>Gender</b>			
Male	\$17,438	27.5%	\$70,603
Female	\$45,890	72.5%	\$63,896
<b>Types of Service</b>			
Hospital inpatient	\$3,910	6.2%	\$4,051
Non-acute institutional care	\$1,568	2.5%	\$1,624
Outpatient medication and administration	\$7,768	12.3%	\$8,049
Outpatient facilities	\$5,537	8.7%	\$5,737
Physician office	\$4,636	7.3%	\$4,803
Durable medical equipment	\$252	0.4%	\$262
Other ancillary	\$1,728	2.7%	\$1,790
Prescription medication without DMT	\$3,999	6.3%	\$4,143
Prescription medication DMT	\$33,930	53.6%	\$35,154
<b>Overall</b>	<b>\$63,328</b>	<b>100%</b>	<b>\$65,612</b>

Source: Lewin analyses of MS prevalence using published prevalence rates and Census population projection for 2017-2019; combined with direct medical cost estimates using 2017-2019 Optum claims,<sup>14</sup> 2019 Medicare Standard Analytical File 5% sample claims,<sup>13</sup> and 2018 Medicare Current Beneficiary Survey.<sup>Error! Bookmark not defined.</sup> DMT: Disease-modifying therapy. Estimates for PwMS <65 years of age are based on commercial claims; ≥65 – on Medicare claims.

**Table 3.** The indirect, non-medical, and costs of services not covered by insurance of MS in the U.S. by cost component (in 2019)

	Total Indirect and Medical Costs (in Million \$s)			Per Person (\$)		
	MS Loss	PC, SC Loss	MS & PC, SC	MS Loss	PC, SC Loss	MS & PC, SC
Indirect Costs	\$16,801	\$4,182	\$20,984	\$17,407	\$4,333	\$21,741
Premature death	\$8,035	NA	\$8,035	\$8,325	NA	\$8,325
Early retirement	\$600	\$243	\$843	\$622	\$251	\$873
Absenteeism	\$3,449	\$2,102	\$5,551	\$3,573	\$2,178	\$5,751
Presenteeism	\$4,243	\$1,652	\$5,895	\$4,396	\$1,712	\$6,108
Social productivity loss in volunteer work	\$474	\$186	\$660	\$491	\$193	\$684
Non-Medical Costs	\$752	NA	\$752	\$780	NA	\$780
Paid daily non- medical care	\$247	NA	\$247	\$256	NA	\$256
Home modification	\$159	NA	\$159	\$165	NA	\$165
Special equipment at home or on a vehicle	\$202	NA	\$202	\$209	NA	\$209
Other expenses	\$144	NA	\$144	\$150	NA	\$150
Healthcare services not covered by insurance	\$342	NA	\$342	\$355	NA	\$355
Healthcare services not covered by health insurance	\$342	NA	\$342	\$355	NA	\$355
<b>Overall</b>	<b>\$17,896</b>	<b>\$4,182</b>	<b>\$22,079</b>	<b>\$18,542</b>	<b>\$4,333</b>	<b>\$22,875</b>

Source: Lewin analyses of the MS Impact Survey data, supplemented with other data sources such as CDC WONDER death records,<sup>16</sup> Bureau of Labor Statistics earnings data;<sup>17</sup> prevalence estimates are from Wallin et al (2019)<sup>1</sup> and Census population projection for 2019.

## References

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